"The Relationship Between Charity and the State in Britain and Canada, with Particular Reference to the Case of Medical Research"

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Dedication

To my parents, Robert and Patricia Deans, who have always sacrificed much for themselves to give me the opportunity to pursue my dreams.
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<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABRC</td>
<td>Advisory Board for the Research Councils</td>
</tr>
<tr>
<td>ACMR</td>
<td>Associate Committee on Medical Research</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>AMRC</td>
<td>Association of Medical Research Charities</td>
</tr>
<tr>
<td>ARF</td>
<td>Agricultural Research Council</td>
</tr>
<tr>
<td>ASH</td>
<td>Action on Smoking and Health</td>
</tr>
<tr>
<td>BBB</td>
<td>Better Business Bureaus</td>
</tr>
<tr>
<td>BDA</td>
<td>British Diabetic Association</td>
</tr>
<tr>
<td>(B)MRC</td>
<td>Medical Research Council (Britain)</td>
</tr>
<tr>
<td>BPA</td>
<td>British Backpain Association</td>
</tr>
<tr>
<td>CAA</td>
<td>Canadian Alzheimer's Association</td>
</tr>
<tr>
<td>CAF</td>
<td>Charities Aid Foundation</td>
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<tr>
<td>CCC</td>
<td>Community Care Campaigners</td>
</tr>
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<td>CCCB</td>
<td>Charity Christmas Card Council</td>
</tr>
<tr>
<td>CCBBB</td>
<td>Canadian Council of Better Business Bureaus</td>
</tr>
<tr>
<td>CCS</td>
<td>Canadian Cancer Society</td>
</tr>
<tr>
<td>CCSB</td>
<td>Canadian Council on Smoking and Health</td>
</tr>
<tr>
<td>CDA</td>
<td>Canadian Diabetic Association</td>
</tr>
<tr>
<td>CFRT</td>
<td>Cystic Fibrosis Research Trust</td>
</tr>
<tr>
<td>CGRC</td>
<td>Canadian Geriatrics Research Society</td>
</tr>
<tr>
<td>CHF</td>
<td>Canadian Heart Foundation</td>
</tr>
<tr>
<td>CMCA</td>
<td>Canadian Masonary Contractors Association</td>
</tr>
<tr>
<td>Acronym</td>
<td>Full Name</td>
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<td>---------</td>
<td>-----------</td>
</tr>
<tr>
<td>(C)MRC</td>
<td>Medical Research Council (Canada)</td>
</tr>
<tr>
<td>CNC</td>
<td>Canadian Neurological Coalition</td>
</tr>
<tr>
<td>COY</td>
<td>Canadian Opportunities for Youth</td>
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<td>CPRI</td>
<td>Christian Prisoners Release International</td>
</tr>
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<td>CPRF</td>
<td>Canadian Psychiatric Research Foundation</td>
</tr>
<tr>
<td>CRC</td>
<td>Cancer Research Campaign</td>
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<tr>
<td>CRPT</td>
<td>Committee for Responsible Public Policy on Tobacco</td>
</tr>
<tr>
<td>CSHA</td>
<td>Chest, Heart and Stroke Association</td>
</tr>
<tr>
<td>DES</td>
<td>Department of Education and Science</td>
</tr>
<tr>
<td>DHSS</td>
<td>Department of Health and Social Security</td>
</tr>
<tr>
<td>DHW</td>
<td>Department of Health and Welfare</td>
</tr>
<tr>
<td>DIG</td>
<td>Disablement Income Group</td>
</tr>
<tr>
<td>EASD</td>
<td>European Association of Societies for Diabetes</td>
</tr>
<tr>
<td>ESRC</td>
<td>Economic and Social Research Council</td>
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<tr>
<td>FCO</td>
<td>Family Care Officers</td>
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<td>FDA</td>
<td>Food and Drug Administration</td>
</tr>
<tr>
<td>FPA</td>
<td>Family Planning Association</td>
</tr>
<tr>
<td>FRNM</td>
<td>La Foundation pour La Research sur Maladie Mental</td>
</tr>
<tr>
<td>GNP</td>
<td>Gross National Product</td>
</tr>
<tr>
<td>HSFO</td>
<td>Heart and Stroke Foundation of Ontario</td>
</tr>
<tr>
<td>ICFA</td>
<td>International Cystic Fibrosis Association</td>
</tr>
<tr>
<td>ICR</td>
<td>Institute of Cancer Research</td>
</tr>
<tr>
<td>ICRF</td>
<td>Imperial Cancer Research Fund</td>
</tr>
<tr>
<td>IRS</td>
<td>Internal Revenue Service</td>
</tr>
<tr>
<td>Acronym</td>
<td>Full Form</td>
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</tr>
<tr>
<td>LAV</td>
<td>Lymphadenopathy Associated Virus</td>
</tr>
<tr>
<td>MDAC</td>
<td>Muscular Dystrophy Association of Canada</td>
</tr>
<tr>
<td>MDGGB</td>
<td>Muscular Dystrophy Group of Great Britain</td>
</tr>
<tr>
<td>NACA</td>
<td>National Advisory Committee on AIDS</td>
</tr>
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<td>NAPT</td>
<td>National Association for the Preservation of Tuberculosis</td>
</tr>
<tr>
<td>NCIC</td>
<td>National Cancer Institute of Canada</td>
</tr>
<tr>
<td>NCSS</td>
<td>National Council of Social Services</td>
</tr>
<tr>
<td>NERCC</td>
<td>Natural Environmental Research Council</td>
</tr>
<tr>
<td>NRC</td>
<td>National Research Council</td>
</tr>
<tr>
<td>NSPCC</td>
<td>National Society for the Prevention of Cruelty to Children</td>
</tr>
<tr>
<td>OHE</td>
<td>Office of Health Economics</td>
</tr>
<tr>
<td>PAYE</td>
<td>Pay As You Earn</td>
</tr>
<tr>
<td>RNIB</td>
<td>Royal National Institute for the Blind</td>
</tr>
<tr>
<td>RNLI</td>
<td>Royal National Lifeboat Institution</td>
</tr>
<tr>
<td>RPI</td>
<td>Retail Price Index</td>
</tr>
<tr>
<td>RSPCA</td>
<td>Royal Society for the Prevention of Cruelty to Animals</td>
</tr>
<tr>
<td>SERC</td>
<td>Science and Engineering Research Council</td>
</tr>
<tr>
<td>SFS</td>
<td>Smoker's Freedom Society</td>
</tr>
<tr>
<td>UGC</td>
<td>University Grants Committee</td>
</tr>
<tr>
<td>UKCCCR</td>
<td>United Kingdom Co-ordinating Committee on Cancer Research</td>
</tr>
<tr>
<td>VAT</td>
<td>Value Added Tax</td>
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<tr>
<td>VSU</td>
<td>Voluntary Service Unit</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<tr>
<td>WRVS</td>
<td>Women's Royal Voluntary Service</td>
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Summary

This thesis examines relations between charities and the state in Britain and Canada: it challenges a common view that government responsibility for welfare provision in this century has rendered charities relatively insignificant and isolated from the political process in both countries. By focusing specifically on medical research charities, evidence is presented to show that lobbying has become an increasingly important aspect of their activity, in spite of legal limitations restricting much of their involvement in the policy process. It is concluded that the law restricting charities from engaging in political activities has had limited success both because of its 'vagueness' and poor enforcement. The only countervailing force keeping medical research charities 'out of politics' to any significant degree has come from volunteers and the donating public, but, even they have had only a limited impact. The degree of political involvement by a charity is now contingent on the policy area in which it operates, the degree of 'hostility' of government policy towards the organisation and its objectives as well as the charity's financial resources.

In light of cut-backs in government expenditure to medical research in the 1980s, of the need to co-ordinate scientific investigations, and of pressures from some volunteers to represent the interests of disease sufferers, as well as a number of other factors, British and Canadian medical research charities have been drawn increasingly into the political process. This evidence suggests that charity-state relations have changed dramatically since the 19th century when charities not only resisted state encroachment into many areas of social welfare, but devoted much of their resources towards encouraging state withdrawal from areas where tax revenues were already being applied. Now charities frequently criticize government policies aimed at cutting-back state funding for programmes in policy areas where charities are operating and also propose new legislation to ensure minimum levels and quality of state-funded services.

Given this, the nature of charity-state relations has changed dramatically and has created difficulties for legislators who have had to reconcile the non-political qualities of philanthropy-including altruism, and community participation - with the reality that much charitable activity is devoted to participating in the policy process. In conclusion the blurring of the distinction between philanthropy and politics has meant that charities have begun to resemble more traditional forms of interest groups while at the same time maintaining their privileged 'tax exempt status'. This is a particularly interesting development given that many British and Canadian medical research charities have been co-opted by pharmaceutical companies to participate in a number of that industry's lobbying campaigns in return for corporate donations.
Chapter One

Introduction

The subject of this thesis is charity-state relations in Britain and Canada. Attention is focused on how and why charities - specifically medical research charities - seek to influence government in each country. Until now 'charity' has not been the concept around which much comparative research has been organized; there are at least three reasons for this.

First, there is the possible confusion between a charity as a legal entity, and charity as it is often used in popular discourse, as an organisation providing benefits to third parties. Second, for many purposes of their operations in countries like the United States, it is non-profit corporation law rather than charity law which is more important for most kinds of organisations having purposes which are legally charitable. Third, the word charity still has connotations of upper-class patronising, and 'Lady Bountifuls' performing good works among the recipients of the services of charities. In place of 'charity', social scientists have used a plethora of terms including 'third sector organisations', 'voluntary sector organisations' and 'non-profit sector organisations'. The problem with these terms is that they are defined loosely and, more often than not, are taken to embrace all agencies 'left-over' once market and governmental
bodies are excluded.

This thesis presumes that charities, as legal entities, do provide the best starting point for an analysis of the relation between a particular distinctive kind of social institution and the state. This is not to deny that, for those concerned with policymaking or implementation, the appropriate starting point may be to identify the institutions to be compared with respect to function, for example, in terms of the kinds of services they provide. Nevertheless, this thesis aims to examine one facet of the merger of ‘public’ and ‘private’ in the area of medical research in Britain and Canada by focusing on charities. Although ‘charities’ have been selected as the ‘unit of analysis’ for this thesis reference to a ‘charity sector’ is avoided. It is recognized that charities operating in different policy areas function uniquely and enjoy rather different relations with government.

One reason for concentrating on Britain and one of its ex-colonies is that governmental relations with private agencies providing social welfare have been similar in the past. This experience is quite different from that in the rest of Europe.


2 This approach towards the study of relations between charity and the state is described in more detail in: Tom Deans and Alan Ware, ‘Charity-State Relations: A Conceptual Analysis’, Journal of Public Policy. 6(1986), pp. 121-135. An earlier version of the article was presented at the panel on ‘Politics, Government and Charities’ at the Annual Conference of the Political Studies Association, Nottingham, 1986.
However, in any analysis involving Britain and Canada, there is a strong argument for including American examples, since that country shares a number of features with Canada, including a federal system of government. Nevertheless, in studying charities and relations with government there is a specific reason for focusing on Canada, rather than on the United States: its charity laws remain virtually identical to those in Britain, while broadly similar American charity laws are paralleled by laws relating to non-profit organisations, which have been far more important in shaping charity-state relations in the United States, (unlike Britain, Canada too has non-profit corporation laws, but these have not been the major influences on the nature of charitable institutions).

Previous studies that have examined charity-state relations as part of larger research projects have either ignored or downplayed the lobbying activities of charities. Instead, they have chosen to focus on how they organize themselves and operate to meet social needs in the presence of a large and comprehensive welfare-state. Research has focused mainly on ways in which charities now complement, supplement and extend the statutory

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systems.4 In doing so, the contributions of charities have been evaluated in the context of their role as institutions in a pluralistic society and governmental system. Curiously though, political scientists have not been at the forefront of this research movement. Instead, economists, sociologists, social historians and social-science-oriented lawyers have formed the vanguard, yet in many cases they have addressed issues which are of direct concern to political scientists. This lack of concern is surprising given the vast number of registered charities operating in Britain and Canada and their enormous financial resources. For example, one estimate of the income of the 130,000 registered British charities is that it constitutes as much as three per cent of the Gross National Product (GNP). In comparison to Canada, 50,000 registered charities are calculated to have a combined income equal to two per cent of GNP.5

In relation to the statutory system, previous studies argue that modern-day charities have had three kinds of contributions to make. First, they have been able to offer services when little or nothing has been available through state mechanisms. In the

4An important example of this kind of research is R. Hadley and S. Hatch, Social Welfare and the Failure of the State. London: Allen and Unwin, 1981.

5See, Charities Aid Foundation, Charity Statistics, 1985/86. Tonbridge: CAP, 1986, p. 6; and S. Martin, An Essential Grace. Toronto: McClelland and Steward, 1985, p. 10. The absence of detailed empirical research into British and Canadian charities is in part attributable to the scant availability of useful data. Moreover, it is frequently true that the data that is available is produced by interested parties - including government departments, politicians and charities themselves.
context of existing provision, a number of studies have documented the capacity of charities to develop innovative programmes and services of 'benefit to the community'. For example, the new methods of treatment that have been developed in work with families, drug addicts and delinquents are at the focus of much of the social welfare literature emerging from Britain, Canada and the U.S. This body of literature has also examined in detail the way in which statutory services have been extended by charities providing alternatives to statutory services (examples include youth clubs and residential care for children, the handicapped and the elderly). These studies frequently conclude that charities not only extend the quality of provision but extend the choices available to service users. Other notable conclusions in this literature are that charities further contribute by attracting people, ideas and material resources that would not have been attracted by statutory organisations. A related theme is that people are often more willing to give time, energy and money to a charity devoted to a specific cause than to a statutory agency. Finally, it is interesting that charities actually offer direct support services to statutory bodies; for example, the Women's Royal Voluntary Service (WRVS) provides meals on wheels, hospital trolleys and so on. However, in all these studies rarely is mention made of the lobbying, (and other political) activities of charities.

The second kind of well-documented contribution that charities make is in improving the quality of government provision. Many British charities provide 'alternative' services to those supplied by the state. The choice for the user means the right to turn down the statutory service, a possibility which provides an incentive for the state to improve the service and to make it more receptive to the user's wants. Another way in which the monolithic qualities of statutory provision may be eroded by philanthropic actions is revealed in studies where charities are observed to be working closely with a statutory body. The very presence of outside organisations like charities can prevent possible abuses of power and stimulate standards of state provision.

Third, the existing literature dealing with charity-state interaction - or lack thereof - has focused most notably on examples of charities that are either the sole or the principal provider of a service. These studies conclude that some recognized social needs have attracted little or no response from the state. For example, the 'need' for a particular service is often rated by government as a low priority, as is the case with


day-care centres for pre-school children. In addition, it has been concluded that these same services are often viewed by elected and non-elected officials as inappropriate for direct statutory involvement as is true of advice and counselling services for pregnant women. However, in these studies too few references, if any, are made to the lobbying activities of charities aimed at introducing or improving regulatory and statutory reforms in these various policy areas.

Other studies of charity-state interaction have focused on aspects of government planning and the role of charities in this process. The conclusions are usually that charities are the ideal medium for spontaneous, speedy and autonomous action. However, these same features have arguably demonstrated there are no guarantees that a charitable response will materialize where need is greatest, that standards of services will be maintained, or that this so-called 'sector' as a whole will operate in a co-ordinated manner. From this, it is often concluded that in the British and Canadian political systems, ultimate responsibility for ensuring that formal provision is made to meet social needs rests with government. Consequently, it is agreed that national


governments must be ready and willing to assume the responsibility of compensating for deficiencies in the pattern of provision. Hence, there must be national policy strategies that include charitable provision of services within the broader context of the statutory welfare system. These same studies point to the use of direct government funding as an incentive for the creation of new charities and the maintenance and expansion of others. The main object of these studies (most of which are American) is to shed light on one of the central issues in political science: understanding the blurring of the distinction between public and private institutions in liberal democracies. Most traditional 'liberal' models of democracies have emphasized the separation of the state from other institutions and organisations. In the United States, where charities have been the focus of more in-depth study by political scientists, the main concern about the apparent merging of charities and the state has been government funding of charities. Salamon has argued that the expansion of the federal government in America in the period 1954-79 was achieved through what he calls 'third party government'. By relying on devices such as loans, loan guarantees, insurance


coverage and the like, the federal government made third parties—
charities, as well as state and local governments—the agents of 
federal expansion. This placed federal officials in the position 
of being held responsible for federal programmes which they did 
not actually control; in his view the federal government came to 
share its authority with private sector organisations having the 
legal status of charities. Yet surprisingly what is absent from 
Salamon's study, as with most other American studies, is a 
complete explanation as to how this developed and the extent to 
which lobbying by charities themselves created and sustained these 
financial subsidies.

The closest that existing studies of charity-state relations 
come to shedding light on how and why charities seek to influence 
governments are those which examine the contributions of these 
organisations to the maintenance of a pluralistic state. However, 
at the focal point of these writings is the services provided by 
charities and the role of volunteers as opposed to their 
representation of specialized 'interests'.13 Here, the principal 
benefits attributed to charities have related to their potential 
as a means of enabling widespread direct public participation. 
This is deemed to be especially important in modern industrial 
states dominated by large-scale political, economic and social 
institutions. Specifically, it is suggested that between the 
loosely structured informal system consisting of friends and

13See A. Holme and J. Maizels, Social Workers and 
family and the more formally organized statutory system, individuals have been able to utilize charities as a medium to associate with others to achieve their own set of altruistic goals and aspirations. These research projects (many of which have been designed by sociologists within pluralist paradigms) conclude that people participating in charitable organisations not only feel less alienated from society but are also engaged in altering its nature. This 'alteration' has been achieved directly through the activities these charities undertake and less directly, through the signals sent by these activities to the statutory system on the nature of shifts in public concerns. It is here that the sociologists' interpretation of charities' contribution to pluralism comes close to shedding light on the lobbying activities of charities. However, their failure to solidify this argument is symptomatic of an assumption that charities are passive institutions ill-adept and dis-interested in articulating their views to government.

The evidence presented in this thesis regarding British and Canadian medical research charities strongly suggests the opposite is true. However, if charities are engaged in lobbying activities, why have political scientists failed to account for this in both their theoretical and descriptive studies of British and Canadian interest groups? There are at least two explanations for this development. First, social scientists like most lay-

people cling to ill-conceived notions that charities are small, loosely-structured organisations, administered principally by unpaid volunteers and are 'fuelled' by altruism and public benevolence. All these assumptions have forged the misperception that charities are generally divorced from the political process, and indeed are legitimated by remaining aloof and politically independent. Second, some believe that government responsibility for welfare provision in this century has rendered charities insignificant and isolated from the political process. However, by focusing specifically on medical research charities in chapters five to eight, evidence is presented to show that lobbying has become an increasingly important aspect of their activity in spite of legal limitations restricting much of their involvement in the policy process. It is concluded that the law restricting charities from engaging in political activities has had limited success both because of its 'vagueness' and poor enforcement. It is argued throughout the thesis that the only countervailing force keeping medical research charities 'out-of-politics' to any significant degree has come from volunteers and the donating public, but, even they have had only a limited impact. The degree of political involvement by a charity is now shown to be contingent on the policy area in which it operates, the degree of opposition to new government policies towards the interests of the organisation and its objectives, as well as the charity's financial resources.

But why study medical research charities in this context?
There are at least four answers to this question. First, medical research charities represent an interesting sub-sector of philanthropy in that they illuminate well the problems associated with the involvement of volunteers in the administration of charities. Second, medical research is a central area of charitable activity in terms of the financial contributions it receives from the donating public. Third, medical research is an especially important area for understanding relations between charities and the state, since the British and Canadian governments also participate directly in funding their own scientific investigations. Fourth, medical research is an area which lends itself to examination by social scientists given that the number of organisations is not unmanageably large. As explained in more detail in Appendix I, the problem of having to take only a ‘representative sample’ of charities is avoided in the case of medical research since virtually all organisations operating in Britain and Canada could be included in the interview schedule. Thus the difficulty which faces researchers studying, for example, poverty relief organisations (where there are a large number of disparate organisations in this field) can be circumvented.

There is a second question that arises, namely why study medical research in a comparative perspective? The most important reason is that there is sufficient in common between Britain and Canada in terms of a shared legal system, relating to charities and some similar social and political structures. At the same
time there are, of course, a number of important differences. For example, the most important perhaps, includes Canada's bi-cultural heritage, which has affected the development of its social institutions, as has the federal political system. It is a combination of both the similarities and differences between Britain and Canada which makes this comparative study of relations between charity and state particularly illuminating.

An important initial point to make is that for some purposes in this thesis reference will be made to England rather than Britain since the legal position of charities is somewhat different in Northern Ireland and very different in Scotland (the Scottish definition of a charitable trust is broader than that adopted in England). However, in discussing specific charities that operate in each of the three regions the term 'British charity' is adopted.15

In this case study of British and Canadian medical research charities, it is argued that, in light of cutbacks in government expenditure to medical research in the 1980's, of the need to coordinate scientific investigations and of pressures from some volunteers to represent the interests of disease sufferers, as well as a number of other factors, charities have been drawn increasingly into the political process. This evidence suggests that charity-state relations have changed dramatically since the

19th century when charities not only resisted state encroachment into many areas of social welfare, but devoted much of their resources towards encouraging state withdrawal from areas where tax revenues were already applied. Charities are shown now to be frequently critical of government policies aimed at cutting-back state funding for programmes in policy areas where charities are operating and also propose new legislation to ensure minimum levels and quality of state-funded services.

Given this, the thesis argues that the nature of charity-state relations has been altered and has created difficulties for legislators who have had to reconcile the non-political qualities of philanthropy - including altruism and community participation - with the reality that much charitable activity is devoted to participating in the policy process. The thesis concludes that the blurring of the distinction between philanthropy and politics has meant that charities have begun to resemble more traditional forms of interest groups while at the same time maintaining their privileged 'tax exempt status'. This is a particularly interesting development given that many British and Canadian medical research charities have been co-opted by pharmaceutical companies to participate in a number of that industry's lobbying campaigns in return for corporate donations.

The problems to be considered in this thesis have now been described in a general way. The substantive part of this research is contained in seven principal chapters while the main conclusions to be drawn from it are outlined in chapter nine. A
summary of the subject matter of each of the main chapters is given below.16

Chapter Two

This chapter has three objectives. First, it provides an introduction to a number of institutional actors in each country included in this study of charity-state relations. Second, it illustrates how charity law has developed in response to reconciling the interests of private philanthropy with the interests of the state. Third, it demonstrates how charity law in its present form, is applied when registering and supervising charities. In doing so, it is further demonstrated that Canadian law is very similar to English law. However, it is argued that there are a number of important differences between the two countries regarding the institutional structures responsible for registering and supervising charities.

Chapter Three

The discussion of charity law is continued in this chapter focusing specifically on the legal rule restricting British and Canadian charities from engaging in political activities. This chapter divides into three sections. The first examines the development in both countries of the common law restriction placed on charities and their involvement in the political process. This discussion takes account of the social conditions out of which the

16For a statement of the conduct of the research in Britain and Canada see Appendix I.
law developed and the policy justifications given by judges in developing this area of law. Section II compares American legislation on the one hand with British and Canadian laws on the other. In section III, attempts at legal reform to deal with the increasing incidence of political involvement by British and Canadian charities are examined.

Chapter Four

The purpose of this chapter is to survey charities' financial sources and to develop a foundation for understanding the diverse relationships between charities and the state. In addition, an explanation is developed as to why charities, especially those operating in the medical research field, have assumed a greater responsibility, with the state's assistance, for the provision of important services. The chapter divides into two sections. A variety of government financial sources available to charities is examined followed by a discussion of the various types of non-financial government support extended to charities in both Britain and Canada.

Chapter Five

This chapter is the first of four chapters focusing specifically on charities which collect and spend, voluntary contributions on medical research. In each of these chapters the main object is to gain an understanding of how, and over what issues, medical research charities interact with government. To provide some context to the case-study, chapter five begins with a
short history of the role of medical research in changing public health. This is followed by a discussion of the history of charities in this policy area, highlighting both their organisational features and their varying capacity to raise voluntary contributions depending on the disease being represented. The chapter concludes by outlining the governmental response to funding medical research in each country.

Chapter Six

This chapter seeks to present an understanding of the interaction between medical research charities and government within the context of theories of public goods. Section I outlines the mechanisms in place to facilitate collaboration between charity and state so as to avoid duplicating bio-medical research. Section II examines examples of charity-government collaboration in funding joint research projects. From this an assessment is made as to whether medical research charities and government view each other as partners or competitors in this policy area. Section III describes how the British and Canadian governments divide their research budgets among various diseases. In response to what charities view as an inequitable distribution of public tax revenue among disease areas, evidence is presented that charities have begun to lobby government despite legal limitations on political activity.

Chapter Seven

Section I of this chapter describes the British government’s
declining commitment to bio-medical research since 1980 and discusses how British medical research charities have successfully increased their incomes during the same period. Furthermore, arguments are outlined as to why charities are ill-suited to assuming a greater responsibility for funding medical research in the wake of declining government commitment to this policy field. Section II examines the federal government’s newly introduced formulae for funding Canadian bio-medical research. It is argued that with this new arrangement, the Canadian government (like the British government) has shifted a portion of its responsibility for funding this policy field to charities. In response, medical research charities in both countries have lobbied government vigorously to spend more on bio-medical research, despite legal limitations to their involvement in the political process.

Chapter Eight

While chapters five, six and seven focus on medical-research-related issues, chapter eight examines charitable involvement in lobbying government on patient services and public-education-related issues. In doing so, the chapter divides into three sections. The first deals with a number of patient-service issues directly related to the Canadian and British pharmaceutical industry. Section II examines patient-service issues unrelated to the industry which have prompted medical research charities to lobby on behalf of disease-suffering volunteers and financial contributors. Section III differs from the previous two sections, in that it focuses not on lobbies organized around patient
services, but rather lobbies organized around preventive medicine. Specifically, it examines the role of medical research charities in the anti-smoking lobby. Here the skill and sophistication of these organisations in pressuring government for legislative reform is revealed.
Chapter Two
Charity and the Law: An Historical Review

This chapter has three objectives. First, it provides an introduction to a number of institutional actors in each country included in this study of charity-state relations. Second, it illustrates how charity law has developed in response to reconciling the interests of private philanthropy with the interests of the state. Finally, it demonstrates how charity law, in its present form, is applied when registering and supervising charities. In doing so, it is further demonstrated that Canadian law is similar to English law. However, there are a number of important differences between the two countries regarding the institutional structures responsible for registering and supervising charities.

While the courts in England and Canada are the final arbiters of whether an organisation is charitable. The vast number of cases, involving the definition of 'charitable purposes' do not reach the courts. Instead, the responsibility for registering and supervising charities lie with the Charity Commission and Revenue Canada respectively. But how does the law define 'charity'? The fact is that 'charity' as a legal concept is not defined. Indeed, in both England and Canada there is considerable ambiguity attached to the terms 'charity' and 'charitable organisation'. In
the context of common law, the issue put before the court is	normally whether a particular organisation has 'charitable
purposes'. Therefore, in a strict legal context the question of
defining the concept of 'charity' is more precisely a question of
interpreting what 'purposes' are charitable. Throughout the
process of determining the status of an organisation's 'purposes'
the administrative bodies in each country, and the courts in the
final instance, apply four legal tests.

These tests can be summarised as follows: (1) Do the
purposes of the organisation fall within the classification of
charitable purposes set forth by Lord Macnaghten in the legal
case, IRC V. Pemsel (1891)? It was in this court decision that
the Judge Lord Macnaghten, held that all charitable purposes could
be categorised as for either a) the relief of poverty or b) the
advancement of education or c) the advancement of religion or d)
other purposes beneficial to the community. (2) Another test
applied by both the administrative bodies and the courts, seeks to
determine whether an organisation's purposes are for the benefit
of the public. This test, while appearing to be identical to the
last section of the Macnaghten classification, is actually
different. It is an additional test to ensure that charities
provide a benefit of a tangible nature to the public or a
sufficient section thereof. For example, an organisation would
not be held charitable if it provided a service of benefit to the

1The Commissioners for Special Purposes of the Income Tax Act
V. Pemsel (1891) A.C. 531 (H.L.)
community but which was inaccessible to a broad cross-section of society. In other words, this second test measures a charity's 'purposes' to determine whether the accessibility of its services are broad enough. In contrast, the last category of Macnaghten's classification is a test of the nature of the benefits derived.

(3) An additional test requires organisations to have purposes that are analogous to those listed in the preamble to the Statute of Charitable Uses (1601).2 (4) The final test comprises a category that examines whether an organisation's objects violate public policy. This procedure includes an evaluation of an organisation's purposes to determine if a) there is an absence of self-help; b) an absence of profit distribution and c) an absence of substantial political activity. If organisations possess any of the above characteristics, they may be refused registration or have their charitable status revoked.

I. The History of Charity Law

This section of the chapter explores the historical development of the existing laws applicable to British and Canadian charities. By examining each of the four tests, the origin and development of charity law is revealed as is its influence on the way charities are now organized and operated. The major substance of charity law, as it is now applied in both countries, was determined largely between the years 1601 and 1891.

However, by 1891 Canada had only existed as an independent nation for 24 years. Therefore, the following discussion of the history and development of charity law must be taken largely to mean a history of English charity law.

There are a number of reasons for examining how this body of law has evolved into its present form. First, lawyers believe that a proper understanding of the present law requires an appreciation of the origin and the development of the common law treatment of 'charity'. Proceeding in this way reveals several important themes. For example, a number of social and political influences have played a decisive role in shaping the laws which regulate charities. From 1601 up to the present day, there has continued the problem of legally reconciling private philanthropy's provision of welfare services with the need for some provision by the state. Even Hobbes, writing in the 17th century recognized the need for some form of state provision to compensate for the inequities associated with organized philanthropy. In the Leviathan Hobbes writes:

"And whereas many men, by accident inevitable, become unable to be left to the charity of private persons; but to be provided for (as farforth as the necessities of nature require), by the Laws of the Commonwealth. For as it is uncharitableness in any man to neglect the impotent; so it is in the sovereign of a Commonwealth, to expose them to the hazard of such uncertain charity."

From 1601 to 1853 the struggle between charity and the state was more precisely a struggle between the church and state, since the former was normally used as the executor of charitable bequests. Although secular charities had existed prior to the mid 19th century their scope of activity, in comparison with church charities, had only started to expand greatly during the period of the industrial revolution. The shift away from using the church as the executor of charitable bequests, to the use of private trusts, was accompanied by a new instrument of state supervision designed to regulate the administration of charitable trusts (the Charity Commission). Established in 1853, after decades of controversy and complaints of inefficiency among charities, the Commission sought to ensure that funds designated for charitable purposes were applied honestly and efficiently.

A. The legal concept of charity

As one legal historian remarked: "The concept of 'charity' is an elusive and every changing concept that is virtually impossible to define". Both Revenue Canada and the Charity


5The Brougham Commission was the antecedent of the Charitable Trusts Acts (1853), (1855) and (1860) which established for the first time a permanent government agency to supervise the administration of charitable endowments. By 1860, the Commission had three full-time commissioners and one part-time commissioner.

Commission have charged that the common law interpretation of
city is antiquated. Disputes over the registration of
charities are referred to the courts, where judges must then
consult a list of charitable ‘purposes’ contained in an English
statute passed in 1601. In order to understand present charity
law, one must first examine The Statute of Charitable Uses (1601),
or The Statute of Elizabeth I, as it is sometimes referred to.

Before the late 16th century there was little need to develop
a concept of charity in English Law. The church, the manor, and
the guilds undertook most social welfare work. Those individuals
who desired to make gifts or bequests for charitable purposes
frequently did so by making them to the church, which in turn
would administer the funds for the purposes requested by the
donor. The ecclesiastical courts supervised the administration of
such funds. However, as medieval institutions like the church
deprecated in importance, merchants and the landed gentry began
assuming a larger role in funding social welfare institutions. Trusts were the legal instrument by which much of this funding was

be found in M. Chesterman, Charities, Trusts and Social Welfare.
London: Weidenfeld and Nicholson, 1979, chs. 2, 3; G. W. Keeton
Northern Ireland Legal Quarterly Inc, 1971; HMSO, Report of the
Committee on the Law and Practice relating to Charitable Trusts.

7British Interview; The Charity Commission, 31 March 1987;
and Canadian Interview; Revenue Canada, Tax Exempt Division, 29

8C.E. Crowther, Religious Trusts. Oxford: George Ronald,
1954, pp. 32-33.
secured. In most cases of benevolent giving in the years leading up to the 1601 statute, a donor would, normally by will, leave a gift to a church, or to some other persons, with instructions that it be applied for a charitable purpose. In 1598 the Court of Chancery assumed jurisdiction from the ecclesiastical courts in enforcing these uses. It was natural that the king, as parens patriae, would assume responsibility through the chancellor for supervising these funds devoted to the public benefit. As can best be determined, it appears that prior to 1601, the court of chancery, in deciding whether a use was charitable, simply asked whether it was or was not for substantive public benefit.9

The Tudor state became increasingly concerned in the late 16th century about the escalating problems of poverty and vagrancy for two important reasons. First, agrarian reorganisation displaced thousands of workers creating large blocks of unemployed workers in many regions of the country. Second, with the advent of new manufacturing techniques and a greater reliance on international trade, the English economy became more buoyant. As a result, there occurred cyclical levels of unemployment which, during downturns, created a large number of destitute labourers and vagrants. Consequently, from 1597 to 1601 the Elizabethan Poor Laws were enacted by Parliament. The notable feature of these laws was that they systematically placed responsibility for the relief of poverty in the hands of local officials. Coinciding

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with the enactment of the poor laws was a dramatic increase in the amount and number of charitable bequests made in aid of the poor and dispossessed. Long and complex debates in response to this outburst of altruism eventually led to the enactment of the Statute of Charitable Uses (1601). Most legal historians agree that Legislators were attempting to encourage more private philanthropy by ensuring donated funds were applied for their intended purposes.10

In essence, the Statute established the administrative machinery to supervise the application of charitable trusts. For example, ad hoc local commissions, appointed by the chancellor, were created to investigate allegations made by private individuals involving "any breach of trust, falsity, non-employment, concealment, misgovernment or conversion of trust money".11 In carrying out their official duties, the appointed local commissioners required a set of guidelines listing the types of uses they should investigate if the need arose. Thus, the preamble to the statute listed a number of representative trusts.12 However, each of these trusts were only held valid if

10Jones, History of the Law of Charity, p. 25.


the principal benefit flowed to the 'poor'. The legislation provided as follows:

Whereas lands ... goods ... chattels ... and money, have been ... given ... by sundry ... well disposed persons ... for ... The relief of aged, impotent and poor people; The maintenance of sick and maimed soldiers and mariners; The maintenance of schools of learning, free scholars in universities; The repair of bridges, ports, havens, causeways, churches, sea banks and highways; The education and preferment of orphans; The relief, stock or maintenance of houses of correction; The marriage of poor maids; The supportion, aid and help of young tradesmen, handicraftsmen and persons decayed; The relief of redemption of prisoners or captives; The aid or ease of any poor inhabitants concerning payment of fifteens, setting out of soldiers and other taxes. Which lands ... goods, ... chattels ... and money, nevertheless have not been employed according to the charitable content of the givers ... by reason of frauds, breaches of trust and negligence in those that should ... employ the same.

The preamble to the Statute of Charitable Uses, was neither intended to represent a definition of 'charity' nor of charitable purpose. Instead it provided an *illustration* of what should be considered a valid charitable purpose. The statute has long since been repealed, but no other legislation has been enacted in either England or Canada which defines the concept of 'charity'.

Nonetheless, the 1601 preamble is still consulted directly or by analogy during cases centering on the validity of a 'purpose'. This is done since the document is said to list those purposes 'illustrative' of what should legally be considered charitable. The legal procedure of referring by 'analogy' to previously decided cases which themselves are based on cases analogous to a purpose listed in the 1601 case is one of the means by which the courts presently rule on the issue of charitable status. This partially explains why the law of charity has a degree of built-in flexibility. What is unusual about this aspect of law is that no statute clearly 'defines' the concept of charity. Instead, reference continues to be made to a statute enacted almost 400 years ago, which itself only lists a number of purposes illustrative of what the law regards as charitable. This has meant, that the courts have enjoyed the flexibility through their own judicial discretion to validate charitable purposes which aim to advance the interests of society. At the same time they have been able to deny status to organisations which, for example, are motivated by the self-interest of their membership. The 1601 statute in itself represented an attempt by the Tudor state to resolve the serious problems of poverty and vagrancy. It did this by encouraging individuals to assist in the relief of poverty through charitable trusts whose activities were controlled by a statutory mechanism. In turn, this meant that a portion of the administrative burden was taken off local governments who were

responsible for enforcing the poor laws.

By most accounts, the legal procedures established in 1601, aimed at supervising charities, were successful for the first 30 or 40 years. However, these procedures were cumbersome and the law began to fall into disrepute with the general public. One of difficulties concerned the commissions enforcement of charitable trusts, since much of this responsibility rested with the general public who were expected to provide information (in the name of the Attorney-General) to, the Chancery court. However, few such actions were ever brought. Thus, for the next one hundred years there were very few legal cases which actually affected the types of purposes which were legally recognised as being charitable. However, under the Mortmain and Charitable Uses Act (1736) the concept of charity was expanded which theoretically enabled it to embrace a new set of organisations. The statute stated that "gifts of land to already established charities, or for new charitable purposes, should be invalidated by the courts unless the recipient was a university, college or school entitled specifically to exemption".15 Politicians of the day were concerned about the church acquiring excessive wealth by way of charitable bequests at the expense of the great landowners who sought to consolidate and maintain landed estates within their families.16 Judges wishing to protect the interest of heirs (and clearly most were disposed to do this) were therefore given the

15M. Chesterman, Charities, Trusts and Social Welfare, p. 56.
16Ibid., p. 36.
discretion in cases covered by the Act to widen the concept of 'charity' by bringing gifts within the Act and then striking them down. For example, a donation of land to a church for the purpose of establishing a hostel for visiting theologians was ruled to be a charitable gift but unenforceable under the Mortmain Statute. However, by invalidating the gift through this type of judicial reasoning, the establishment of 'hostels' became a newly recognized charitable purpose. By doing this, legislators, without fully realizing the impact this would later have, broadened the interpretation of a valid charitable purpose by allowing the courts to recognize a new set of organizations as being charitable. These newly recognized charities were still required to have purposes either identical or at least analogous to ones listed in the 1601 preamble. By doing this, Chesterman remarks that the Mortmain Act distorted the interpretation of the 1601's concept of 'charitable' since it no longer required a purpose to contain a 'public benefit' objective principally aimed at benefiting the poor.17 Prior to the Mortmain Act, the courts had held that the list of illustrative charitable purposes found in the 1601 statute had to also be of some benefit to the poor. This meant that during the pre-Mortmain Act period the scope of charitable activity was greatly limited. However, with the enactment of the Mortmain legislation public benefit was not simply equated with benefit to the poor but instead to 'any section of the community'. This permitted a much wider variety of

17Ibid., p. 56.
organisations having purposes held to be analogous to those listed in the 1601 statute to be considered charitable. As a result, organisations having principal purposes other than for the relief of poverty, for example, public school's providing education for the sons and daughters of the very wealthy, were held to be valid purposes. In essence, the Mortmain legislation is primarily responsible for widening the gap between our popular notion of charity as being purely altruistic organisations and what is actually held to be charitable under common law (this presently includes a large number of educational, medical research, and animal welfare charities that are completely unrelated to poor relief). While the Mortmain Act has provided the legal device for expanding the interpretation of a valid charitable trust, for more than two centuries this was largely discouraged by the courts throughout the 18th and early 19th century. Judges were concerned about bequests made for charitable purposes which threatened to deprive a testator's family of its 'rightful' due. So long as the bequests only involved personal property, family members could be protected by giving 'charitable' a narrow meaning and holding invalid, on grounds of uncertainty and/or perpetuity, only 'non-charitable' bequests. This restrictive approach was adopted by the courts in Morice V. Bishop of Durham (1805). In this legal case, Lord Chancellor Eldon, the presiding judge, held that the trust bequeathed to the Bishop of Durham (the executor) was not

18 Ibid., p. 57.

charitable since the objects of the bequest were uncertain. The gift was also invalidated due to the court's sympathy to the general anti-clerical movement at the time.20

Aside from the development of the law's interpretation of a valid charitable purpose, one feature that has long characterised English and Canadian charities is their exemption from a variety of taxes. However, very little is presently understood of the legal principles or guidelines tax officials have adopted in determining tax exemptions. In 1799, the first income tax statute was passed in England which provided the exemption of all 'corporation(s) fraternit(ies) or societ(ies) of persons established for charitable purposes only'.21 It appears that initially the Commissioners of Inland Revenue adopted the same definition of charity that had developed in trust law. However, to ensure that this particularly lucrative tax concession was not granted to too many organisations, the Commissioners in the Treasury lobbied for a much more narrow definition of charity. In


21Income tax ceased to be applied in 1816 to all corporations including charities, but, when, reinstated in 1842, the exemption to charities was subsequently reapplied. The fact that income tax and the Inland Revenue were not firmly entrenched in Britain's commercial culture by the 19th century partly explains why supervisory responsibilities went to the Charity Commission as opposed to the Inland Revenue. In Canada, when philanthropic activity did require government supervision at the beginning of the 20th century, income tax was firmly established and thus may be a partial explanation as to why responsibility for supervising charities went to Revenue Canada as opposed to a separate agency modelled after the Charity Commission. Another explanation is that Canada did not have old, corrupt, inefficient trusts which required modernizing. This was one of the main issues in the 19th century debate in England over the need for a Charity Commission.
1863 the interests of the Inland Revenue were taken up by Gladstone, who was then Chancellor of the Exchequer. Parliamentary debates reveal that Gladstone argued that endowed charities engaged in the relief of poverty (which were usually older organisations deriving their income from the interest or investment of bequeathed money) should not be entitled to exemption. He argued that by exempting them from paying income tax on their accumulated income, the state and others who did pay tax would subsidize these organisations. Moreover, he suggested that the financial subsidisation of the charities was not accompanied by any form of state control. While Gladstone’s attack did not materialise into legislative reform, it did help Inland Revenue officials to defend their new policy to grant the coveted tax exempt status only to organisations engaged in the ‘relief of poverty’. Over the next 23 years, this view remained unchallenged. However, in 1886 when the Commissioners of Inland Revenue refused to grant an exemption to a trust, the precedent

22 The following excerpt from his Financial Statements of 1863 summarises his concerns,

"If we have the right to give public money, we have no right to give it in the dark. We are bound to give it with discrimination; bound to give it with supervision; bound as a constitutional Parliament, if the Hospitals are to receive a grant, to bring them within some degree of control." Quoted in D. Owen, English Philanthropy 1660–1960, p. 331.

Furthermore, in his speech in Parliament, Gladstone noted that following his argument in his financial statement of 1863 he was struck "by the skillful manner in which the charitable army, so to call it, has been marshalled". Quoted in Owen, English Philanthropy 1660–1960, p. 332.
setting case *Commissioners for Special Purposes of Income Tax V. Pemsel* was launched.23

The judicial decision of this legal case continues to provide the Charity Commission and Revenue Canada with lines for deciding what organisations should become recognised officially as charities. In addition, the courts in both countries continue to rely on the Pemsel decision in providing four categories of charitable purposes. Because this common law case is so important in terms of the history of charity law and has impacted greatly on the way charitable organisations are organised and operated, there is utility in briefly stating its facts.

In 1813, certain areas of land were transferred to trustees to apply the income for the general purpose of establishing and administering a number of Protestant Episcopal Churches (commonly known as the Moravian Church). The substantive issue put before the court was whether the purposes of the trust were charitable within the meaning of 'charitable purposes' under the Income Tax legislation. The Income Tax Commissioners argued the concept of charity, as properly used in the income tax legislation, should be restricted to its ordinary meaning; namely the 'relief of poverty'. Pemsel on the other hand (who was the Treasurer of the Moravian Church) argued that even in the context of tax legislation the word 'charity' ought to be given its technical meaning; the meaning it had acquired in trust law.

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In long and detailed judgements the House of Lords ruled in favour of Pemsel. Lord Macnaghten, who wrote the leading majority opinion, expressed an important reason as to why the court ruled against the Income Tax Commissioners. Macnaghten felt that the commissioners had acted improperly in changing their administrative practice by adopting a too restrictive definition of charity. He stated that:

With the policy of taxing charities I have nothing to do. It might be right, or it may be wrong, but speaking for myself, I am not sorry to be compelled to give my voice for the respondent. To my mind it is rather startling to find the established practice of so many years suddenly set aside by the administrative department of their own motion, and after something like an assurance given to Parliament that no change would be made without the interposition of the legislation.

Second, and probably the more important aspect of the case (other than its holding that charitable purposes have the same meaning for tax as they do for trust law) is the four-fold classification of charitable purposes developed by Lord Macnaghten. In the course of giving his reasons for judgement he stated that:

Charity in its legal sense comprises four principal divisions: trusts for the relief of poverty; trusts for the advancement of religion; trusts for the advancement of education and trusts for other purposes beneficial to the community, not falling under any of the proceeding heads.

24 Ibid., p. 591.
25 Ibid., p. 591.
By 1891, the most important legal principles had been firmly established in practice which to this day affect the character and scope of English and Canadian charity law. For example, the purposes listed in the preamble to the Statute of Charitable Uses (1601) are now being referred to directly or by analogy in determining the validity of charitable purposes. In addition, the Macnaghten classification provided a contemporary interpretation of ‘charitable purposes’ which captures the ‘spirit and intendment’ of the preamble to the 1601 statute. It is these two legal devices which serve as the basis for determining whether or not an organisation is worthy of charitable status. In addition, several other important legal tests have developed naturally in response to the changing social and political conditions under which charities now operate.

26Particular thanks to John Dewar, School of Law, University of Warwick, for synthesizing the legal importance of a) The Statute of Charitable Uses (1601), b) The Mortmain and Charitable Uses Act (1736), c) Morice V. Bishop of Durham (1805) and d) IRC V. Pemsel (1891).

27Basically the courts of virtually all Commonwealth countries use the same methodology in determining whether a particular purpose is charitable. And in Canada the courts will frequently cite and rely upon decisions from other Commonwealth countries, particularly, of course, decisions of the courts in England. The American courts also apply the common law definition of charity and their decisions are usually discussed under the same headings as decisions from Commonwealth courts. However, American courts do not feel as bound as Canadian courts to refer to the categories set out in Pemsel’s case or to the Statute of Charitable Uses (1601). Therefore, American legal decisions are seldom cited by Canadian courts. However, the legal principles applied are basically the same.
B. Charity law in England and Canada

In England, and indeed in most Commonwealth countries including Canada, there are a number of 20th century court decisions regarding the definition of a ‘charitable purpose’. Underlying these decisions are four tests which the courts invoke when deciding whether or not a ‘purpose’ is charitable. This section of the chapter reviews each of these four tests, in order to illuminate the legal principles underlying the common law interpretation of ‘charity’. This serves to pinpoint exactly which types of organisations qualify for charitable status, and to illustrate the wide variety of activities which these organisations are now engaged in.

(i) Pemsel's case

In the process of determining charitable status, the courts first examine whether an organisation’s purposes fall within one or more of the categories listed by Lord Macnaghten in Pemsel's case 1891. This means that a trust or organization's purpose must be unequivocally for a) the relief of poverty, b) the advancement of education, c) the advancement of religion or d) some other purposes beneficial to the community. In both countries, the courts are compelled to rule that a ‘purpose’ is not charitable if it cannot be categorised according to the options listed in Macnaghten's decision.

One question frequently posed is, why is the categorisation significant particularly when the fourth category (purposes beneficial to the community) could be taken to embrace the first
three categories? In resolving this question, legal experts agree that if the 'purposes' fall within one of the first three categories mentioned in Pemsel's case, the courts are then compelled to rule that the organisation or trust is for a 'public benefit'. However, if the 'purposes' fall within the fourth category, the applicant organisation must prove that the 'purpose' is indeed for a public benefit.

English and Canadian legal experts are of the opinion that the categories listed by Macnaghten provide judges with a list of conveniences. However, Lord Wilberforce in the precedent setting case of Scottish Burial Reform and Cremation Society v. Glasgow Corporation (1968) shed a somewhat different light on the Macnaghten classification scheme. As he states:

But three things must be said about it, which its author would surely not have denied: first that, since it is a classification of conveniences, there may well be purposes which do not fit neatly into one of the other headings; secondly that the words used must not be given the force of a statute to be construed; and thirdly, that the law of charity is a moving subject which may well have evolved since 1891.  

(ii) Public benefit

The second test that English and Canadian courts apply when rendering decisions on charitable status measures the ability of a 'purpose' to confer a tangible benefit on the public. Most law text-books view this second test as having two aspects. First,

some interest must be furthered by the 'purpose'. For example, in the case of the *Scottish Burial Reform and Cremation Society v. Glasgow Corporation* (1968) the court held that based on evidence showing that public benefits could be derived from cremation, the society was ruled a charity. The basis of that decision rested on the belief that as a non-profit making society, whose purpose was to encourage and provide facilities for cremation, a 'social interest' was indeed being advanced. In another case, *Gilmour v. Coats* (1949), a trust for reclusive nuns was invalidated on the grounds that an insufficient degree of benefit to the public was being provided. In commenting on this case Maurice remarks:

> "There was evidence before the House of Lords and the courts below concerning the doctrine of the Roman Catholic Church with regard to the benefit conferred by the contemplative life, not only on those who followed it themselves but also, through the efficacy of their intercessory prayers, on members of the public, bringing about their spiritual improvement, as well as by the example afforded by the nuns' lives of self-denial in order to attain greater love of God and union with him."

The second aspect of this test involves an organisation illustrating to the court that the 'public' will benefit from its proposed 'purpose(s)'. Public in this context is taken to mean not simply a small number of persons but rather some substantial

29Ibid.

30*Gilmour v. Coats* (1949) A.C. 495.

'cross-section of the community'. It is only then that a purpose meets this basic requirement and is considered to be for a public benefit hence, charitable. However, the notion of a 'cross-section of the community' is loosely defined, and again, only serves as a guiding principle for determination of public benefit. To reduce the ambiguity of this concept, English and Canadian courts have not granted charitable status to trusts or organisations if their purposes do not confer benefits to a sufficiently large number of persons. Furthermore, they will refuse to do so if the benefit is not potentially available to the public.32 For example, virtually all activity in aid of the sick or disabled meets the 'public benefit' test. Charitable status has been accorded to trusts and other organisations which establish or maintain clinics, hospitals and convalescent homes, to provide medical and hospital equipment or to advance medical science. However, a number of organisations have failed to pass the public benefit test. For example, organisations promoting 'alternative methods' of healing which have very little degree of acceptance by the medical profession, have normally been refused charitable status.33

(iii) Preamble to the Statute of Charitable Uses (1601)

The third test applied by the courts has caused the most

32This issue is discussed in virtually all the introductory law textbooks, but see in particular P.S. Atiyah, 'Public Benefits in Charities', Modern Law Review, 21 (1958), pp. 138-139.

difficulty for legal experts. It states that an organisation's 'purposes' must be analogous to the list of charitable uses outlined in the Statute of CharitableUses (1601). In most cases a charitable organisation's purpose(s) will fall within one of the four categories listed by Lord Macnaghten in the Pemsel case. This is taken to be a sufficient condition for validating charitable purposes since the four-fold classification is said to capture the 'spirit and intendment' of the 1601 statute. However, when there exist some doubts as to the validity of an organisation's purposes, that is if they do not fall neatly in one of the Macnaghten categories, then reference must be made to the Statute of CharitableUses (1601). This was determined in the previously discussed case Morice v. Bishop of Durham (1805). In this legal case it was held that the courts should draw an analogy between a disputed 'purpose' and purposes listed in the preamble of a previous case which in turn had been held to be directly analogous to a purpose listed in the preamble. While this may seem confusing, an example illustrates best what is meant. In the case Scottish Burial Reform (1968), where it was ruled that the provision of a crematorium was charitable, the court was persuaded by the evidence that the purpose was analogous to the preservation of cemeteries, which had been held to be a charitable purpose because it was analogous to the upkeep of a churchyard, which had been held to be charitable because it was analogous to the repair of churches which was mentioned in the preamble. This example seems far-fetched since 'analogy drawing' could be extended one
hundred fold. So, why do the courts continue to do it? It can only be assumed that the preamble to the Statute of Charitable Uses (1601) was never intended by its framers to be a complete or even representative list of charitable uses. Consequently, it is presumed that those who drafted the Statute sought to give the concept of charity a degree of flexibility to adapt to changing social, political and cultural conditions. However, it is interesting that this 'flexibility' did not preclude 'purposes' once held charitable to become non-charitable under common law. For example, some of the purposes listed in the Statute such as trusts for the marriages of poor maids or relieving low-paid workers from paying taxes, would probably no longer be considered charitable themselves. The Act itself, of course, has been long since repealed. Nevertheless, the process of analogous reasoning permits the courts to adopt the concept of charity to modern social and political conditions while fulfilling their mandatory legal obligation to consult the 1601 statute. In doing so, British and Canadian courts have been able to develop the concept of charity within the spirit and intendment of the Elizabethan preamble. The extent to which the courts come close to legislating for new charitable purposes is illustrated by the case of animal welfare charities. There is no example in the Statute of Charitable Uses (1601) that remotely resembles an animal charity. However, the preamble to the 1601 statute does

340f course, once the courts adopted the preamble in defining the meaning of charities, the fact that the statute was repealed has been of little consequence.
contain the maintenance of schools of learning, free schools and scholars in universities. From this it was established that the advancement of education including research is a valid charitable purpose. In 1857, a trust to fund an institution for studying and curing diseases of animals useful to man was held to be charitable. In 1864, this precedent was followed by holding a gift to the Society for the Prevention of Cruelty to Animals to be charitable, and this in turn was followed in numerous other cases of animal welfare charities. Picarda explains that the basis in England and Canada for considering such trusts charitable today is "because they promote morality and check man's innate tendency to cruelty and are thus of benefit to the community". This type of judicial reasoning further explains how we are left with a wide gap between popular notions of charity as being concerned with purely altruistic concerns and what is actually now held to be charitable under common law.

(iv) **Absence of self help, profit distribution, and substantial political involvement**

The fourth and final test that the courts apply concerns a number of characteristics of which charities are prevented from acquiring. These three characteristics have emerged, over the last one hundred years as a reflection of the changes that have occurred with regard to the type of services that charities now

35 University of London v. Yarrow (1857) 1 De Gand J72.

(a) **Self-help organisations**

English and Canadian laws are identical in that almost all 'self-help' organisations have been refused registration as charities. In both countries the term self-help is taken to mean organisations whose primary objectives are to confer benefits (usually financial) upon its membership out of a common fund wholly or substantially made up of the member's contributions. As Chesterman remarks, such organisations are deemed to lack the necessary element of altruism to enable them to qualify as a charity.38 As a result, most trade unions and professional and trade associations fall outside the parameters of charity. However, certain self-help organisations, particularly in England can acquire charitable status by applying to the Registrar of Friendly Societies. These bodies acquire the organisational form of a self-help group but are actually concerned with the welfare of non-members. While the vast majority of friendly societies are considered self-help organisations, a small number are not and thereby are eligible to apply for charitable status. The dual status of 'self-help and charitable' is only conferred on those organisations which can illustrate to the courts that their purposes are primarily charitable and that any financial rewards to the organisation's members, are purely incidental. For

38Ibid., p. 175.
example, a fund maintained by 250 residents of Brixton to provide free home nursing for Brixton children recovering from meningitis was granted charitable status since the fund was available to a section of the public that did not contribute to the fund. Had the fund only been available to the children of paying subscribers, the organisation would not have been granted charitable status.39

In both England and Canada there are relatively few organisations that are both 'self-help' and 'charitable'. This is true since self-help organisations, as their label implies, are designed to advance the interests of its membership, a feature which in many cases is counter-opposed to the underlying principle of altruism. However, there are 'hybrid' organisations and the two principles of self-help and altruism can legally exist side by side. For example, in England in 1985, Alcoholics Anonymous introduced a Bill into Parliament so that it could legally refuse to accept donations. The charity's members who rely on will-power in their battle against alcohol addiction sought the legal power to decline cash gifts since they endangered the organisation's guiding principle of self-help. The unprecedented move came after two legacies of about £10,000 each were made to Alcoholics Anonymous which, reluctantly, they were required to accept. This unusual case illustrates that charities may have 'purposes' which involve both self-help and altruism and which ultimately are

39Ibid., p. 177.
recognised by the law as being charitable.40

(b) Absence of profit distribution

In Canada, unlike England of course, there are both federal and provincial laws relating to organisations which do not distribute profits to their membership. Non-profits, as they are popularly referred to, have a number of distinguishing features. Although they are permitted through commercial activity to acquire profits, they are forbidden from distributing these profits to their membership. Non-profit corporations normally acquire their initial operating capital from fees paid by subscribing members. These organisations are not considered charities since they fail to pass the various tests described above.41 The Canadian Masonary Contractors Association (CMCA), for example, is a non-profit organisation whose purposes are to advance the non-financial interests of its membership. This is achieved through lobbying the federal and provincial governments for legislative changes that would be advantageous to their trade. There are a

40The Times. 29 November 1985.

41Organisations wishing to obtain non-profit status register as do charities under Part II of the Canada Corporations Act (1979) RSC C-32. The major difference between the two types of non-profits (charitable non-profits and membership non-profits) relates to the way they are treated under tax legislation. For example, charitable foundations — those organisations solely involved in granting money to charities which do provide services — must adhere to strict disbursement requirements. At present Canadian foundations must distribute 90 per cent of their income acquired either from endowments, income acquired from investment of these endowments, or from public donations. Like charitable non-profits, membership non-profits are not taxed on any profits they make from fund raising retail activities, government grants or investment income.
number of reasons why this organization is not considered a charity. First, the CMCA's purposes do not fall within any of the categories outlined in the Pemsel case. Second, and as discussed in the next sub-section, this organization is actively involved in lobbying the government for legislative reform and therefore violates the legal principle restricting charities from engaging in substantial political activities. Third, the CMCA does not provide a tangible public benefit to the 'community' or to a considerable cross-section thereof. Finally, the CMCA is ineligible for charitable status since its purposes do not fall within 'the letter or the spirit and intendment' of the preamble to the *Statute of Charitable Uses* (1601).

While the CMCA is not 'charitable' for the reasons mentioned above, Canadian laws do not treat it as being a 'for-profit' organization. Instead, like charities, non-profits such as the CMCA enjoy a tax exempt status and are immune from a number of regulatory statutes including securities legislation. In other words, in Canada there are statutory provisions for a separate type of organisation that lie somewhere between private philanthropy and the business sector. In contrast to Canada, the concept of a non-profit organisation has neither popular currency nor legal status in England. The closest legal structures found in England that approximates the Canadian non-profit is the

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company limited by guarantee. However, organisations adopting this legal form are not granted the same tax exempt status enjoyed by their Canadian counterparts.

In both countries the law not only strictly prohibits charities from distributing profits but it legally bars the organisation's trustees from receiving remuneration for their services. But of course, this does not mean that charities are not permitted to have paid employees. Oxfam, England's largest charity in terms of income, presently employs 600 people in England and 200 employees overseas, and Save the Children Fund which has a permanent paid staff of 800 in England and an additional 1,400 abroad. Sheridan makes the point that legal requirements calling for a separation between those at the administrative helm of an organisation from those involved in 'day-to-day' administrative activities, restricts the flow of profit, 'in the guise of remuneration', to those in ultimate control of a charity. If an organisation is found to contravene the non-profit distributing rule, then non-registration or de-registration of an organisation's charitable status is normally the course of action pursued.

(c) Political involvement

The common law principle that charities cannot have purposes

which are substantially political is the final test which the courts apply when determining whether a trust or organisation is charitable. As Chesterman remarks:

...the word political takes on a number of different meanings each one of which is taken to be a sufficient condition for being a non-charitable purpose ... and include purposes (1) to further the aims of a recognised party, (2) to promote the spread of a general political doctrine, such as socialism, (3) to persuade the public attitude of mind towards some broad social question, such as community relations or international peace, or (4) to attempt to bring about or oppose changes in the law.

As with the other tests, there are numerous examples in English and Canadian common law history illustrating why charities have been denied charitable status on the grounds of 'substantial political activity'. For example, in 1898 an English court held that a trust’s purpose for ‘religious and mental improvement’, was substantially intermingled with furthering Conservative Party principles and, thus, was non-charitable. A more recent case concerning Amnesty International [McGovern v. Attorney-General (1981)] involved purposes which included the relief of prisoners of conscience and attempts to secure their release. These were held to be political, hence non-charitable, since among other things the organisation attempted to change the laws of foreign

This discussion illuminates just one of the case law examples relating to charities and political involvement. A number of other complex legal issues relevant to the study of charity-state relations are addressed separately in chapter three.

II. Registration and Supervision of Charities

One dimension of charity-state relations involves the state’s responsibility for registering new charities and supervising the activities of those already in operation. Throughout section I of this chapter it was argued that the courts in both England and Canada are the final arbiters of whether an organisation’s purposes are charitable. However, since the vast number of cases involving the definition of ‘charitable purposes’ do not reach the courts, the administrative procedures governing the official registration of charities are equally important to examine. In this section first a brief description of the registration procedure which charities must follow is given, and an historical account is provided as to why such procedures differ considerably in the two countries. After this, evidence is provided to show the economic advantages extended to organisations qualifying for

47There are certainly other case law examples concerning charities and substantial political involvement. See Animal Defence and Anti-vivisection V. I.R.C. (1950) 66 L.T.R. 1091 (Ch. Div.), where it was decided that, even though the Society’s object of opposing vivisection might be educational, on the evidence, another object of this Society was to obtain the repeal of the Cruelty to Animals Act (1876); therefore its purposes were held political and hence not charitable.
charitable status in England and Canada. Finally, a brief description and evaluation is made of the state's ability to supervise charities after they have been registered so as to ensure their administration accords with the law.

A. Registration

Registration of new charities in Canada is a two-step procedure. In the first instance an organisation must file its proposed objects with the Department of Consumer and Corporate Affairs and register under Part II of the Canada Corporations Act (1970). The advantages of having tax exempt status comes only after the second step which involves applying to Revenue Canada for a charity tax number. In other words, the responsibility for determining charitable status rests with Revenue Canada, not with the Department of Consumer and Corporate Affairs. Officials within the Tax Exempt Organisation Division of Revenue Canada base their decisions to register new charities on the common law interpretation of 'charity'. If an organisation's 'purposes' meet the common law tests, it then receives a charity tax number, automatically, thereby permitting its income to be tax exempt. Furthermore, this exemption allows donors to deduct any gift to charity from their taxable income.48

48Para. 110(1) of The Canadian Income Tax Act (1952) R.S.C. C148 as amended by 1970-71-72, C. 63, provides that "within limits, a taxpayer can deduct contributions to the following organisations: (i) registered charities, (ii) registered Canadian amateur athletic associations, (iii) housing corporations resident in Canada and exempt under this part by Paragraph 149(1) (i), (iv) Canadian municipalities, (v) universities outside Canada prescribed to be universities, the student body of which ordinarily includes students from Canada to which her Majesty in
In England, responsibility for registering new charities lies with a government department which is separate from the department responsible for administering income tax. The Charity Commission is a government agency, responsible to the Home Office. It is empowered to register new charities and has the jurisdictional authority to grant these organisations a number of fiscal privileges. In deciding whether or not an organisation is a charity, the Charity Commissioners carry out a quasi-judicial function. During particularly complicated and contentious cases involving registration or de-registration, the Charity Commission communicates extensively with the Inland Revenue. Thus the difference between the two countries is that in Canada a government department primarily concerned with collecting taxes registers and supervises charities. Revenue Canada executes its 'registration' and 'supervision' responsibilities in an ancillary capacity to its main purpose. In contrast, there exists a much clearer separation between the two functions in England: the Inland Revenue is responsible for collecting taxes and the Charity Commission is responsible for applying charity law. 

right of Canada has made a gift during the taxpayer's taxation year or the 12 months immediately preceding that taxation year."

The Charity Commission determines the 'charitable status' of all organisations seeking registration. If a decision is made to register an applicant organisation, then the Inland Revenue takes this as a sufficient condition to exempt the said organisation from income tax, capital gains tax, capital transfer tax, corporation tax, development land tax, national insurance and stamp duty. The charity will also receive at least 50 per cent reduction in local authority rate. However, the local authority has the discretion to waive some or all of the remaining half.
In England the procedures which applicant organisations must follow to become registered are relatively straightforward. After a charity’s trustees have submitted an application form, accompanied by a copy of the organisation’s governing instrument, the Commission’s staff indicate whether the application succeeds or fails. While the application is being processed — and this can vary from two months to two years — the trustees may submit arguments to the Commissioners in person, in writing or by telephone. The cases which are difficult to decide (a small minority) must be resolved in consultation with the Inland Revenue, a procedure specifically outlined under section 9 of the Charities Act (1960). However, most applications are granted approval mainly because they are drafted in consultation with organisations, such as the National Council of Social Services (NCSS) which have staff with an expert knowledge of charity law. In addition to consulting outside organisations, trustees often refer to the Charity Commission’s Annual Reports when drafting their applications. These reports specify recent changes to the guidelines that the Commissioners use when deciding on the validity of an applicant’s purposes. If an organisation formulates an application which is rejected, the organisation’s trustees are entitled to pursue an informal procedure of internal appeal. This requires the ‘Officers of the Commission’ and the

50 Chesterman, Charities, Trusts and Social Welfare. p. 115.

51 Internal appeals are referred to in both the Annual Reports of the Charity Commissioners and in the Goodman Report, but as Chesterman notes the precise procedures are scarcely publicised.
trustees of the failed application to submit written arguments stating their case to the 'Board of the Charity Commission'. If the application is again rejected, the applicant(s) can take legal action in an effort to force the Charity Commission to register them. In both England and Canada, this last procedure is both expensive and time-consuming, and therefore seldom used.

In Canada, if the decision is made to grant an organisation charitable status, it then becomes eligible to receive a wide range of fiscal privileges. At the present time, Revenue Canada receives approximately 3,500 applications for registration each year which is similar to the number received by the Charity Commission. Whereas the Charity Commission has a staff of 450, there are only 35 members of the Tax-Exempt Organisation Division of Revenue Canada, who review the merits of all applications for registration. 52 In Canada, the process is conducted relatively informally. Information circular No. 80-10 sets out which documents a registered charity must file, these include: an application for registration form, financial statements, governing documents and a statement of aims and objectives. 53 Upon receipt of these documents a Revenue Officer reviews them; if there are any queries the registrants receive assistance from Revenue Canada in completing the forms properly. If there are no difficulties with the applicant's registration it will be approved in a matter


of weeks. However, if the forms are not completed properly, or more information is required, it may take up to a year to finalize the registration procedure. On average it takes three to four months for an organisation to receive charitable status.54

Since Revenue Canada’s primary function is to collect taxes, it is generally accepted that its ability to oversee the registration of charitable organisations is limited. In fact, in the 1977 report by the National Advisory Council on Voluntary Action entitled, People in Action, it was recommended that:

The responsibility for registration and deregistration of charitable organisations be transferred from Revenue Canada which is only concerned with the collection of revenue, to the Secretary of State, which has somewhat broader concerns. The department should be authorised and encouraged to take a more flexible view to objects and activities which are for the general good of the community.

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The most common criticism levelled against Revenue Canada concerns its ability to register charities, since such decisions are normally legal in nature and thus not adequately addressed by a department staffed primarily with accountants. Recent suggestions in Canada, advocating a separate agency to register and supervise charities, parallel the English example where the Charity Commission performs these same functions. For example, those supporting the adoption of a similar government department


in Canada have emphasized that it could be properly staffed, as it is in England, with lawyers possessing an expertise in the area of charity law. The claim has also been made that a separate agency could be given statutory powers that extend and improve the state's authority to monitor and regulate the activities of charitable organisations. In interviewing a Revenue Canada official it was suggested the best model for Canada would be the English legislation entitled the Charities Act (1960).56

An important question to resolve is why different institutional structures have developed in two countries which employ identical legal criteria when determining charitable status. The answer to this question is partly entwined in the long and complex history of philanthropy in England when compared to the relatively youthful history of the charitable movement in Canada.

Beginning in 1601, with the enactment of the Statute of Charitable Uses was a provision for the Lord Chancellor to authorise the appointment of the Bishop of any diocese and others with him to act as commissioners to enquire into the abuses and breaches of trust of any property given for such 'charitable and godly uses' as were listed in the preamble. The reason the first regulatory powers rested with the Bishop reflected the fact that most charitable donations were made to the church.57 However, by 1853 with the mounting fear the church had already acquired far

56 Canadian Interview; Revenue Canada, Tax Exempt Organisation Division, 29 January 1987.

too much land, and thus was eroding the power of the land owning class, legislative reforms were drafted which withdrew the regulatory powers away from the church and placed them into the hands of a separate statutory agency. In addition, by 1853 there existed not only a growing number of social welfare organisations that were completely dissociated from the church, but there had been a long-standing concern about the ways in which many old charities, including educational charities, were being administered. In response to what was essentially viewed as corrupt behaviour, the Brougham Commission in 1816 had begun a comprehensive fact-finding investigation into the abuses of charitable trusts in England. Over a period of 21 years the Commission toured the country and engaged in a thorough and painstaking survey of the administration of virtually all charitable endowments in England and Wales. As Owen remarks: "The Commission’s chairman Lord Brougham never hesitated to press such advantages he enjoyed, and he was not reluctant to poke his investigating finger into ancient and dignified endowments. It was, in his view, unfortunate that London schools so often used their resources to board and clothe a small number of pupils rather than provide education for a large number." The Brougham Commission’s most important contribution - although one that was delayed by bureaucratic squabbles - was establishing the Charity

59 Chesterman, Charities, Trusts and Social Welfare, pp. 63-64.
Commission as a permanent government department designed to oversee the administration of private non-church controlled charities. As stated above, corrupt activities associated with the administration of charitable trusts were, primarily limited to older, and larger endowed charitable trusts. In response to an increasing number of cases of breach of trust the Brougham Commission outlined provisions for chancery suits to be filed by the Charity Commission against defaulting trustees. Furthermore, the Charity Commission was given powers to correct the administration of ‘old trusts’ by assuming the responsibility to alter a charity’s purposes if they were no longer enforceable.61 This process is referred to as cy-pres (as near as possible) and is a power still enjoyed by the Charity Commission. When taken in the context of charity law, the Charity Commission has the power to modify a charity’s purposes to one similar to the original purposes specified by the testator/testrix if they are no longer enforceable. Another power granted to the Charity Commission at the recommendation of the Brougham Commission was to give them the jurisdiction to investigate any suspected abuses in the administration of all non-church charities by sequestering their annual accounts and to remove trustees if such investigations revealed abuses of the law.62 Nevertheless, the point must be made that since the Charity Commission was precluded from sequestering the accounts of church controlled charities - indeed

61Ibid., p. 193.

where most of the corruption existed - the Charity Commission was largely ineffective in supervising their activities. Owen cites an example of the types of activities that were taking place in mid 19th century England that reinforced the Brougham Commission's decision to establish a separate agency to oversee the administration of charities. This was the case of Hiron's Hospital in 1869:

Here it appeared the Earl of Guilford who owed his post as master of St. Cross to his father, the Bishop of Winchester, was profiting personally by about £1200 annually though evidently doing well enough by the inmates and keeping the premises in good order. Actually the Hospital had had a long and, at times, inglorious history of misappropriation of revenue by its masters, and the clergy-man was by no means the worst offender. 63

At the point in time when the Charity Commission was first created, one should bear in mind that Canada was not yet an independent country. Indeed, it was not until 14 years later in 1867 that Upper and Lower Canada, along with several of the maritime provinces, united to form the basis of what is now Canada.64 While the first Canadian government did adopt a large number of institutions and procedures from the British they did not, however, create a Charity Commission. There was no need to do so. In England, the creation of the Charity Commission was a response to the problems associated with private philanthropy

64British North America Act (1867) 30-31 Vic., C. 3.
which had developed over a period of 250 years since the major
reform of 1601. However, Canada did not have a long history of
philanthropy and the abuse of it, thus there was no need to create
an institution modelled after the Charity Commission. In Canada,
in 1867, there were no 'old charities' in existence; the problems
associated with the administration of this type of charity in
England were irrelevant to Canadian politicians and public
officials. Furthermore, at the time of Confederation the overall
amount of organized philanthropy was small in comparison with
these activities in England. Given this, the Revenue Department
was not overburdened with the administrative responsibility of
registering and supervising these organisations.

Another explanation for the absence of a Canadian Charity
Commission relates to the size of each country. In a country as
large as Canada, it would have been virtually impossible, not to
mention very costly, to supervise charities centrally as did the
Charity Commission from its London headquarters. An alternative
approach of setting up regional Charity Commission offices across
the country from Nova Scotia to British Columbia would also have
been expensive. Indeed a Revenue Canada official offered this
kind of explanation as to why the British model has yet to be
adopted.

“Canada is 1,000 miles wide and 4,000 miles long
and yet has only 25 million people. However,
London alone has 6.8 million in a city that is

65S. Martin, An Essential Grace. Toronto: McClelland and
20 miles across. It would be ridiculously expensive to monitor a charity operating in Coquitlam British Columbia from a downtown office in Ottawa. In contrast, it is perfectly feasible for the Charity Commissioners in London to scrutinize the activities of a Canterbury based charity.66

Instead of creating a separate department the federal government has utilized the resources of local and regional Revenue offices to monitor the activities of charities. The problem with this arrangement is that many offices are under-resourced in terms of staff possessing legal expertise in the area of charity law.

A final explanation as to why different approaches to supervising charities has developed in each country (and one more difficult to substantiate) concerns two important characteristics associated with Canada's historic struggle to become an independent nation.67 First, Canada is unique in that it is a blend of British and French colonisation.68 At the time of

66Canadian Interview; Revenue Canada, 29 January 1987.


68The literature on the relationship between English and French cultures and the impact that this relationship has had on shaping Canadian politics is very extensive. Perhaps the most insightful is Herbert Guidon, 'Two cultures: An essay on Nationalism, Class and Ethnic Tension in Contemporary Canada', in O. Kruhley, R. Schultz and S. Pohinushchy, The Canadian Political Process: A Reader. Toronto: Holt Rinehart and Winston, 1976. A more historical and Anglo interpretation is presented by Ramsey,
Confederation (1867) a number of concessions were made to Quebec (then Lower Canada and predominantly French) in order to persuade it to join Ontario (then Upper Canada and predominantly British) and the other maritime provinces including New Brunswick, Nova Scotia and Prince Edward Island. One of the most important concessions was that Quebec was permitted to retain its civil law traditions but more important, Federal politicians from Quebec were given the opportunity to evaluate the utility of transplanting British rules, procedures and institutions to Canada. While House of Commons Debates do not reveal that Quebec politicians discussed a motion to create a Charity Commission it may be speculated that, if such an idea had been put forth, it would likely have been rejected by Quebec politicians. Such resistance was displayed when, for example, the federal government sought to establish other institutions which threatened to usurp the church’s traditional, social, economic and political control of the province.69

A Charity Commission in Canada has yet to emerge as a response to the issues and problems associated with private institutionalised philanthropy. However, at the present time there is growing pressure from the Canadian Council of Better Business Bureau (CCBBB) - a peak interest association representing Canadian businesses - on the federal government to create a


Charity Commission in Canada. In the absence of such a reform, the CCBBB has implemented its own programme for supervising the activities of Canadian charities (this is examined later in this chapter).

B. Registration and tax privileges

For most British and Canadian charities, the main advantage of charitable status is exemption from direct taxation. Having acquired charitable status through registration with the Charity Commission or Revenue Canada, charities in their respective countries are automatically entitled to a number of tax privileges. The major difference between the tax treatment of British and Canadian charities is that Canadian taxpayers can deduct charitable contributions from their gross income before it is assessed for federal income tax. The private British donor, on the other hand, receives no allowance in respect of charitable contributions. Instead the charity to which a person has given their contribution may itself reclaim the tax at the basic rate paid by the donor if it was made under covenant.

The covenant system appears originally to have arisen as an unintended consequence of a provision of the Income Tax Act (1803). This statute allowed annual income disposed of under the conditions of a Deed of Covenant not to be deemed income of the donor. Since then, the tax paid and deducted by the payer is

70Canadian Interview; Canadian Council of Better Business Bureaus, 22 December 1986.

deemed to be part of the income of the payee. Substantially the same provision, is enacted by Sections 52 and 53 of the Income and Corporation Taxes Act (1970), but only the basic rate of tax and not any of the higher rates, may be credited in this way.72 In the case of a charity, the logic runs as follows: the donors, paying a net sum from his fund of taxed income to a charity, is assumed to have paid the basic rate of tax, but the charity is exempt from the income tax; so the charity may recover the tax at the basic rate from the Inland Revenue. When the Conservatives formed the government in 1979 the income guaranteed by the covenanting system declined when the basic rate of tax was lowered from 33 per cent to 30 per cent. This represented a cost to charities whose outstanding net deeds of covenant were then supplemented by taxes reclaimed at a lower rate than had been in effect when they were first written. As discussed in chapter 4 section II, the British government amended other tax laws in 1985 - particularly VAT rules - in order to compensate for lost ‘covenanted income’.73

Organisations registered by the Charity Commission are eligible for a number of other tax related privileges. For example, under the Income and Corporation Taxes Act (1970) section 360(2), all capital owned by a charity is exempt from Capital Gains Tax. This is equally the case in Canada under section 4(b)

72Ibid., p. 237.

of the *Income Tax Act* (1962). Furthermore, since 1976 Estate Duty has been replaced in Britain by the Capital Transfer Tax. The three principal exemptions enjoyed by outright gifts to charity are: 1) gifts to a total value of £2,000 in any one year; 2) gifts made to charity a year or more before the death of the donor; or 3) gifts made to charity within the year of death of the donor or by his will up to a limit of £100,000. Apart from these general exemptions for charitable gifts, the Treasury has power to exempt gifts of property which they consider of national interest. For example; historic houses, scenic land and even books. Not only the gift itself, but an endowment for its upkeep may be exempted.74

British charities are also partially exempt from paying rates to local authorities. Presently, local authorities are free to relieve charities of rates to any extent they deem appropriate to a minimum level of 50 per cent. It may be argued that there is an inconsistency in a situation where charities are exempt from income tax on the rent of properties they let but must pay rates on property they occupy. However, rates have been the only form of taxation available to a local authority, and since charities are not uniformly distributed over the country, the burden of relief to charities varies from local authority to local authority. The recommendation of the Goodman Committee was that the mandatory rate for relief should be raised from 50 per cent to

75 per cent, but the burden of mandatory relief should be borne by the Central government rather than by local authorities. This issue may have become irrelevant now with the present government’s proposal to replace rates with a poll tax.

Further discussion of the tax privileges granted to British and Canadian charities is contained in chapter four. The important point to note here is that the registration of a charity is important for two reasons. First, is the role it plays, in the public’s perception, in apparently legitimizing an organisation and its activities. This ‘official recognition’ is crucial for any organisation dependent on voluntary contributions of money and labour. Second, registration of charities in both countries extends significant fiscal privileges that are not enjoyed by other non-charitable organisations. In many cases, organisations unsuccessful in acquiring charitable status have been unable to operate without these economic advantages. There are, of course, exceptions including Amnesty International and the Anti-Vivisection League.

C. Supervision of charities

Since charities in both England and Canada enjoy a tax exempt status and a number of other fiscal privileges, there is a particular concern that they should conduct their activities in strict accordance with the law. The public which makes donations, charities which obey the law, and governments which provide income

75Ibid., p. 14.
to charities, have a vested interest in seeing that organisations manage their affairs honestly and efficiently.

(i) Revenue Canada

In the case of Revenue Canada, it appears that the 35 member staff in the Tax-Exempt Organisation Division spend very little time monitoring the ongoing activities of registered charities. As Brooks argues ... 'once a charity is registered, there is almost no government oversight ... Revenue Canada simply has not been given the resources to monitor the ongoing activities of charities'.76 Improprieties involving charities are normally brought to the attention of Revenue Canada by affected third parties. If there is substantial evidence to suggest illegalities the case is then referred to the Federal Court of Appeal. Launching an appeal is an extremely expensive venture and thus very seldom done. This is evidenced by the fact that the courts did not hear a single appeal brought by Revenue Canada to strip an organisation of its charitable status during the period 1973-1983. Furthermore, in interviewing a Revenue Canada official it was revealed that only 18 charities have been deregistered since 1974. The respondent agreed that Revenue Canada does not play an active 'watch-dog' role over the activities of Canadian charities to ensure their administration accord with the law. Department officials admit that the legitimacy of Canadian charities is determined at the initial stage of registration. After this procedure is completed, charities are simply required to file

Annual Information Returns. As one respondent noted; "50,000 Canadian charities and 3,500 newly registered organisations each year are simply entrusted to perform as good corporate citizens."77

Government supervision of Canadian charities has been so relaxed that a non-governmental interest group has established its own programme to monitor charitable activity. In 1985 the Canadian Council of Better Business Bureaus (CCBBB) set up its Philanthropic Advisory Service. The CCBBB works with local Better Business Bureaus (BBB) to assist consumers, encourage self-regulation of business, and promote confidence in the private enterprise system. Since 1912, the BBB system has monitored advertising, mediated business - consumer disputes, corrected abuses in the marketplace and provided information to businesses and consumers. The CCBBB is supported by membership dues and grants from many large corporations and by 17 autonomous BBB’s across Canada. To maintain its impartiality and independence it refuses to accept funds from government agencies or charitable organizations. The CCBBB has patterned its programme for supervising charities on the Philanthropic Advisory Service in the United States. In essence, the CCBBB’s Canadian Philanthropic Advisory Service has sought to educate donors about charities

77 Canadian Interview; Department of Health and Welfare, 30 January 1987. The poor supervision of Canadian charities is compounded by the fact that Revenue Canada’s ‘Tax Exempt Organisation Division’ is responsible for applying not simply charity law but other complex pieces of tax legislation that are applicable to non-charitable, non-profit organisations.
worthy and unworthy of financial support. While the CCBBB never recommends any one charity over another, it does offer information to help donors make their own giving decisions. Presently it receives 12,000 telephone calls each year from individuals and companies who have been solicited by charities for voluntary contributions. The programme is especially useful for corporations many of which receive hundreds of letters each year requesting donations. In the absence of this programme many companies would have to incur the cost of hiring a person to determine which organisations are reputable. The programme’s ancillary purpose is to encourage charitable organisations to accept the responsibility of self regulation and adhere to ethical practices outlined in their ‘Standards for Charitable Solicitations’.

The CCBBB has 22 standards that are divided into five categories namely: public accountability, use of funds, solicitation and information materials, fund raising practices and governance. The Philanthropic Advisory Service operates by collecting and distributing information on hundreds of charities that solicit nationally, or have national or international programme services. It routinely asks these organisations for information regarding the programmes and fund raising when they have been the subject of inquiries. In doing this, the CCBBB relies on other Canadian BBB’s as well as on 168 American BBB’s to disseminate its educational materials and to report on organisations whose fund raising efforts are local in scope. When
it receives numerous inquiries about a national charitable organisation, it evaluates the information in relation to the CCBBB's Standard for Charitable Solicitation. When warranted by the number of inquiries, CCBBB officials write a report summarizing the organisation's current operations. If the standards are not met, the charity is included on a list which is published annually. In 1986, 36 Canadian organisations appeared on this list including charities like, 'Jesus to the Communist World', 'Toronto Spitfire Wheelchair Club', and 'Against Drinking and Driving'.

In the area of medical research, the CCBBB has encountered few examples of administrative improprieties. However, Mr. Warren Clayson, the Director of CCBBB qualified this by explaining that several organizations have misled the public by advertising unrealistically small fund raising expenses:

"What we see happening with medical research charities is organisations which devote a lot of money to television advertising and fund raising - yet classify these expenditures as 'public education'. The medical research charities have been able to get away with this since they are 'educating' the public about disease prevention. The same holds true of television evangelists— for example, it is difficult to measure how much 'preaching' is related to advancing its charitable purposes and how much is related to raising voluntary contributions."

78Canadian Interview; Canadian Council of Better Business Bureaus, 22 December 1986.

79Ibid.
In their own defence, the 18 Canadian medical research charities interviewed, all agreed that the CCBBB has tended in the past to be slightly overzealous in monitoring their activities. In particular, many small charities representing less popular diseases argued that the CCBBB was insensitive to the fact that more had to be spent on their fund raising in order to establish a public profile. As is discussed in chapters five and six, this expenditure has been crucial in correcting the imbalance between high incidence rates of relatively unknown and horrific diseases like ileitis and colitus and the small amount of money traditionally raised on their behalf.

The CCBBB has also been interested in determining how a charity's fund raising costs relate to voluntary income and government grants. For example, if a charity raised all of its £15 million annual income from donations and spent only £1.5 million on fund raising, the CCBBB would classify that ten percent expenditure rate as 'acceptable'. However, if that same charity had received £12 million of its total income from the government, in the form of grants or fees for contracted services, the charity would have spent £1.5 million but raised only £3 million from the public. This costs/donation ratio would be deemed unacceptable by the CCBBB. This has not been problematic for Canadian medical research charities, though, since they derive only a very small proportion of their income from the federal and provincial governments.80

80 Ibid.
Lastly, CCBBB officials have been concerned about charities that do not include their employees' salaries under 'administration' but rather under 'programmes' in their Annual Reports. In so doing, the CCBBB claims that charities are able to project an unrealistic image of their efficiency and resourcefulness. These two qualities are crucial for any charity interested in gaining the public's trust and confidence. While many of the CCBBB's concerns are important and useful for achieving a more responsible charity sector, there are problems relating to the programme's usefulness. The major criticism of it concerns the reliability of the information the CCBBB collects from the charities it is investigating. The CCBBB has no means of forcing a charity to 'open up its books' and has no assurances that the information it receives is accurate and up to date. Unlike Revenue Canada, of course, the CCBBB does not have the legal authority to conduct 'blind' or 'random' audits. The only power enjoyed by the CCBBB is that charities refusing to supply the necessary information are included on their 'Failure to Meet Standards List' which is freely available to the public.

(ii) The Charity Commission

As we have noted, the Charity Commission maintains a staff of 450, many of whom are legally trained solicitors. In comparison to Revenue Canada, the Charity Commission exercises slightly better oversight of charities, in that its official duties go beyond simply registering new organizations. In part, this is due to the Charities Act (1960) which is generally agreed to have
extended the regulatory powers enjoyed by the Commission. For example, the Act specifies that the Commission has jurisdiction over all charities irrespective of their legal form although some organisations are exempt.81 This means that certain companies limited by guarantee, unincorporated associations, and certain organisations registered under the Friendly Societies Act are required to register with the Charity Commission in order to acquire a tax exempt status. Second, the 1960 Act gives the Commission the authority to ‘freeze’ a charity’s bank account, whereupon its assets are vested with the Commissioners. Furthermore, the Commissioners are granted the additional power to remove individuals in control of a charity if an investigation into its affairs reveal that misconduct or mismanagement has taken place. This last power, in particular, has broadened the Charity Commission’s scope of authority and has given it a major advantage over its Canadian counterpart in supervising charities. There is, in fact, no comparable legislation to the Charities Act (1960) in Canada. As a result, Revenue Canada officials have not enjoyed the same statutory authority to enforce ‘charity law’. Inter alia this has meant that Canadian charities continue to operate in a climate that is far less restrictive than in England.

The approach of the Charity Commissioners seems to be one of

81Exempt charities are generally accountable to some other authority. For example, universities to the University Grant Committee and Friendly Societies to the Registrar of Friendly Societies. As mentioned in chapter seven section I. B, The Medical Research Council in Britain is a charity - but would not be recognized as one - and is responsible to the Department of Education and Science.
dealing with complaints about charities as they arise rather than exercising any sort of positive policing function. In interviewing one charity executive, considerable concern was expressed regarding a newspaper story alleging some form of impropriety by a charity operating in the same service area.82 The respondent had contacted the Charity Commission and was told that it had no special information on the subject, but that it had seen the story and were launching an investigation. This is typical of the way the Commission usually proceeds. They will receive complaints or allegations of improper conduct not only from the press but also from private citizens - often from disgruntled officers or ex-officers of the charity. In interviewing a Charity Commission official it was explained that the vast majority of cases were resolved informally by correspondence and that only about ten cases a year require more formal inquiries. The respondent explained that with an annual budget of £2.5 million it was impossible to expect the Commission to exercise any sort of detailed surveillance over some 130,000 charities. Moreover, the argument was made that government departments providing grants, subsidies and fees should assume a greater responsibility for ensuring that public money is not being wasted by charities through mismanagement or misconduct.83

One area of supervision which the Commission might seem to

82British Interview; Brain Research Trust, 2 March 1987. The respondent was reacting to allegations of improprieties associated with the administration of the Mental Health Foundation.

83British Interview; The Charity Commission, 31 March 1987.
take a more active role, is scrutinizing a charity's financial accounts. However, the resources devoted even to this process are modest. All charities (other than exempt organisations) must keep proper financial records and submit their annual statement of accounts to the Commission. These accounts are then made available for public inspection. They do not as the law presently stands, necessarily have to be professionally audited. However, one of the recommendations of the Goodman Committee was that there should be a statutory requirement of professional audit for the accounts of charities whose income exceeds a certain figure. Charities with smaller incomes were recommended to require only an independent audit. The Goodman Committee also recommended that accounts should be accompanied by a report setting out in sufficient terms, the activities of a charity during the past year and its intentions for the succeeding year. The 1987 Report to the Home Secretary and the Economic Secretary to the Treasury (The Woodfield Report) further recommended that all local charities should be required to send a copy of their accounts to their relevant local authority and that all charities should be obliged to furnish copies to members of the public on payment of an appropriate fee.

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85 Goodman Committee, *Charity, Law and Voluntary Organisations*, p. 113.


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argued that the statutory and non-statutory requirements for the submission of annual charity accounts have been widely ignored by large numbers of charities and have not been effectively enforced by the Commission. A further problem has been that even when accounts are submitted there is no standard format, for example, only one third of the accounts submitted are normally professionally audited.87

Like Revenue Canada, the Charity Commission does not have the staff to review the accounts of every charity each year. Instead, they examine the accounts of about six or seven thousand charities annually. Therefore, given the number of charities, there is no guarantee that the accounts of each organisation will be examined more than once every five years. The poor level of submission of charity accounts and limited scrutiny have not only undermined effective monitoring and control but has posed difficulties for the police in carrying cases of suspected fraud and abuse through to successful prosecution.88 In comparison, Revenue Canada has enjoyed one advantage over the Charity Commission in that its files are computerized thus enabling officials to issue ‘cautionary letters’ when charities have failed to submit their complete financial statements. Computerization has also provided Revenue Officials with accurate and up-to-date files for litigation proceedings to defend their decisions to deregister


88National Audit Office, Monitoring and Control of Charities in England and Wales, p. 2.
In Britain the examination of a charity's accounts involves checking on such matters as whether an organisation's funds have been expended on charitable purposes and in accordance with its articles of association. This is done to ensure that the charity is in no danger of insolvency. According to the Goodman Committee Report, the examination of the accounts quite frequently is followed by recommendations to bring the charity's objects and administration up-to-date.90

The Goodman Committee did not believe that these arrangements were adequate. They recommended that the Charity Commissioners be given the power to grant registration subject to a review of an organisation after three years of its operation. Additionally, it was argued that every charity should have its accounts examined at least once every five years. They also wanted the Charity Commission to acquire a staff with sufficient accountancy skills to advise whether the system of preparing accounts is adequate to give relevant information to the public. Finally, they suggested the Commission - with the assistance of a lay-board - should periodically review the question of how much detailed information should be given to the public about the expenditure of charities on their 'objects'.91

89Canadian Interview, Revenue Canada, Tax Exempt Division, 29 January 1987.
90Ibid., p. 113.
91Ibid., p. 114.
Though the Goodman Committee, in effect, suggested tightening up the arrangements for supervising charities' accounts, they saw the Commission's role more as a supportive agency. In doing so, they envisioned a greater role for the Charity Commission to advise and persuade charities to acknowledge their own responsibilities to become more accountable to the public. In this context, the Goodman Committee's recommendations were not proposing a radical change in the Commission's mandate. Instead, they were proposing to increase the Commission's resources to enable it to discharge its present responsibilities more effectively. The Woodfield Report supported this proposal by recommending that the Charity Commission be given more resources to strengthen its advisory services to charities particularly by extending its existing range of leaflets dealing with the registration and administration of charities.92

(iii) Charity fraud

In comparison to Canada, the British government seems to be more conscientious about supervising charities. However, there is ample evidence to suggest that both the Charity Commission and Revenue Canada, require substantially more legal and accounting staff in order to detect abuses of the law. It is arguable that such provisions would pay for themselves by recouping lost revenue associated with tax fraud. This point is substantiated by the 1986 investigation into the affairs of the Roman Catholic Church.

92Home Secretary, Efficiency Scrutiny of the Supervision of Charities, p. 25.
in England and Wales. After one year of auditing it was discovered that hundreds of thousands of pounds had been claimed in tax rebates in cases where the donor was not eligible to make a covenant. The amount owed to the Inland Revenue from just one diocese was estimated to be between £200,000 and £400,000.93 Furthermore, a small Stoke-on-Trent charity was used to 'launder' millions of pounds of money from around the world. Among those said to have used the charity to hide large sums of cash was the ex-president of the Philippines - Ferdinand Marcos. The Vincent Foundation, set up in 1983 to help women in trouble with the law received cash from international financiers in the form of short term loans. The conditions of the deal were that large amounts of cash, sometimes exceeding £2 million, were deposited into the organisation's bank account and the charity would then claim the interest as a charitable donation. After a designated period of time the businessmen would ask for the 'principal' back from the charity without information being passed to the Inland Revenue.94

The rising incidence of charity fraud found in Britain led the National Audit Office in 1987 to recommend improved communication between the Charity Commission and the Metropolitan Police and that each should be given more resources to detect frauds. Presently, the police pursue individual cases of charity fraud in collaboration with the Charity Commission. However, no regular liaison or meetings to discuss wider problems related to the

94The Times, 23 March, 1986.

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control of charities has been initiated by either the Charity Commission or Police Department. Currently, the police are involved with charities mainly through their investigation of allegations of criminal activity. The Charities Act (1960) makes no provision for specific offences involving charities, so police prosecutions must be brought under other legislations such as the Theft Act (1969). Since charity related fraud cases are not separately identified within the available statistics the police have no overall understanding of the extent of crime involving charity operations or the trustees of charities.95

In Canada in December 1986, the Executive Director of the Heart and Stroke Foundation of Ontario was charged with embezeling $50,000 (£25,000). He was later found guilty in April 1987 of diverting voluntary contributions, earmarked for the charity's general revenue account, into his own pocket. The fraud remained undetected for several years since the only money misappropriated was contributions sent directly to his office. It was eventually discovered, though, when an individual who had previously contributed $4,000 (£2,000) to the charity later contacted the organization's fund raiser to inquire how his money was being spent. When the fund raisers could find no record of his contribution, an internal investigation was launched. During the course of that investigation, the accused tried surreptitiously to pay back a portion of the money he had embezzeled. In doing so,

95National Audit Office, Monitoring and Control of Charities in England and Wales, p. 11.
he was discovered and subsequently charged.  

In each of the examples of charity fraud described above, the interests of the individual donor were clearly exploited. While at least in theory the British state can deal with many kinds of abuses involving charities [through powers extended by the Charities Act (1960)] it is not well suited to protect potential donors from fraudulent or incompetent fund raisers. As Chesterman explains, the Charities Act paralleled the 19th century legislation by attempting to focus primarily on charitable trusts, rather than on fund raising charities. Since Canadian law has closely paralleled British common law, government charity administrators in the former country have been equally ineffective in addressing new and sophisticated fund raising improprieties. If Canadian and British charities continue to increase their provision of services to compensate for the reduction in like government services (see Chapter seven for the case of medical research) the need for more effective government supervision of charities will become more clearly apparent.

96 On 2 December 1986 I scheduled an interview in Toronto with the Executive Director of this charity for 22 December. On 19 December he was arrested by the Toronto Metropolitan Police Force and therefore was unavailable for our meeting. As an alternative I was re-scheduled to interview his assistant. During our meeting and after asking questions regarding the fraud, the respondent took to thinking I was a CBC reporter and requested I erase our tape recorded conversation. The aforesaid account of this incidence is therefore based entirely on my recollection of that meeting.

97 Alan Ware, Between Profit and State. Cambridge: Polity Press, forthcoming manuscript, p. 10.

Chapter Three
Charity Law and Political Involvement

In Chapter two it was argued that indirect public subsidies, relating to tax relief are available only to bodies which are legally charities. And in order to become a charity, an organisation must not engage in political activities. This chapter examines what constitutes ‘political activities’ and assesses how this aspect of charity law has influenced charity-state relations in Britain and Canada. The discussion here provides an important introduction for the comparative study of relations between medical research charities and the state in Britain and Canada (in chapters five to eight). In these later chapters it is shown that despite the law, medical research charities have become increasingly political in lobbying government for legislative and regulatory reform.

This chapter divides into three sections. The first, examines the development in both countries (with occasional reference to the United States) of the common law restriction placed on charities and their involvement in the political process. In a general context, this reveals both the surprisingly fragile doctrinal base underlying this legal rule and also the social conditions out of which the law developed. This section explores the case law on the subject in considerable detail; it is
not intended to be a full analysis of the law, but instead a review of the policy justifications given by the judges in developing this area of law. Section II compares American legislation relating to charities and their political involvement on the one hand with British and Canadian laws on the other. This examination highlights problems in this area of law in each of the three countries and illustrates the distinctly different approach which American legislators have adopted in dealing with politically active charities. Section III begins by examining a number of official reports and their recommendations for English legal reform. In contrast to Britain, the issue of 'charity and politics' has not been the subject of official inquiry in Canada. Nonetheless, the Canadian government has introduced much more progressive reforms than Britain in this area. In Canada, pressure for reform has come not from studying the problems of charity and political involvement, but rather as ad hoc responses to a series of government controversies from 1978 to 1983.

I. Development of the Common Law Principle Restricting Charities From Engaging in Political Activities

The very first English legal case to state that trusts established with political objectives were not charitable is Bowman v. Secular Society Ltd (1917). Lord Parker, who decided the case, held the "Law has always refused to recognise political objects as charitable ... since trusts for the attainment of these

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1Bowman v. Secular Society Ltd. (1917) A. C. 406 (H. L.).
objects have always been invalidated. This prohibition on political activities was later affirmed in a host of other English and Canadian legal cases. Some judges have expressed great puzzlement at the lack of 'judicial authority' attached to this principle, but not one has been inspired to impugn its validity. Not only was there no judicial authority for Lord Parker's assertion in Bowman (1917), but previous common law cases had held the exact opposite. The only related judicial decisions on which the Bowman case was decided were those dealing with 'superstitious uses' and 'purposes' ruled to be against state interests. The former had been completely overruled by statute by 1846 and the latter was confined narrowly to a small number of legal cases. During the 15th and 16th century a number of 'superstitious' uses or 'purposes' were held both by statute and common law to be non-charitable. A superstitious use was defined broadly as "one which had for its object the propagation of the rites of religion

2 Ibid., p. 442.

3 See, for example, Re Patriotic Acre Fund (1951) 2 D.L.R. 624, 634 (Sask. C.A.), C.J.S.; National Anti-Vivisection Society v. Inland Revenue Commissioners (1948) A.C. 31 (H.L.).

4 The deciding judge commented in 1948 that "it is curious how scanty the authority is for the proposition that political objects are not charitable ..." National Anti-Vivisection Society v. Inland Revenue Commissioners (1948) A.C. 31, 54 (H.L.). In the same case Simonds L.J. also reflected on the "paucity of the judicial authority on this point ... But the truth and the reason of the thing appears to me so clear that I neither expect nor require much authority". Ibid., p. 63.

not to be tolerated by the law."6 Tudor, the leading commentator on charities in the late 19th century, stated that "persons who, differ from established religion and are obvious to the law to be against superstitious uses, may be divided into three classes: Protestant Dissentors, Roman Catholics and Jews."7 As religious tolerance gradually increased superstitious uses were rendered valid by statute. The first legislation to validate 'uses' or 'purposes' relating to the Jewish religion was passed in 1846. Since that time, all 'superstitious uses' have been considered charitable on the grounds of 'advancement of religion' but must also, like other non-religious charities, pass the public benefit test.

Since the Bowman decision, all subsequent English and Canadian cases holding political objects to be non-charitable rely upon it. However, as one commentator suggests, the 1917 case was based on 'slim authority'. Only one of five judges giving reasons for their ruling addressed the issue. The case cited for the basis of that decision was De Themmines v. De Bonneval (1828).8 Lord Parker's task in the Bowman case was to resolve whether Bowman's next-of-kin was correct in disputing a bequest made to the Secular Society Ltd. The Society's main object was to promote the principle that human conduct is based upon natural knowledge, and not upon supernatural belief. The Society recommended the

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6Ibid., p. 19.
7Ibid., p. 20.
abolition of all support, patronage or favour by the state of any particular form or forms of religion, and numerous other secularising goals, many involving legislative changes. Lord Parker ruled in favour of the next-of-kin by invalidating the bequest on grounds of 'political involvement'. More precisely he reasoned this was the law not because such purposes were illegal, but in his own words ... "because the court has no means of judging whether a proposed change in the law will or will not be for the public benefit, and therefore cannot say that a gift to secure change is a charitable gift".10

Throughout the 1920's and 1930's a number of judicial decisions in England re-affirmed Lord Parker's ruling holding that political purposes were not charitable in law. However, in Canada it is interesting to note that the Bowman case was not cited until 1937. Prior to this, Canadian courts treated the question of charities and their political involvement in somewhat different terms. In Canada, at the turn of this century, a number of political purposes were in fact held to be charitable. For example, one organisation sought to promote temperance legislation and another to promote aid and the protection of citizens of the United States of African descent in enjoying their civil rights.11 However, in the Canadian case Re Knight (1937),

10Ibid., p. 20.
it was decided that a gift ‘to the Henry George foundation was ‘political rather than charitable’. The organisation was established for the purpose of promoting the doctrines of the late Henry George including his theories and principles respecting the single tax.

In both countries, the courts have followed the decision in National Anti-Vivisection (1948), in deciding that political activities constitute non-charitable purposes. For example, in Canada the Saskatchewan Court of Appeal followed this decision in Re Patriotic Acre Fund (1957) and Re Loney (1953).

English case law examples are more numerous; a review of two important legal decisions help to clarify several aspects of this law. First, the argument that organisations constituted for political purposes cannot be characterised as charitable applies whether an organisation’s objects expressly refer to political purposes or political purposes are implicit in the organisation’s objects. For example, in McGovern V. Attorney General (1981), Mr. Justice Slade refused to grant an application by the trustees of the Amnesty International Trust for a declaration that the trust be registered under the Charities Act (1960). The trust’s

12Re Knight (1939) 2 D.L.R. 285, 288 (Ont. S.C.).

13See Re Patriotic Acre Fund (1951) 2 D.L.R. 624, 636 (Sask. C.A.) and Re Co-operative College of Canada (1975) 64 D.L.R. (20) 531 (Sask. C.A.). See also Re Loney (1953) 4 D.L.R. 539 (Man. Q.B.) where a “gift for the purposes of promoting and propagating the doctrines and teaching of socialism was held not charitable”.

objects were aimed at "attempting to secure the release of prisoners of conscience". The courts ruled the trust’s purposes were furthered by procuring "the reversal of the relevant decisions of governments and governmental authorities". Similarly, in Animal Defence and Anti-Vivisection Society v. I.R.C. (1950), the Society’s objects were stated to "oppose vivisection and all experiments on animals calculated to cause pain". Mr. Justice Dankwerts rejected the Society’s claim by arguing that "the matters which are to be done ... must necessarily in the end involve an attack on the Cruelty to Animals Act (1876) and the promotion or the support of legislation for repealing that Act and for suppressing vivisection altogether."

A second aspect of the law is that charitable organisations may influence legislation if their activities are incidental and ancillary to their primary charitable objects. For example, in National Anti-Vivisection (1948), Lord Simons validated a trust by ruling the organisation’s political objects were "merely ancillary to the attainment of what is ex-hypothesi a good charitable object". The Charity Commission has applied strict guidelines regarding what should properly be considered primary and ancillary

15 Ibid., p. 501.
16 Ibid., p. 514.
17 Animal Defence and Anti-Vivisection Society v. I.R.C. (1950) 66 T.L.R. 1091 (Ch.).
18 Ibid., pp. 1095-96.

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objects at the initial stage of registration. This has been done to avoid granting charitable status to organisations which may be disposed to confusing their charitable and political objectives. Paradoxically, although charitable status is denied to straightforward campaigning organisations or pressure groups, it is permitted to many bodies which employ political lobbying methods as a subsidiary part of their activities. Gladstone explains this in saying:

"This does not mean that a charity cannot seek changes in the law or in administration or even to advance human rights. It can provided that end is a charitable purpose and among those specified by the charity's trust deed."

In this way, certain pressuring and promotional activities are allowed, as long as they are not party political. Consequently, the law has recognized as charitable, The National Council for Civil Liberties, Age Concern, and MIND, all of which have, through lobbying and public education, attempted to influence the legislative process and government policies. The style of such political activities is held to be crucial by both the Charity Commission and Revenue Canada. For example, reasoned memorandums have been acceptable but public demonstrations have not been. Charities have all had to proceed carefully with their


political activities. For example, MIND had to answer its critics for holding membership in Unemployment Alliance, a lobby group aimed at increasing public awareness to the 'evils of unemployment'. MIND, successfully managed to trace a connection between its main concern with mental health and the effects of unemployment.22

Until recently, to be registered under the Income Tax Act (1952), Canadian charities have been strictly prohibited from engaging in any form of political activity even if it is only ancillary to their main charitable objects.23 This was based on the relevant definitions in the Income Tax Act (1970) which specified that registered charities must devote "all their resources ... to charitable activities".24 However, after a much publicized controversy surrounding Revenue Canada's interpretation of 'permissible political activities', Departmental officials in 1986 drafted new legislation. The new legal rules brought Canadian charities in-line with their British counterparts by allowing charities to engage in political activities that are incidental and ancillary to their main charitable objects. The details of this new legislation are dealt with later in Section III of this chapter.

English and Canadian courts have adopted four guidelines in


distinguishing primary charitable objects from those that are political and ancillary. As outlined in chapter two Section I.C; charities are held to be political, hence non-charitable, if their main activities include: (1) attempting to bring about, or oppose, changes in the law; (2) furthering the aims of political parties and promoting political doctrines; (3) affecting foreign relations; and (4) propagandising, including attempts to persuade the public to adopt a particular attitude towards some broad social question.25 Each of these categories is examined below.

A. Promoting or opposing changes in the law

An organisation will not be considered charitable if one or more of its purposes includes promoting changes in the law. This policy guideline finds its origin in the case National Anti-Vivisection Society V. I.R.C. (1948). The central issue in the case was whether the Society was eligible to claim an exemption from income tax on the grounds that it was a charitable organisation. However, the Society’s main object was held to be for the complete abolition of vivisection through its campaign to repeal the Cruelty to Animals Act (1876) and its substitution by

new legislation. A majority in the House of Lords held the trust was non-charitable on two grounds. First, the organisation was not for the benefit of the community or a sufficient section thereof as stated in the fourth category outlined by Lord Macnaghten in Pemsel's case. Second, the Anti-Vivisection Society's purposes were viewed as being for an alteration in the law; they were therefore considered 'political' hence non-charitable.

The reasoning developed in relation to this legal rule is straightforward. Judges have argued they have no reasonable means of asserting whether or not a change in the law, influenced by a charity will confer a substantial public benefit to the community.

However, this type of judicial reasoning has been strongly criticized by a number of British and Canadian legal commentators. Alternatively, they have endorsed the approach adopted by American judges. In that country, judges are at liberty to recommend changes in the law. In fact, as Ritchie states, "there are few people better qualified than judges to assess whether a change in the law would be for the public benefit."26 In the U.S., the relevant question is not whether a particular legislative outcome is in itself for the public good, but instead whether having all viewpoints presented on legislative issues is a public benefit. As Gravells candidly remarks:

"There seems no reason why judges should be

unable to determine whether the advocacy of change, in particular laws, is for public benefit. It may be possible to decide it is, even if there remain doubts about the rights and wrongs of the change itself. In a free democracy, the promotion of controversial views may well be for the public benefit."

British and Canadian Judges have refused to accept this responsibility and have continued to hold purposes involving direct and indirect changes in the law as 'non-charitable'. For example, in 1972, a British student union (itself a charity) wished to subscribe to a campaign against the government's policy on free milk supplies to school children. The object of the campaign was admittedly according to its own literature, political, and an injunction was granted against the student union's officers prohibiting them from applying union funds to this purpose.28

B. Supporting political parties and promoting political doctrine

English and Canadian courts have held that if it promotes the interests of a particular political party a trust's purpose is political, hence non-charitable. For example, in 1929 a gift "to the British Primrose League of the Conservative Cause to be used as a habitation in connection with the league or in a manner which


28Baldry V. Feintuck (1972) 1 W.L.R. 552
would benefit the cause of a political party"29 was invalidated. Furthermore, Mr. Justice Vaisey in Re Hopkinson (1949) struck down a gift on trust "for the advancement of adult education with particular reference to the following purpose, ... the education of men and women of all classes (on the lines of the Labour Party's memorandum ...) to a higher conception of social, political and economic ideas and values ..."30 The memorandum cited by the testator was aimed at furthering the ends of socialism and encouraging the solution of contemporary problems by the application of socialist principles. The object of the gift was not to influence the content of a particular piece of legislation but rather to advance the fortunes of one political party and its policies. Similarly, in Bonar Law Memorial Trust V. I.R.C. (1933), a trust to establish a college run by members of the Conservative Party sought to be exempt from income tax. They argued that students were admitted without reference to their political leanings. Some lectures were given on Conservative Party organisation and, during the holidays the building was used to give courses restricted to Conservative Members of Parliament. Mr. Justice Finlay held that a trust for the furtherance of a particular political party could not be ruled a charitable trust. On the facts, the Bonar Law Memorial Trust was held to be closely

29Re Jones (1929) 45 T.L.R. 259 (Ch. Div.).

30As stated in the dictum in Re Hopkinson (1949) 1 ALL E.R. 352 (Ch. Div.).
aligned to the Conservative Party and therefore invalid. In the Canadian case, Re. Loney (1953), a trust "for the purposes of promoting and propagating the doctrines of teaching socialism" was held to be non-charitable on similar grounds.

As previously noted, if an organisation is able to demonstrate to the courts that political activities are ancillary to its main charitable object, then charitable status will be conferred. For example, in Re. Scowcroft (1898), a bequest of a building known as the Conservative Club and Village Reading-Room ... to be maintained for the furtherance of Conservative principles and religious and mental improvement was ruled valid:

In the Judge's own words it was argued:

"The furtherance of religious and mental improvement is ... an essential portion of the gift. It is therefore, a gift in one form or another for religious and mental improvement, no doubt in combination with the advancement of Conservative principles ..."

To make the same point, in the case Re. Arthur McDougall Fund (1957), a trust was held charitable even though it was established by a political society devoted to advancing the concept of proportional representation. The decision was even upheld under

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32As stated in the dictum in Re. Loney (1953) 4 D.L.R. 539.

33Re. Scowcroft (1898) 2 Ch. 641-2 (Ch. Div.). The decision handed down in this case is credited with laying the legal foundation on which the Bowman (1917) case was later decided.
an appeal since the organisation's purpose was viewed as advancing education in the area of political science. The basic lines of reasoning adopted by the courts in the above decisions, are as follows. Judges argue they cannot validate gifts from charities to political parties or recognise organisations as being charitable if they advance only one political doctrine. As the final arbiter, they have no way of determining whether disputed 'objects' are for a public benefit. To proceed otherwise, judges have feared "encroaching on the functions of the legislature and prejudicing their own reputation for political impartiality." 35

C. Affecting foreign relations

Judges have invoked the principle that charities seeking to affect relations are deemed to be political, and hence (because of Bowman) non-charitable. For example, in Re. Strakosch (1949), the courts ruled a gift invalid for any purpose which in their opinion is designed to strengthen the bonds of unity between the Union of South Africa and Britain. The decision was reached despite the plaintiffs plea that the gift would help to appease strained racial feelings between the Dutch and English speaking communities in South Africa. 36 In a similar case, an organisation aimed at promoting a closer and more sympathetic understanding between English and Swedish people was held non-charitable under English

34 Re. Arthur McDougall Fund (1957) 1 W.L.R. 81 (Ch. Div.).
36 Re. Strakosch (1949) Ch. 529 (C.A.).
common law. Furthermore, Oxfam has encountered legal problems for publishing its own 'politically tainted' literature. Commenting on Oxfam's efforts to resolve the problems of poverty in Nicaragua, Roger Scruton argued in The Times on 8 April, 1986 that the literature distributed by this charity asked for 'public support of the Marxist government of Nicaragua'.

The most publicised legal case in which a charity was ruled to have affected foreign relations, involved Amnesty International (1981). The objects of this organisation included, "attempting to secure the release of prisoners of conscience and procuring the abolition of torture and inhumane or degrading treatment or punishment" and were ruled non-charitable on these grounds. In arriving at his conclusion, Mr. Justice Slade asserted that the organisation's main purpose was to alter another country's laws both directly and indirectly. His decision was based on two assumptions. First, Slade argued that even in the case of a proposed change in domestic law, "the court has no adequate means of judging whether a proposed change in the law of a foreign country would or would not be for the public benefit." Second, he assumed that by holding the trust to be charitable, relations

37 See Anglo-Swedish Society V. I.R.C. (1931) 147 T.L.R. 295. It was held that the organisation was not charitable because it was essentially a trust to promote an attitude of mind concerning a view of one nation by another.

38 The Times. 8 April 1986.


40 Ibid., p. 507.
between Britain and other foreign countries, might be strained. In other words, Mr. Justice Slade decided this case by taking into consideration public policy issues. In advancing this argument in his dictum the following was stated.

"Before ascribing charitable status to an English trust of which a main object was to secure the alteration of a foreign law, the court would ... be bound to consider the consequences for this country as a matter of public policy. In a number of such cases there would be a substantial prima facie risk that such a trust, if enforced, could prejudice the relations of this country with the foreign country concerned."

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Because the Attorney-General in both England and Canada administer charitable trusts when executor(s) are incapable of carrying out their responsibilities, there is concern a greater relaxation of this restriction would damage state relations with other countries. Most legal commentators suggest this would not be the implication since it is difficult to imagine a foreign country viewing the Attorney-General's administration of a charity as representing a state endorsement of its purposes. In America, however, charities have been permitted to advance purposes which affect foreign relations. The most obvious example is charities aimed at promoting peace by disarmament, as well as those aimed at promoting peace by preparedness for war.42 Obviously, these organisations often set their objective to alter domestic laws and

41Ibid., p. 507.
the laws in foreign countries. However, their fundamental *purpose*, to guarantee international peace, also involves influencing existing relationships between nations. Nevertheless, American legislation openly recognises these overtly political activities as 'open territory' for charity. The most striking demonstrations of the potentially political nature of American charities (in the context of affecting foreign relations) were revealed between 1952 and 1967. During that time, a large number of grant making foundations secretly received funds from the Central Intelligence Agency on the basis that, in turn, they would make grants to 'approved' charities operating mostly in the sphere of education and culture within developing countries. American cultural aid, although dispensed by 'neutral' organisations of a philanthropic nature, was thus significantly tinged with political doctrines favouring 'freedom' under American-style capitalism. In the context of 'charity law', what matters is not that the U.S. was thus distributing its own political propaganda, but that charities were the medium for this.43

D. Disseminating propaganda and attempting to change social attitudes

Organisations attempting to persuade people to adopt particular attitudes have been held non-charitable on two broad grounds.44 First, the courts have ruled them 'non-educational' as


44The acceptance of the two general principles embodied in the law is beyond dispute. Curiously, the article on 'charities' in the most recent edition of Halbury's laws of England appears to
defined in the *Pemsel* case, if all sides are not presented. Second, they are normally ruled to provide no public benefit since they are political (that is to say the courts have no way of deciding whether they will benefit the public). While this last line of reasoning has been discussed in sub-sections A, B, and C, the first requires more elaboration.

In the context of charity law, propaganda, as opposed to education, has been defined as presenting only one side of an issue or presenting unsubstantiated opinions. The legal case *Re. Bushnell* (1975), involved a trust "for the advancement and propagation of the teaching of socialised medicine". A testator who died in 1941 bequeathed his residuary estate on trust to publish books and other literature, promote lectures and establish an institute, all for the purpose of spreading knowledge about 'the socialized application of medicine to public and personal health and well-being'. However, the main purpose was held by the court to be for 'illustrating that the full advantage of socialized medicine can only be enjoyed in a socialist state'. Mr. Justice Goulding held the trust non-charitable on the ground, be outdated. Indeed, it is a replication of the law as stated in the very first edition of Halsbury. See T. Holden, *Halsbury's Laws of England*. London: Butterworths, 1974, vol. 5, para. 543, where it is stated that "the promulgation of particular doctrines or principles not subversive of morality of otherwise pernicious, and not in furtherance of the principles of a particular political party, nor involving pressure on the legislature to achieve a political object in changing the law of the land, may be charitable". This accurate statement of the law in 1908, is outdated today.

45*Re Bushnell* (1975) 1 W.L.R. 1596, 1605 (Ch. Div.).
inter alia, that the socialist element in the trust gave it a substantial political flavour. The judge further concluded the trust could not be supported as an educational trust and therefore was not considered charitable under common law. He remarked: "the testator never for a moment, as I need his language, desired to educate the public so that they could choose for themselves, starting with neutral information, to support or oppose what he called 'socialised medicine'. The test of 'neutral information' as a criterion of education may seem stringent: this is particularly true in the U.S. For example, the American Senator, Daniel Patrick Moynihan, threatened U.S. foundations with deregistration if they were not "even handed in the political consequences of (their) activities, seeking neither to advance nor impede any cause except that of understanding and competence". However, British legal historians have not been convinced that the judge in the Bushnell case wished to extend the law this far. Rather, it has been argued his judgement was more analogous to an earlier American Treasury regulation stating an organisation was not educational if "formed to disseminate controversial propaganda". The judge in the case further stated, "I think he (the testator) was trying to promote his own theory by education,

46 Ibid., p. 1605.


if you will propaganda, but I do not attach importance to that word."49

Many British and Canadian charities have sought to advance a variety of causes, but this has not impeded their charitable status so long as the promotion of legislation is merely ancillary to their charitable purpose. There are at least three problems for the courts in deciding whether a charity’s purposes are educational (hence charitable) or propaganda (hence non-charitable).

First, the most significant problem involves distinguishing between educational material and propaganda. Regardless of how they are defined, the difference between the two terms only become apparent when taken in their literal contexts. Some argue that all education is infected with the biases of the educator. Even if bias is not apparent from the material presented, it is from the material that was not presented but might have been. The only real differences between these two scenarios is not what information they provide the reader with, but the form in which it is presented. Thus, for example, one commentator has noted, “advancement of inter-social harmony can be described as education of different racial groups about each other’s way of life, and propagation of right or left-wing doctrines may be charitable if it can be described as education in political science”.50

Second, even assuming there is a difference between

49Re Bushnell (1975) 1 W.L.R. 1605 (Ch. Div.).

50Chesterman, Charities, Trusts and Social Welfare, p. 159.
propaganda and educational material, the judgments about this involve subjective considerations so that it provides a basis for the censorship of ideas, or at least differential state support for some ideas. The fact that distinguishing between 'education' and 'propaganda' leaves vast room for the reflection of a judge's or administrator's political biases is widely recognised. For example, a member of the U.K. House of Commons Expenditure Committee made the following comment about the judge deciding the Re Bushnell case.

"... he was probably a Tory himself. Most of the judges are, in fact, right-wing reactionaries and, therefore, whatever one might have to say on the impartiality of the judges, it is not always the case in a case like this where there might be a political context which might be at variance with the views of the judge."

Even if this allegation is unfounded, it does reveal the potential conflict of interest of involving judges in essentially political questions.

Third, when organisations disseminate propaganda it can not be clear to judges whether it's against the public's interest. For example, even though a person is being presented with only one view, they are nonetheless being educated. Having heard all views from different organisations, it is arguable that individuals are able to form their own judgement. One legal expert has argued "if

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one reason that the advancement of education is for the public benefit is that it enables people to make educated judgements, then allowing them to hear from the strongest advocates of each side of an issue is arguably the best means.".52

There are few case law examples of charities actively involved in disseminating propaganda and attempting to change social attitudes. Nevertheless, cases involving the question of 'charities and propaganda' have demonstrated the court's eagerness to disallow these types of charities to exist. Judges have argued if charities were permitted to promote propaganda and receive immunity from income tax, the public might be misled into believing such views were supported and endorsed by the state.53

II. American Law Versus English and Canadian Law

Aside from several minor differences, English and Canadian law have treated the issue of charities and political involvement in virtually identical terms. However, in the United States, different guidelines in this area of law have been developed and given statutory force. In each of the three countries the issue of charities and politics has only recently become a pervasive problem, for two important reasons. First, charitable organisations, whether involved in third world relief or medical research, recognise government-sponsored action is often more

52Ibid., pp. 313-320.

53See IRC V. Yorkshire Agricultural Society (1927) 1 K.B. 611.
effective in resolving problems than is philanthropy on its own.\textsuperscript{54} As a result, many charities have attempted to achieve their objectives by affecting government legislation. Second, because charitable status automatically entitles organisations to a host of fiscal privileges, an increasing number of groups with mainly political objectives have sought to operate in some limited ways under the banner of charity. It has been shown that since 1917 English and Canadian law have limited the amount of political activity which charities may involve themselves, but this is not the case in the United States. From 1919 to 1969 American law closely paralleled English and Canadian law over the question of charities and political activities. The United States Treasury in 1919 issued a regulation providing that "associations formed to disseminate controversial or partisan propaganda are not educational within the meaning of the statute".\textsuperscript{55} This judicial line of reasoning remained intact until a number of widely-reported cases brought by the Internal Revenue Service (IRS) against certain tax-exempt organisations resulted in strident

\textsuperscript{54} However, Third World relief charities are conscious of the fact that they are often able to implement and administer programmes and achieve certain goals that government agencies are unable to because of their 'private status'. Charities that have accepted large government grants have frequently encountered problems in the 'field' since their 'private non-governmental' status has been perceived by the host government/people to be politically tinged. See generally, Peter Burnell, \textit{Third World Charities in Britain and Official Funding}. University of Warwick: Politics Department Working-paper No. 46, 1987.

demands in the late 1960s for law reform. The most publicised cases involved the Sierra Club - an environmentalist group - and a number of public interest law firms. In these cases, legal experts argued that the courts had no means of determining when an organisation's activities had become substantially political. This, in turn, lead to serious charges against the IRS of selective and random enforcement practices. The urgency for legislative reform increased after a number of challenges were initiated to test the Revenue Code's constitutionality. The central issue related to restrictions on the deductability of donations to charities involved in lobbying for legislative reforms. These constitutional challenges included impermissible vagueness, denial of equal protection and restriction on free speech. The problem of distinguishing political from charitable purposes in the U.S. is complicated by the First Amendment's guarantee of freedom of religion and particularly 'the free exercise thereof'. The Free Exercise clause has been held to justify political activity when the church in question regards the legislation as religious: an example is the promotion of Temperance or Sunday Observance Legislation. Both of these


57For a summary of the various legislative proposals made between 1969 and 1974 and a reprinting of the major bills presented to Congress, see Filer, Giving in America: Toward a Stronger Voluntary Sector, p. 917.

58Girard Trust Co. V. Commissioner (1941) 111 F 2d 108.
have been held to be political objectives in England and Canada. Conversely it has been argued that American tax treatment favouring religious organisations undermines the principle of neutrality implicit in the First Amendment's proscription of governmental interference with religion. It was suggested by the Filer Commission that this principle of neutrality may require that in this respect religious organisations should be treated in the same way as other American charities; "that is, with no substantial advantage or disadvantage applied to religious organisations merely because they are religious". Under English and Canadian laws, charities established for the advancement of religion receive no special advantage or disadvantage with regard to political activity.

By the late 1960s, the taxation and regulation of American charities came under close scrutiny from several congressional committees. One aspect of this investigation related to the political activities of private foundations. One concern was that private foundations had become too financially supportive of political activists aligned with particular parties and even political candidates. Congressional committees also concluded that some of these political activities were aimed at furthering the self-interest of individual charities and their major donors.

59 Lords Day Alliance of Pennsylvania V. United States (1946) 65 F Supp 62. The Lord's Day Observance Society is a charity in England because it was established in the 19th century prior to the Bowman decision in 1917.

In response new legislation - the Tax Reform Act (1969) - was enacted containing precisely defined rules prohibiting private foundations from engaging in political activities. However, the prohibition, was subject to three important exceptions which permitted grant-giving foundations to (1) make available the results of non-partisan analysis, study or research; (2) to furnish technical advice or assistance in response to requests by governmental bodies and (3) to attempt to influence legislation concerning the existence of the private foundation, its powers and duties, its tax exempt status, or the deduction of contributions to it.61

Legislation relevant to charities which actually deliver services are more complex than those applied to private foundations. Nevertheless, the statutory framework can be simply explained in the following way. Certain organisations in the United States, often referred to as 'section 501(c)(3)' organisations, are entitled to have their income exempt from tax and also to receive tax deductible charitable contributions. These 'section 501(c)(3)' organisations include corporations "organised and operated exclusively for religious, charitable, scientific, testing for public safety, literary or educational purposes."62 However, the 1969 legislation outlines three principal forms of activities which would lead an organisation to

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61See the United States, Tax Reform Act (1969), especially section 4945.

be classified as a 'social welfare group' and therefore non-charitable. These include: (1) attempting to influence legislation, (2) participating in political campaigns on behalf or in opposition to any candidate for public office, and (3) having a 'primary objective' that may be attained by legislation or defeat of proposed legislation. The legal rules applicable to social welfare groups are covered under section 501(c)(4) of the Internal Revenue Code.

American courts have encountered the same difficulty as their British and Canadian counterparts in determining what constitutes a 'primary objective'. In general the American regulations go into much more detail as to the precise form of activity that is allowable. For example, specific guidelines are in place which determine the extent and conditions under which charities may circulate the voting records of Congressmen. The English and Canadian tendency on the other hand, is to make a more general assessment as to whether political activity is a primary or ancillary purpose. Thus, English and Canadian charities appear to be more free than their American counterparts in proposing new legislation or making representations to government officials and Members of Parliament about legislation that affects their charitable purposes. This is conditional on such activities remaining ancillary to their charitable purposes. Conversely, the American regulations define 'political' more closely in terms of

interference with the legislative process, including elections.

As in the U.S. it has become increasingly difficult for the Charity Commission, and Revenue Canada to consistently draw an accurate line between politics and philanthropy. The task has been made more difficult by the increasing number of overtly political organisations seeking the fiscal privileges attached to charitable status. As a result, in each of the three countries many charities with both political and charitable purposes have feared deregistration. In reducing this anxiety many organisations have divided themselves into two distinct parts; the main body to advance their charitable objectives and the subsidiary organisation to advance their political objectives. In the United States the ‘social welfare group’ structure is most often adopted as the subsidiary organisation for lobbying government. While classified as non-charitable and ineligible to receive tax deductible contributions, they may receive tax exempt status. In Britain and Canada, many organisations have also separated their political and charitable activities by creating subsidiary organisations. However, in contrast to the social welfare group in the U.S., British and Canadian subsidiaries are ineligible to receive comparable tax exemptions.

An example of a British organisation with specifically political purposes is the Disablement Income Group, (DIG). Its objectives include:

"securing the provision for all disabled people of a national disability income including an allowance for the extra expense of disablement;"
to cooperate with other bodies working in the field; for the improvement of the economic and social position of disabled people and the chronic sick; to promote research into the economic and social problems of disablement."

However, in this case a close alliance of political and charitable purposes is achieved by establishing two bodies. One is a non-party, non-charitable pressure group concerned with legislative reform. The other is a registered charity concerned with the collection and dissemination of information about the economic and social problems of disabled people. Clearly, research and the collection of information about social and economic problems are charitable purposes at law. Even though the organisation may serve an object that is not charitable - political pressure for a statutory disablement income - its own charitable status is not affected. Two other publicised British examples of this practice include Amnesty International (political) with its subsidiary, Prisoners of Conscience Fund (charitable), and Christian Aid (charitable) with its subsidiary, Defence and Aid Fund (political). While this strategy has reduced the chances of a charity being deregistered for unlawful political activities, there are other practical disadvantages such as keeping separate accounts and maintaining separate payrolls.

66 Ibid., p. 361.
medical research, none of the British and Canadian respondents acknowledge their organisation had adopted this strategy.


This section examines issues raised during public debates in Britain and Canada relating to charities and their political involvement. In looking at Britain, two official reports are examined: the Charity Commission's Annual Reports published by the Home Office, and the House of Commons Expenditure Committee's Tenth Report entitled: The Charity Commissioners and their Accountability, 1974-75. Also examined is the Report published by the National Council of Social Service - the Goodman Report (1976). In contrast to Britain the issue of charities and political involvement has not been the focus of official inquiry in Canada. For example, the issue was not addressed in the 1966 Carter Report on taxation nor was it dealt with in the 1975 Department of Finance Green Paper on charities. Nevertheless, it is possible to examine the issue from a different perspective by reviewing a recent controversy involving Revenue Canada. In 1978, Revenue officials introduced new guidelines regarding the restriction of charities from political involvement. The issue of charities and politics has arisen in different contexts in the two countries, nevertheless a review and discussion of these public debates illustrates the diversity of opinions concerning this aspect of charity law.
A. Charity Commissioners' Annual Reports

In consideration of the growing number of complaints regarding political activities, the Charity Commissioners' 1969 Annual Report listed two classes of 'political' activities which they believed could be justified as being proper for charities. First they stated that if government officials or Members of Parliament asked a charity for information or evidence, it would be proper for that charity to be able to respond to such requests. The Commissioners suggested extending the principle further by regarding the government as implicitly inviting comments when they set forth their proposals in Green and White Papers.67 From this position they went one step further by stating: "When a parliamentary bill has been published, a charity will be justified in supplying relevant information to a Member of either House and such arguments to be used in debate as it believes will assist the furtherance of its purposes."68 In recommending this, the Commission drew a fine distinction between initiating political action (an illegal activity) and participating in policy debates in a restrained manner (a permissible political activity). However, the Commission qualified this by listing its second class of permissible political activities, cases where a charity might

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67A Green Paper is a consultative document in which the government sets forth for discussion proposals that do not necessarily represent their own policy. The Government takes a greater degree of responsibility for proposals set forth in a White Paper.

be justified in initiating political activities:

"It is unobjectionable for a charity to present to a government department a reasoned memorandum advocating changes in the law provided that in doing so the charity is acting in furtherance of its purposes. On the other hand, a charity can only spend its funds on the promotion of public general legislation if in doing so it is exercising a power that is merely ancillary to its charitable purposes. But here again difficulty arises in defining the boundary between what is merely ancillary and what amounts to adopting a new purpose itself. A charity would be well advised to seek advice either from legal advisors or from us before undertaking any such activities."

The Charity Commissioners returned to the issue of political involvement in their 1976 annual report. The Commission stated that during the previous year it had a number of complaints regarding charities involved in the area of family planning, abortion and anti-smoking. For example, the Commission was asked by a number of non-charitable anti-abortion lobbying groups to deregister the Family Planning Association (F.P.A.). This charity was accused of failing to give proper information and instruction concerning the need for, and value of sexual restraint and because it was engaged in lobbying for legislative changes. The Charity Commissioners argued that organisations like F.P.A., The British Pregnancy Advisory Service and the Pregnancy Advisory Service, all of which are registered charities, were not, on the evidence

69Ibid., para. 16.
accumulated, in league with pro-abortionist lobbying groups. This case highlights the strategy adopted by some non-charitable organisations holding certain beliefs to strip charities advocating contrary beliefs of their tax exempt status. This would remove an organisation's fiscal privileges and place it on a more equal financial footing with non-charitable organisations advocating opposite points of view.

Similarly, the Charity Commission stated in its 1978 annual report that, during that year, they reviewed the activities of three international relief charities concerning alleged political involvement. War on Want, Oxfam and Christian Aid Division were all required to meet officials from the Charity Commission to explain their behaviour.71 This was done prior to the Commission deciding on whether legal action should be initiated. The Charity Commission concluded that the Christian Aid Division had previously made grants to the World Council of Churches' Commission on Churches' Participation in Development. The objects of this organisation were aimed at "enhancing political action, mobilising public opinion and effecting structural change within societies in an attempt to tackle those causes of poverty which lie in the economic, social and political structures of communities".72 The Charity Commissioners reacted by advising the charity's trustees that such activities were not within the

72Ibid., para. 27.
parameters of the original set of 'objects' agreed upon at registration. As a result, future grants made to the World Council of Churches were required to be given for objects exclusively charitable in law.73 While the Charity Commission has had the authority to pursue a much more aggressive approach in dealing with these organisations, normally only a written warning is issued. This approach has been favoured for two reasons. First, for the Charity Commission to proceed directly to litigation in every instance of detected breaches of the political bar rule would be costly and time consuming.74 According to one respondent, the Commission's limited resources have primarily been allocated to programmes responsible for detecting other illegal activities such as tax fraud. However, this directly contradicts the recent conclusions reached by the National Audit Office in its 1987 report.75 Second, the Charity Commission has preferred to view itself as an information and co-ordinating agency genuinely dedicated to assisting charities rather than functioning as a strict government watch-dog agency.76

The Charity Commission's annual reports reveal a partial response to charity demands to 'clarify' the law regarding the types of political activities considered permissible. The

73Ibid., para. 27.
76Ibid., pp. 3-4.
prevailing misconception is that the Charity Commission has the jurisdictional authority to draft new legal guidelines. As the Charity Commissioners themselves point out, their responsibility is merely to interpret the guidelines as formulated by the courts. Attempts to redefine the law in the direction of increasing the limitations placed on a charity's political activities, would be met with considerable opposition. A similar situation developed in Canada when Revenue Canada officials issued an information circular in 1978 in an attempt to clarify the legal interpretation of similar guidelines. While the Commission has advocated law reform in this area it has yet to provide its own set of recommendations. Given its limited resources and hence limited success in applying this aspect of charity law, most Commissioners have favoured a greater liberalisation in the types of political activities considered acceptable.

B. The House of Commons Expenditure Committee's Tenth Report, 1974-75.

The second report to examine the issue of charity and political involvement was the House of Commons Expenditure Committee's, Tenth Report: The Charity Commissioners and Their Accountability, 1974-75. Most commentators agree this study was the first to put forward substantive recommendations aimed at resolving the problem. During its hearings, the Commission accumulated considerable evidence from a wide body of interested

77 Ibid., pp. 3-4.
78 Ibid., pp. 4-5.
organisations. For example, the Charity Law Reform Committee demanded in its submission to the Expenditure Committee that legislation barring charities from political involvement be overturned. Furthermore, they argued the expansion of the welfare state had forced charities to alter their role from one of pioneering to one of supplementing statutory welfare services.

"In the past and particularly in the 19th century, charities were at the forefront of social change. They pioneered subsidised housing, prison visits, care of the handicapped, labour exchanges, adult education and many other services now too often taken for granted. In those days, the only possible method of ameliorating conditions was by approaching the general public for support. The government took little interest in social legislation, and charities played a major role in radical, pioneering work."

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When the welfare state began to assume much of the work previously performed by charities, it was widely believed the latter would 'fade away'. However, it became apparent there were, and continue to exist, major gaps in the welfare state. In response, many charities began to provide services similar to those provided by the state. The Charity Law Reform Committee further stated in its submission that this has created two problems for charities in relation to their restriction from political activities. First, organisations providing services supplementary or complementary to state-provided services have

naturally criticized and commented on the quantity and quality of government welfare programmes. Second, many charities, for example those relieving the poor, felt their contributions have contributed to delaying public policy to solve the more fundamental causes of poverty. In response, the Charity Law Reform Committee suggested "the sensible solution, consistent with the traditional pioneering role of charities, seems to be for them to investigate and define needs, to undertake small-scale pilot schemes, and to press the community and the government, as its agent, to accept their responsibilities and extend welfare services". As the members of the Expenditure Committee themselves recognised, "the ban on politics simply makes this approach impracticable." Despite the law, many charities have followed the Charity Law Reform Committee's recommendations. This is true of the Child Poverty Action Group, a charity whose purpose is to promote action for the relief (directly or indirectly) of poverty among children and families with children. In the broad sense of the term, this charity would seem to be politically active although not specifically partisan. In this case the organisation's primary focus is a 'deserving cause', the relief of poverty among children, which it pursues irrespective of whether

80 Ibid., pp. 361-362.
81 Ibid., p. 358.
82 Ibid., p. 358.
the relief emanates from the public or private sector.83

The Expenditure Committee was strongly influenced by the evidence submitted by the Charity Law Reform Committee. In their recommendations, the Expenditure Committee, like the Charity Commission in its Annual Reports, accepted that the existing restrictions on political activities were impractical and outdated. As a result, the Expenditure Committee further recommended that the area of permissible political involvement be expanded and given statutory force. This, the Committee argued, would relieve part of the apprehension charities experience when becoming politically involved, and invigorate the public policy process in allowing them to openly comment on government programmes. The Expenditure Committee's Report also recognised the severe financial limitations placed on the Charity Commission and sympathized with their inability to supervise both the financial and political activities of 130,000 registered charities. In combination with the broad-guidelines relevant to the political bar rule, which the Charity Commission has been required to enforce, this aspect of Charity law was concluded to be largely 'unenforceable'.84

C. Goodman Report, 1978

The Third report to address the problem of 'political

83 Brenton, The Voluntary Sector in British Social Services, p. 98.

84 House of Commons Expenditure Committee Volume of Evidence and Appendices, pp. 360-362.
involvement', was the Goodman Report (1978) sponsored by the National Council of Social Services. The Committee devoted chapter IV of its report entirely to 'political activity'. After long and complex explanations outlining how and why charities are allowed to engage in political activities ancillary to their main objects, the Committee summarised its conclusions. First, it rejected the notion that fiscal privileges accorded to charities should be extended to organisations having political objectives as recognised by law. Furthermore, it was not persuaded by evidence submitted by a number of charities that broadening the definition of a 'charitable purpose' would invigorate political life by involving more participants in the policy process. In one submission, a charity maintained it would merely continue to bandage the wounds of society instead of actually preventing the injuries if the restrictions were not lifted.85 While the Committee rejected the extension of fiscal privileges to charities with political purposes, it did not accept the proposition that charities should be divorced from political activity altogether. In fact, the Goodman Report states the importance of striking a balance between, advocating or promoting the continuance or change in the law or government policy, and supporting (directly or indirectly), a political party or individual standing for election.86 The Committee reaffirmed that only charities engaged

86Ibid., para. 104.
in political activity ancillary to their legally recognised purposes should be considered permissible. Second, the Committee stressed it was not desirable for politically motivated organisations to camouflage themselves as charities. However, they recognized that in financial terms organisations having purposes undeniably political in nature are often 'better-off' by passing themselves off as charities. As a result, they strongly recommended that greater resources be given to the Charity Commission to detect this type of activity.87

In response to the increasing number of organisations that have split themselves into two divisions - one charitable, one political - the Goodman Committee argued this would undermine the charity movement’s credibility. They claimed this strategy had effectively allowed charities to insulate their charitable activities from 'political taint'. While charitable donations given to organisations are required by law to be spent on their charitable purpose(s), the Committee recognized that many charities use funds to finance the political wings of their organisation. This activity is generally not discouraged for two reasons. First, the Charity Commission has not had the resources to audit effectively the financial transactions of all registered charities. Second, where this strategy has been adopted and where control is interlocking, the use of such funds has been extremely difficult to trace.88

87Ibid., para. 104(c).

recommendation was for stricter legal guidelines to discourage organisations with both a charitable and political wing from confusing the two. In other words, a greater separation rather than unification under a 'charitable banner' was recommended.89

The Committee's recommendations are best understood in the context of its view of charity's role in society. As Lord Goodman explained; "charity has a moral connotation which itself attracts support and some are concerned that the notion of a charity being permitted to become involved in political activity may detract from the special status accorded in the minds of many to charities."90 This was particularly the belief of the 19th Century philanthropist who saw his role essentially as that of using his own resources to alleviate distress or provide some other social benefit. Particularly with the growth of statutory services in the post-war period, there has been as the Charity Commission expressed it:

"... an increasing desire of charities for involvement in the causes with which their work is connected. Many organisations now feel that it is not sufficient simply to alleviate distress arising from particular social conditions or even go further and collect and disseminate information about the problems they encounter. They feel compelled also to draw attention as forcibly as possible to the needs which they think are not being met, to rouse the conscience of the public, to demand action and to press for effective official provision to be made to meet

89Goodman Committee, Charity Law and Voluntary Organisations, para. 105.
90Ibid., para. 105.
Thus the activities charities now pursue represent a continuum from social research to outright political lobbying. The problem is where on this continuum the law should draw the line if the distinction between charity and politics is to be preserved. The attitude of both British and Canadian charities is understandable. Their resources are limited - in many cases manifestly inadequate to deal with the magnitude of the problems they encounter. As discussed in chapters five and six, British and Canadian medical research charities have lobbied their respective governments to spend increasing amounts on researching their specific 'disease area'. Rather than using their resources to 'tinker at the edges of a problem', medical research charities in both countries have used part of their voluntary income to initiate, or augment, government programmes capable of making a more sizeable impact. The potential achievements of the state, with its enormous financial resources, are far greater than any charity is able to accomplish on its own. When for example the Labour government decided in 1969 to cut back £20 million on foreign aid, this involved more money than Oxfam, one of Britain's richest charities, had raised for expenditure on foreign aid since its inception in 1942.92


D. Summary

Despite each of the recommendations for legal reforms put forward by the Charity Commission, the House of Commons Expenditure Committee and the Goodman Committee, legislative amendments regarding charities and their political involvement have yet to be enacted. As a result, British charities continue to operate with a great deal of uncertainty when participating in the policy process. Each of the three studies reviewed above did not advocate a complete nullification of the law barring charities from politics. Instead, each demanded clearer guidelines be legislated in order for charities to determine what constitutes, for example, 'ancillary political purposes'. The urgency for such legal reforms in Britain were evidenced in each study by the increasing number of overtly political organisations attempting to pass themselves off as charities to qualify for privileged tax treatment.

E. Canada: 1978-1983

Although the issue of 'charity and politics' has not been the subject of official inquiry in Canada, the Canadian government has introduced much more progressive reforms in comparison to its British counterpart. In Canada, pressure for legal reform has come in response to a series of government controversies lasting from 1978 to 1983. The first controversy involved a new interpretation by Revenue Canada of the 'political bar rule' which sparked considerable debate among politicians, public officials,
charity administrators and the general public. The issues emerging throughout the duration of that controversy, revealed a number of competing legal viewpoints.

In February 1978, Revenue Canada officials, at the behest of their Minister Monique Begin, published a draft Information Circular listing what it considered to be the legal parameters regarding the political activities of charities.93 The document's basic thrust was that "an object is normally said to be 'political' if its ultimate intention is to influence the policy making process ... of any level of government."94 Furthermore, it considered an activity political if it was designed to embarrass or otherwise induce a government to take a stand, change a policy, or enact legislation for a purpose particular to the organisation carrying on the activity.95 The circular then went on to distinguish between non-political and political activities. (1) The following were defined as non-political:

- Presenting briefs with recommendations, to appropriate government bodies, whether or not they were solicited, provided they were not part of a campaign to influence

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94'Revenue Canada 'Registered Charities - Ancillary and Incidental Political Activities,' Information Circular 87-1. Ottawa: Queen's Printer, 1987, para. 4(a).

95Ibid., para. 5.
legislation.
- Making representations to appropriate elected representatives or government officials.
- Publishing an impartial and objective magazine.
- Holding conferences in which all sides of a public question are presented.

(2) The following activities were defined as political, and thus prohibited:

- Lobbying, whether conducted directly or indirectly.
- Public demonstrations, which are intended to apply pressure upon a government.
- Writing form letters to solicit members of the public to write letters of protest to their elected representatives.
- Supporting a political party.
- Writing letters to editors of newspapers which air political views or attempt to sway public opinion on a political issue.

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The circular's publication provoked firm condemnation from opposition members in the House of Commons, newspaper editors, and, from charities, in particular, from a number of large religious organisations. Before examining the concerns expressed throughout the duration of this controversy it is useful to review the events leading up to the circular's release. In early 1976, a religious organisation with charitable status, known as Christian

96Ibid., para. 6.
Prisoners Release International (CPRI), had planned a protest march on the Russian Embassy in Ottawa. When reapplying for charitable status that same year CPRI was threatened with deregistration on the grounds that it repeatedly failed to file required financial reports. However, Revenue Canada also informed CPRI that its participation in the march would constitute 'political activity' and would therefore be refused registration as a charity under the Income Tax Act. The matter was publicised when debated in the House on May 10, 14 and 14 June 1976. Throughout these debates the government was repeatedly questioned as to whether the Department of External Affairs had placed pressure on Revenue Canada to deregister CPRI, and whether the department had written statements clarifying what was considered legitimate political activities.97 While this incident drew Revenue Canada's attention to the immediate need for a clearer statement of the law, the information circular was not formulated until the summer of 1977. In the House of Commons on 1 May 1978 the Revenue Minister stated she had requested her own departmental officials to draft the document. This was done in response to requests by a women's association who, in applying for charitable status, wished guidance on what constituted prohibited political activities.98


98H.C. Debs. (Canada), 30th Parliament, 3rd Session Vol 5, Col 5001, 5118, and 5188.
The information circular was published in February 1978, but was not raised in the House of Commons for several months. However, on 1 May the Liberal government was questioned extensively about the document and was accused of deliberately attempting to intimidate charitable organisations by prohibiting them from engaging in political activities. The tenor of the questions raised in the House were as follows.

"In view of the fact that the Mennonite Central Committee has already responded by having interviews with officers of National Revenue, trying to define what the government is getting at in this regard, and that the government agreed that the Mennonite Central Committee can raise questions in respect of capital punishment, the purchase of fighter aircraft or a change in milk policy but cannot get involved in one of the church coalitions having to do with the upcoming disarmament assembly at the United Nations, will the Prime Minister indicate whether this action of intimidation in the circulation of last February is a direct attempt to remove the legitimate political rights of thousands of voluntary organisations in this country."

The government’s strategy was to argue the information circular was not government policy but rather an attempt to publicize to charities what the common law rules stated. Once understood that the document ‘stated the law’ and did not represent a shift in government policy, many of the subsequent questions and comments voiced in the House became critical of the
policy underlying the law. As Conservative MP Flora MacDonald stated on 3 May 1978:

"How can these charitable organisations, most of which are attempting to ameliorate the plight of certain underprivileged groups of people, be made to flourish when all of the avenues of affecting change are being closed to them, if they are not allowed to lobby, to hold public demonstrations or to conduct letter-writing campaigns to elected representatives, how can they make the government aware of their concerns? How can they get their point across if effective methods of doing so are considered to be what this government terms political and, as it says, "a threat to their status as charitable organisations"? We are not talking about partisan political efforts here at all. What the government says in its circular is that it sees any involvement in the political process, even that of recommending legislation on an issue of national concern, as a questionable and perhaps even subversive activity by these groups."

Two days after the matter arose in the House of Commons, Senators Godfrey and Forsey not only criticised, in the Senate, the policy behind the circular and the language used, but also Senator Gray, who, they claimed, had drafted the document. 102 On 4 May, Senator Gray answered his critics by announcing the circular's withdrawal so that it could be reviewed and reworded in order to avoid future ambiguity. 103 On 17 May before the House of Commons Standing Committee on Finance, Trade and Economic Affairs, Senators Godfrey and Forsey not only criticised, in the Senate, the policy behind the circular and the language used, but also Senator Gray, who, they claimed, had drafted the document. 102 On 4 May, Senator Gray answered his critics by announcing the circular's withdrawal so that it could be reviewed and reworded in order to avoid future ambiguity. 103 On 17 May before the House of Commons Standing Committee on Finance, Trade and Economic Affairs,

102 S. Debs. (Canada), 1978, Vol 2, Col 7728.
Senator Gray further noted, that in revising the circular, "I hope to hear the views of some charitable organisations to make sure that our message, when next it goes to them, will not cause the unfortunate reaction that we have been experiencing."104

Although the circular was withdrawn, the matter continued to arise during 'question period' in the House of Commons. Opposition members were concerned with the rules that would be applied once the circular had been withdrawn. In response, Liberal government members explained the circular merely represented Revenue Canada’s interpretation of law as formulated by the courts. Therefore its publication and subsequent withdrawal were stated to have no effect on the law’s substance.105

The interesting aspect of this controversy is that the press and many charities completely misunderstood the circular’s status as issued by Revenue Canada. Both seemed irritated that civil servants at Revenue Canada were permitted to promulgate rules relating to charities’ political activities. Others, particularly opposition Members of Parliament, felt the document represented a change in government policy. This view was a combination of the issue being legally complicated, and potentially damaging to the Liberal government. The opposing Conservative and New Democratic


Parties felt the latter would be accomplished if publicly demonstrated the government was formulating policy restrictive to all Canadian charities. In other words, the opposition attempted to seize the opportunity to embarrass the government. In retrospect, Revenue Canada was merely attempting to provide charitable organizations with their interpretation of the law as decided by the courts. Critics failed to recognize that Revenue Canada, similar to the Charity Commission, had no authority to make new laws. Instead, the Department’s information circular merely attempted to deduce the current law from existing common law cases. Revenue Canada officials accepted the possibility that their interpretation of permissible political activity might be overruled by the courts. Nonetheless, the Department was obliged to respond to requests from charities for more specific legal guidelines.

The issue disappeared from June 1978, until December of that year. On 11 December, it surfaced in the House of Commons during debate on the proposed Canada Non-Profit Corporations Act. Again the opposition members of the House attempted to inculcate a 'crisis atmosphere' by suggesting the government had been negligent in discharging their responsibilities to public officials. In doing so, they further accused Revenue Canada of 'intimidating' charities. The following extract from House of Commons debates captures the opposition's strategy:

"First, it (the information circular) was based on a couple of court cases that were certainly not recent and which showed very little relevance
to the present situation. The interpretation that was put on these cases went, from my point of view, way beyond what those particular cases in effect decided. I thought it entered very much into the situation of departmental officials, if not ministers, beginning to intimidate or, to some degree, limit the freedom of action of charitable organisations of this country."

Conservative opposition members of the House, attempted to promote themselves as the protectors and advocates of Canadian charities. The following statement by H. Monroe in the House of Commons on 11 December 1978, best illustrates this point.

"I find that sort of circular issued to organisations which are fulfilling a very important role in our society an abomination. They are fulfilling a role that no government in any democratic country will ever be able to fulfil or should fulfil. These channels should be open to our citizens to express themselves, and to influence legislation and legislators."

When the issue had first arisen in the Spring of 1978 the media, particularly editorialists of several large Canadian newspapers, strongly criticised the Liberal government for their


107H.C. Debs. (Canada), 30th Parliament, 4th Session, Vol 2, Col 2013. In noting that the law stated in the circular was still being enforced, Miss Flora MacDonald recounted the situation of the Brampton Woman’s Centre. In the Spring of 1978 in order to become registered under the Income Tax Act, they apparently were required to sign a statement that they would take no part in political activities; this they refused to do and were therefore denied charitable status.
poor judgement in discerning the interests of Canadian charities.108 In a widely reported Canadian Press story senior executives of several large charities had been interviewed and asked to comment on the government’s ‘information circular’. On 16 April 1978, the following conversations were reported. First, the editor of the United Church Observer, revealed that “his magazine and many church leaders, had repeatedly breached Revenue Canada’s strict guidelines for charitable activities.”109 For example, it was suggested that demonstrations by church members against the Vietnam war violated Revenue Canada guidelines but were never enforced since they were foolish and unenforceable. In the same article, Ms. Dudley of the Migraine Foundation, explained she never hesitated to encourage the public to write letters to politicians, urging legislative reform. As she stated, “I’d be willing to make a guess that 50 per cent of the legislation passed in this country has been at the urging of some group. If you ever just sat and waited for the government to propose legislation, nothing would happen.”110

Most newspaper articles included criticisms of Revenue Canada’s allegedly arbitrarily enforced legal standards. This

108The debates in the House of Commons concerning the information circular were widely reported by the Press. See, for example, ‘Opposition charges church ‘intimidation’’, Montreal Star, 2 May 1978; ‘Political rule aimed at scaring churches, Tory MPs suggest’, Globe and Mail, 2 May 1978; and ‘P.M. suspends policy of gagging charities’, Toronto Star, 2 May 1978.


110Ibid., p. 8.
point was made by comparing organisations that had qualified as registered charities, with those that had not. The Ottawa Citizen on 16 April 1978 reported on an Ontario-based charity registered by Revenue Canada, and it compared it to a similar organisation denied registration on grounds that its purposes were partly political. After comparing copies of 'application materials' submitted to Revenue Canada, including their 'stated purposes' or 'objects', the Ottawa Citizen argued the two organisations were virtually identical in their degree of political involvement. Consequently, the paper argued that Revenue Canada officials were guilty of abusing their quasi-judicial authority in applying this rule. The apparent lack of uniformity in Revenue Canada's decisions on granting or refusing charitable status highlights the point that, like its British counterpart, it does not have the resources to systematically screen an organisation's proposed objects or purposes when first applying for registration.

Given that the circular's publication did not represent a major shift in government policy and that the document was drafted in response to requests from charities, it is surprising the press adopted the position it did on the issue. Both the Toronto Star and Globe and Mail vehemently attacked the circular in their editorials. On 18 April 1978, the Toronto Star in an editorial entitled "Ottawa shouldn't muzzle charities" urged:

"The Trudeau government is off base in its effort to muzzle voluntary organisations that campaign


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for a better deal for the physically handicapped, native peoples, needy citizens and other groups.

An amendment to the Income Tax Act, clearly defining a charity and its activities in terms of what it does today - and that certainly goes far beyond distributing food baskets to the poor and includes advocating change in public policy - is in order.

Meanwhile, let's put those guidelines where they belong - in the paper shredder."

The Toronto Star further reported that Canadian charities had acquired and consolidated public support by holding public meetings, by writing to politicians of all parties, by appearing on broadcast shows and by conducting advertising campaigns. They argued that charities should consider these activities a 'right' not a privilege. In their view the right to urge governments to change policies was fundamental in a democracy and should not be denied to citizens whether acting as individuals or in association.

For three years the issue of charities and political involvement seemed to either disappear or to have been resolved.


113 See in particular, 'Let charities speak out freely', Toronto Star. 29 April 1978; and 'Ottawa sees the light over charity rights', Toronto Star. 4 May 1978. This article is especially interesting in that it offers a popular and contemporary view of the changing role that charities play in social welfare. "A definition pertinent to today must surely recognise that the role of a voluntary association goes beyond distributing food baskets to the poor and includes efforts to change public policy, to alleviate poverty, help the handicapped or achieve other social reforms".
However, in 1981 Revenue Canada attempted to deregister one charity and refuse another tax exempt status. Both decisions were based on the assumption that each organisation was actively engaged in political activities. One case involved Renaissance International, an Ontario-based evangelical organisation. On 23 November 1980, Revenue Canada notified the charity's trustees that deregistration was to take effect immediately. This decision was reached on evidence illustrating that the charity had purchased two full-page advertisements in a local newspaper urging voters to elect a 'moral majority' in the federal election. Moreover, the advertisement expressed their criticism of pro-homosexual candidates in the Toronto civic race. In appealing this decision the court heard that Renaissance groups across the country were self-proclaimed right-wing fundamentalists who frequently prepared and publicised moral report cards on candidates during election campaigns. Despite this evidence, the case was dismissed from the Federal Court of Appeal on 17 November 1982. Apparently, Revenue Canada had violated principles of natural justice by failing to meet with Renaissance International prior to issuing the revocation order. It is remarkable that the issue of 'political activities' was not even addressed.

The second case arose in February 1980, when Revenue Canada


refused to register the Manitoba Foundation for Canadian Studies as a charity under the Income Tax Act. The Foundation's main object was to publish *Canadian Dimension*, a left-of-centre economic magazine. However, in a letter drafted by Revenue officials, the organisation's publication was accused of drifting into the realm of political activity by promoting only one strand of political ideology. In other words, the magazine was considered political propaganda. As the letter read:

"On the basis of the material contained in the Canadian Dimension magazine, it would appear that its main goal is not to educate the reader in the sense of training the mind in matters of political science but to promote a particular ideology. Accordingly, the purpose of the magazine does not come within the meaning of education in the charitable sense."

In responding to Revenue Canada's decision, the Manitoba Foundation for Canadian Studies launched an appeal in the Federal Court but later terminated litigation for financial reasons. While each case did not alter the substance of charity law, both helped to thrust the issue back into the public domain. For example, several national charities offered to help defray the costs of hiring legal counsel and were prepared to petition to intervene in one or both of these cases. However, the offer to

116 The letter sent from Mrs Betty Wardle, chief official of the charitable and non-profit organisation section in Revenue Canada to the lawyers for the Manitoba Foundation for Canadian Studies is reproduced as an appendix to K. Smith, 'Political Activity and Charitable Organisations', *The Philanthropist*. 11(1983), p. 16.
petition was later withdrawn since it was impossible to estimate the cost of litigation for each case. Furthermore, both legal battles caught the attention of the media and again sparked public debate concerning changes in the law. For example The Toronto Star editorialised:

"The law should be amended to recognize the 20th century role of a charity so that it can collect contributions from individual Canadians without constantly having to worry whether the tax man is going to revoke its status and disallow deductions for the donations.

It is, of course, necessary to draw a line between political and charitable activities. But the line should be drawn at partisan political activities, designed to further the interests of a particular political party or individual, while leaving the churches and voluntary organisations free to attempt to change and influence public policy for the public good."

Discussion in the press and House of Commons over these cases was not as great or as strident as in the 1978 controversy. When commentators were confronted with actual cases, they were more aware of the need for some limitation on charities’ political activities. Furthermore, by 1980 the press, and even opposition Members of Parliament, seemed to realize the issue of charities and politics was more legally complex than they first believed.

Most informed observers later agreed the information circular


118See, 'Define role of charities', Toronto Star. 8 February 1981.
did not represent a shift in government policy but rather an attempt to clarify existing guidelines as defined in common law.119

F. Charity law reform in Canada

In response to public debates sparked by the 'information circular', Revenue Canada undertook consultations with representatives of major Canadian charities. All participants in the consultations agreed that charities should not be permitted by the Income Tax Act to be involved in partisan politics (for example, actively supporting or opposing candidates for public office) but that the Act should be amended to permit registered charities to be engaged to a certain degree in non-partisan political activity. The proposals for amendments were reviewed by the members of the consultative group, were announced by the Minister of Finance in the May 1985 Budget, and were passed into law on 13 February 1986.120

The new legislation states that an organisation seeking charitable status which engages in political activities which lie beyond those ancillary and incidental to its charitable purposes is ineligible for registration. Politically active organisations qualify for registration only if they intend to carry out ancillary and incidental political activities in order to further

119 Canadian Interview; Revenue Canada, Tax Exempt Division, 29 January 1987.

120 'Registered Charities – Ancillary and Incidental Political Activities,' Information Circular 87-1, p. 1.
their charitable purposes and charitable activities. Charities wishing to sponsor political activities which go beyond the limits permitted by the Income Tax Act, may set up a separate tax-exempt organisation or trust to pursue those activities which would otherwise interfere with a charity’s status under the Act. However, under the new legislation charities could not fund such separate organisations or otherwise make their resources available to them.121

In order to understand the new limitations imposed on Canadian charities in this respect, it is useful, to categorize potential activities into three separate categories; they are as follows:

(i) charitable activities not subject to any limitations;
(ii) prohibited activities; and
(iii) political activities allowed within Expenditure limits.

(i) **Charitable activities not subject to any limitations**

The new legislation states that activities charitable at law are not subject to any limitation under the Income Tax Act. This remains true even if the activity has some political element or flavour to it, provided the activity is fundamentally charitable. Whether an activity is fundamentally charitable or political depends on the facts of each situation. In other words, it is a matter of degree that must be judged by the courts or Revenue

121Ibid., p. 2.
Canada on a case by case basis. However, as a general guideline, activities of a political nature can be one of the means employed by charity to further a charitable end but cannot predominate the organisation's efforts or become an end unto themselves. For example, a charity whose purpose is to protect wildlife and the environment might, in conjunction with its research, conservation, and public education programmes, ask people to press for stricter legislative standards for industrial waste disposal. The political activity of pressing for legislative change is 'ancillary and incidental' in this case, because it is directed towards the organisation's charitable purpose of protecting the environment and is subordinate to the education and other charitable programmes of the organisation. Therefore it would be allowed subject to the established expenditure limitations. By contrast, an organisation formed solely, for example, to press for the adoption of a flat tax system or some other purpose that could only be achieved through legislative reform, would have a political not a charitable purpose. This is true even though it might engage in research and public information programmes to support lobbying efforts. As illustrated in chapter seven section II, the 'ancillary and incidental' clause has made it possible for Canadian medical research charities to lobby government to increase its financial

122Ibid., p. 2.
123Ibid., p. 8.
124Ibid., p. 8.
commitment to basic scientific investigations.

Although activities designed to persuade government to adopt a particular viewpoint can be considered political, Revenue Canada views the following items to be charitable activities. These apply only so long as the devotion of resources to such activities are reasonable in the circumstances (for example, when intended to inform and educate by providing information and views designed primarily to allow full and reasoned consideration of an issue rather than to influence public opinion or to generate controversy). These items include:

"- oral and written representations to the relevant elected representatives or public servant to present the charity's views or to provide factual information,

- oral and written presentations or briefs containing factual information and recommendations to the relevant government bodies, commissions or committees, and

- the provision of information and the expression of non-partisan views to the media."

All resources used directly in preparing or substantiating the representations or presentations described above are now treated as resources devoted to charitable activities.

(ii) **Prohibited activities**

Under the new legislation, Canadian charities may not oppose or endorse a named candidate, party, or politician. The charity's
resources may not be devoted directly to such activities, or devoted indirectly through provision of resources to a third party engaged in partisan political activities. Furthermore, the courts now view purposes that can only be achieved by legislative reform as political and not charitable in nature. Consequently, an organisation formed to achieve a particular legislative or other policy purpose, whether it be disarmament, tougher or looser abortion laws, the abolition or reinstatement of capital punishment, or the like will be ineligible for registration. Another organisation whose purpose is to amend a zoning by-law or to increase restrictions on broadcasting is considered to operate for a political purpose.126

(iii) Political activities allowed within expenditure limits

The new legislation designates activities that cannot themselves be considered charitable activities but are subordinate to be bona fide charitable purposes. These activities may be considered political and are permitted within designated expenditure limits. Examples of activities that would normally fall within this category are:

- Publications, conferences, workshops and other forms of communication which are produced, published, presented or distributed by a charity primarily in order to sway public opinion of political issues and matters of public policy;

- Advertisements in newspapers, magazines or on television or radio to the extent that they are

126 Ibid., p. 9.

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designed to attract interest in, or gain support for a charity’s position on political issues and matters of public policy;

- public meetings or lawful demonstrations that are organized to publicize and gain support for a charity’s point of view on matters of public policy and political issues; and

- mail campaigns - a request by a charity to its members or the public to forward letters or other written communications to the media and government expressing support for the charity’s views on political issues of public policy."

The legislation provides two tests which are used to control a charity’s expenditures on the political activities described above. The first test is based on a calculation using the total amount of revenue for which the charity issued tax receipts in its previous fiscal period. In short, a charity that meets its disbursement quota (by spending at least 80 per cent of its receipted donations of the previous year on charitable activity) and in doing so spends no more than ten per cent on permitted political activities, would be operating within the new rules. The second test is operational in nature. The provisions permitting political activities require that where a charitable organisation engages in political activities, substantially all of its resources must be devoted to its charitable activities. Substantially all in this context means 90 per cent or more of a charity’s financial, physical and human resources may be devoted to its charitable programmes and activities over a programme.

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127Ibid., pp. 9-10.
The regulation of Canadian charities under the Income Tax Act is based on a self-assessment system. Therefore, the charities themselves are required to apply the two expenditure tests each year in order to ensure compliance with the requirements. It should also be noted that the tests are independent since they are calculated on two different bases—receipted amounts versus resources.

In conclusion, this 1986 legislation provided Canadian charities with a set of precisely defined guidelines regarding the parameters of permissible political activities. In doing so, Canadian laws did not depart from British common law in 're-defining' the concept of 'charity' or 'political involvement'. Instead, the new legislation merely set down specific limitations regarding the amount of resources Canadian charities could devote to political activities. In Britain, the tendency of politicians, public officials and other interested parties has been to study the problem of charity and politics but not to move swiftly in drafting new statutory guidelines. In Canada, the reforms were a manifestation of public debate and concern over controversial applications and enforcement of rules restricting charities from participating in the political arena.

128 Ibid., p. 8.
129 Ibid., p. 5.
Chapter Four

Sources of Charity Income

Thus far the phrase charity-state relations has been used in a general context. This has been appropriate in our discussion of how government policies have affected the registration and supervision of charities (chapter 2) and how it limits their political activities (chapter 3). However, in examining how charities interact with the state it is necessary to recognize this relationship varies depending on the policy area under discussion. British and Canadian charities, depending on their area of activity, have been subjected to very different government policies. Thus, in reality there are many different kinds of charity-state relations that are worth exploring. A common feature of most of these relationships is that government has, in one way or another, relied in recent years increasingly on charities to provide services furthering government policy.

In response to a failing welfare state, the British and Canadian governments have increasingly relied on charities to provide important social services. This suggests that charity-state relations have changed dramatically since the 19th century when charities not only resisted state encroachment into many areas of social welfare, but devoted much of their resources towards encouraging state withdrawal from areas where tax revenues
were already being applied. This represents a major departure from the competition between charity and state to acquire from the other more responsibility for the delivery of social services. It is interesting that, some charities, for example those involved in medical research, have voiced strong opposition to government cutbacks. Their claim is that charities presently do not have the resources to provide services at comparable levels of quantity and quality. In Britain, the Association of Medical Research Charities (AMRC) has actively lobbied the government to increase its commitment to basic medical research. This is in stark contrast to the traditional belief of most 19th century charities, as typified by the Charity Organisation Society, that they were better equipped than government to provide these essential services. The present approach by charity is compatible with the post 1945 consensus that government has been better able to provide services in certain policy areas. However, the interesting point is that it is government which now takes the view that more should be done by charity.

To test the hypothesis that the state has been active in promoting a charitable reformation in both countries, we examine not only direct government aid but also what is described as 'indirect' government aid. This second form of assistance involves recent government policies aimed at creating a tax environment that seeks to increase the amount of personal and corporate donations made to charities. With indirect aid, government officials are unable to directly influence a charity's
activities. Government control may not appear to be a problem in areas like medical research where government policy and the policy of the medical research charities is thought to be the same: to find a cure for a particular disease. However, since medical research charities also fund public education campaigns and patient service programmes there are examples where the aims of charity and those of government clash. For example, British and Canadian medical research charities have devoted an increasing amount of their resources to reducing the incidence of particular diseases and this has included lobbying for legislative changes. Smoking is an obvious example: cancer research charities have demanded that the government increase taxes on tobacco products and ban smoking in public establishments and, in Canada, on domestic airline flights (see chapter eight, section III). For the small number of medical research charities in receipt of direct government aid the possibility exists for government to provide funds which are in turn used to lobby itself. Governments may wish to stop this through imposing conditions on grant usage. Consequently, even in the case of medical research, the state and charity may not have totally compatible aims.

The chapter divides into three sections that are, in turn, divided further into a number of different sub-sections. We begin with an examination of the variety of non-government sources of finance available to charities and identify the advantages and disadvantages of each. A major theme developed is that there are several draw-backs for charities that remain financially
independent from the state which tend to be over-shadowed by the more obvious disadvantages attached to direct government funding. Section II examines the variety of government financial sources available to charities. Here an initial distinction is made between direct and indirect government aid. In doing so, a challenge is made to the view that the recent revival of charities in both countries has been fostered principally by the extension of government grants and contracts. Instead, it is argued that recent tax legislation has indirectly had an equally important effect in stimulating charitable activity in both countries.

In discussing direct government assistance we examine the various funding structures of the two governments and the policy areas in which they operate. It is argued that neither the British nor the Canadian government has a coherent and all-encompassing policy for funding charities; instead this is a departmental responsibility that is often run on an ad-hoc basis and includes only short-term planning. The discussion then shifts to an examination of the various funding arrangements utilized by individual departments and an assessment is made of the effects of each on the operation of recipient charities. Finally section III of the chapter identifies the various types of non-financial government support extended to charities in both Britain and Canada.

The purpose of this chapter is to survey charities' financial sources and to develop a foundation for understanding the diverse relationships between medical research charities and the state.
Additionally, an explanation is developed as to why charities, including those operating in the medical research field, have assumed a greater responsibility with the state's assistance for the provision of important services.

A full examination of the role of charity in the context of the welfare state could be made only by relying on a wide variety of sources, ranging from official government reports and statistics to parliamentary debates and the information provided by charities themselves in their annual reports. However, the information provided by these sources has many limitations in that it reflects the form in which it was collected and the purposes for which it was collected as well as the difficulties encountered in gathering the data. Consequently, much of the data relating to charities that can be compiled is expressed in terms of what is accessible and measurable such as the number of paid individuals employed by charities or their annual incomes. The focus of this chapter is on the sources of charity finance, the amount of government grants, trends in subsidy policies and a host of other related issues which concern the state's financial relationship with charities. However, a note of caution must be sounded concerning the reliability of the data presented when discussing these themes given the fact that much of it is produced by interested parties—including government departments, politicians and charities. Inevitably, some of this data reflect a desire to plead a case, formulate an argument or create a certain climate of opinion in order to advance particular interests.
I. Non-Government Sources of Finance Available to Charities

English and Canadian charities presently derive their income from a wide variety of non-government sources including:

- self-generated investment income
- corporate donations
- grants from charitable trust (foundations)
- retail income,
- individual voluntary donations

Understanding both the advantages and disadvantages of these different sources of income help to put into perspective government financing of charities. It also contributes to our understanding the problems encountered by privately-funded charities which, because of government cut-backs to statutory agencies providing like services, have had to assume a greater responsibility for their provision. In both countries the literature tends to emphasize the disadvantages associated with direct financial aid to charities – which usually involve discussions of government control and the threat that this poses to a charity’s independence. However, the weakness of most of these studies centres on their failure to examine the problems inherent with other non-government sources of finance. Additionally, they fail to provide an explanation as to why charities and government have been eager to utilize each others resources.

A. Investment income:

Among the larger British and Canadian charities, investment
income has become an increasingly important source of finance. Although there are few studies explaining this trend, it is likely related to a conscious effort by charities to generate their own reliable source of income instead of depending on fluctuating private donations from outside sources. In the case of some charities there is often no choice but to retain capital, notably where a bequest is stipulated as not being available for current expenditure. A recent survey in Britain suggests that charitable grant-giving trusts (otherwise known as foundations) which do not actually provide services, tend to generate a high proportion of income from their own investments.¹ Since there is a general trend towards retaining funds for investment, rather than expending them upon charitable purposes, charities have developed into 'institutions for the retention and accumulation of capital' (see chapter five, section IV. A). A fact often not realized is that:

Charities do not immediately spend every pound that they receive by way of income, for along with private investors and a wide range of investment institutions, such as insurance companies, banks, unit trusts and investment trusts, it constitutes an important source of investment finance within the economies of both countries.²

Charity investments constitutes an increasingly important


source of investment finance within the country's economy. This is evident from data produced by the Diamond Commission, which suggests that the proportion of ordinary shares quoted in U.K. companies held by British charities rose from 2.6 per cent in 1963 to 4.4 per cent in 1973. More recent data illustrate that among all British charities investment income has increased each consecutive year from 1983 to 1986 but that in proportion to other sources of charity income it has remained constant - see Table 4.1. In the specific area of medical research, Table 4.24 illustrates that the total amount of investment income of the 14 British medical research charities appearing in the Charities Aid Foundation's list of the 'top 200 grant-seeking charities' between 1982 and 1986 increased by £5,206,000. Among these organisations, investment income as a proportion of their total voluntary income fluctuated considerably between 1982 and 1986 but in each year, except 1983, remained considerably below comparable sector-wide figures.

One of the most obvious advantages enjoyed by charities which

3HMSO, Royal Commission on the Distribution of Income and Wealth, Report No. 2. London: HMSO, 1974, p. 17. The Report also indicated that this increase in share ownership by charities is partly attributable to the widening of trustee investment powers affected by the Trustee Investment Act (1961).

Table 4.1


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<td>Total Amount of</td>
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<td>88,940</td>
<td>106,380</td>
<td>119,627</td>
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<td>Investment</td>
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<td>Income by</td>
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<tr>
<td>British Charities</td>
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<tr>
<td>(£000)</td>
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<td></td>
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<tr>
<td>Investment</td>
<td>21%</td>
<td>21%</td>
<td>21%</td>
<td>20%</td>
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<tr>
<td>Income as a</td>
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<tr>
<td>Proportion of</td>
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<tr>
<td>Total Charity</td>
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<tr>
<td>Income</td>
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<tr>
<th>Year</th>
<th>Total</th>
<th>Incomes</th>
<th>Incomes as % of Total Income</th>
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<th>Incomes as % of Total Income</th>
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<td>1992</td>
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Table 6.2

Investment Income of British Medical Research Council in the
rely heavily on investment income is the freedom to expend their profits as they see fit, provided they are for 'charitable purposes'. The major drawback is that of the risk of losing invested capital - especially in the stock market. However, critics of charities which are heavily dependent on investment income often fail to appreciate that other sources of income are even less secure. For example, a major economic depression would greatly affect private and corporate donations as well as government's ability to give grants. While the value of charitable investments in the stock market would also surely depreciate in these circumstances and most charitable organisations would not be bankrupted: they have portfolio investments in safe securities, guaranteed annuities, bonds, gold and real estate. However, despite the relative security of investment income, the donating public often demand their contributions be put to 'use' immediately as opposed to being invested in term-deposits or stock portfolios as a means of generating future income.

B. Corporate donations

According to a study published in 1971, donations from British companies represented a more significant source of charity income than they did at the beginning of the century.\(^5\) In both

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\(^5\) Shenfield, *Company Boards*. London: Longman, 1971, Chapter 4. Shenfield's data was derived from entries made in published company accounts in accordance with S. 19 of the *Companies Act* (1967). Like most data collected on corporate donations, the term is taken to include contributions made by companies from pre-tax profits and from employees contributing to
Britain and Canada, companies were also found to be making other direct non-charitable contributions to pension schemes, sick pay, redundancy payments and the like. Contributions to charitable organisations were viewed as representing another, less direct, contribution to social welfare, but one upon which certain charities had become increasingly reliant. However, while corporate donations have been important for some charities, a study conducted in the mid 1970's concluded they were not as significant as other sources of income generated by retail activity and government grants and contracts. In fact, the success of these other sources of income during that period attributed to a tapering off of corporate support to charities. This is indicated by data showing that an average of 0.47 per cent of gross trading profits donated to charities by corporations in 1965 declined in 1974 and 1975 to 0.26 per cent. However, by the 1980's this decline in corporate support abated and as illustrated in Table 4.3 corporate support actually increased each year from 1983 to 1986. What is extraordinary about this data is that despite a decrease in the number of 'donating' U.K. employees between 1985 and 1986 by 61,938, total corporate donations as a proportion of total voluntary income actually increased during company sponsored charity schemes.


7Ibid., p. 34. The study by Shenfield reveals that there has been a tendency for medium sized British companies to donate a higher proportion of their profits than the smaller or even larger companies.
Table 4.3


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<tbody>
<tr>
<td>Total Corporate Donations (£)</td>
<td>34,394,145</td>
<td>43,049,688</td>
<td>46,029,539</td>
<td>57,978,481</td>
</tr>
<tr>
<td>Number of UK Employees</td>
<td>3,495,340</td>
<td>3,802,976</td>
<td>3,904,117</td>
<td>3,842,179</td>
</tr>
<tr>
<td>Donations per Employee (£)</td>
<td>9.84</td>
<td>11.32</td>
<td>11.79</td>
<td>15.09</td>
</tr>
<tr>
<td>Corporate Donations as a Proportion of Total Voluntary Income</td>
<td>3.7%</td>
<td>4.3%</td>
<td>3.7%</td>
<td>4.45%</td>
</tr>
</tbody>
</table>

that same period.

Company donations have traditionally been heavily biased towards higher education and there has been an understandable inclination to support schemes from which the company or its employees will derive benefits.8 A sample survey of donations by 62 British companies in 1960 found that 62 per cent of the total amount given went to education and 20 per cent to social welfare. The rest was split between health - 6.4 per cent - and religious charities - 4.4 per cent. The figure of 62 per cent for gifts to education was made up of 26 per cent for company related educational schemes and 36 per cent for other educational purposes.9 The same study illustrates how corporate donation policies have traditionally been oriented towards themselves and how heavily dependent recipient charities can be on these funds. For example, in the area of medical research, expenditures by the pharmaceutical industry on all types of charitable activity have increased dramatically since the early 1970’s but their contributions to medical charities for research have risen even faster. As Falush remarks, "in addition to increasing its total charitable contributions by six per cent from 1961-62, the pharmaceutical industry increased its financial support for medical research by 18 per cent during the same period."10 However, in interviews with 44 British and Canadian charities (18

8Shenfield, Company Boards, pp. 110-118.
9Ibid., pp. 115-118.
10Falush, Trends in the Finance of British Charities, p. 34.
Canadian and 26 British) 40 respondents believed the particular disease they represented influenced the level of corporate support they received from the pharmaceutical industry. The four charities disputing this correlation (three British and one Canadian) disagreed with the assumption that pharmaceutical companies support research into disease areas where incidence rates are high and where the potential market for new medicines is the greatest. Chapter eight, section I, argues that medical research charities which have been willing to support pharmaceutical lobbies for greater patent protection for new medicines, shorter drug development periods and lower drug prices, have been financially rewarded by this industry. Furthermore, British and Canadian respondents generally commented that corporations other than pharmaceuticals tend to skew their financial support to medical research charities that fund research into ‘popular diseases’ such as cancer and heart. If indeed this is true the ‘firm’ can be seen to be basing its ‘giving decisions’ on similar criteria as those traditionally adopted by individuals which as discussed in chapter five section III. B, ignore important factors such as the incidence rate of a particular disease.

The major draw-back to corporate donations is like that of individual voluntary donations in that charities having little popular appeal, either because they are controversial or cater to

11 In particular this view was expressed in British Interview, Muscular Dystrophy Group of Great Britain, 19 February 1987.
very specialized interests, do not easily commend themselves to industrial support. For example, a charity in the non-medical research field such as the 'National Council for the Unmarried Mother and Her Child' whose work has seriously been hampered for lack of funds, received less than £1,000 from companies in 1967 (representing only 1.5 per cent of its annual income). Thirty-six companies made contributions but these tended to be token contributions of only £25 to £50.12

C. Grants from charitable trusts (foundations)

Another source of income for charities is grant-giving trusts, or foundations as the larger ones are sometimes called. The largest British ones include Wellcome, Nuffield, Leverhulme and Cadbury, and in Canada, Devonian, Massey and Carnegie.13 In most instances, they were founded by, and received their capital from, either individuals whose wealth was derived from industry or commerce or companies bearing the name of an individual. Instead of dispensing social welfare on their own behalf, or doing so by means of direct gifts to active grant-seeking charities, companies, transfer their philanthropic contributions to grant-making trusts which, in turn, make donations to grant-seeking charities. The assets of the top 200 foundations have grown over


13One of the best sources on the topic of grant-giving charities or foundations is B. Whitaker, The Foundations. London: Eyre Methuen, 1974. The book primarily examines foundations in the United States but has some reference to British and Canadian charities as well.
the past ten years due in part to the revaluing of their property and premises. As illustrated in Figure 4.1, the constant (inflation adjusted) value of trust holdings showed little or no growth during the period 1979-82. The proportion of assets paid out by British foundations declined from 22.8 per cent in 1979 to 9.2 per cent in 1986 - see Figure 4.2. However, since 1982 the assets of British foundations have grown sharply from £429 million to £1.412 billion in 1986 (constant terms). Finally as Figure 4.3 illustrates, grants made by the top 200 foundations since 1977 have grown in constant terms (inflation adjusted) from £91 million to £125 million in 1986.14

In both Britain and Canada, smaller grant-making trusts expend funds in ways that often reflect the current wishes of the founder or its trustees.15 Charities whose activities do not mesh with such 'wishes' are again vulnerable to fluctuating levels of public support depending on the popularity of their cause at any given time. The wealthier foundations which distribute the largest 'gifts' are commonly concerned with specific areas of charitable activity. In Britain, for example, the Gulbenkian Foundation takes a particular interest in the arts, as does the


Value of Assets of British Foundations in Real Terms.

* Constant figures are calculated by using Retail Price Index of September 1977 as a base.

Figure 4.2

Proportion of Grants to Assets of Top 200 Foundations in Britain.

Figure 4.3

Grants Made by British Foundations in Real and Current Terms.


* Constant figures are calculated by using Retail Price Index of September 1977 as a base.
Massey Foundation in Canada. Likewise, in the area of medical research some of the largest foundations are wholly committed to one particular disease, often heart disease and cancer. This raises the problem that most low profile diseases, such as spina bifida and hydrocephalus, are not generously funded by the large foundations.\textsuperscript{17} This situation, like corporate and individual donations, leaves many charities constantly scrambling to raise funds to finance existing programmes. The ability of many charities to engage in long-term planning and to expand their research programmes is limited.

D. Retail income

Little at all has been documented about the commercial activities of charities. This is partly because in Britain and Canada the borderline between commercial activity and other fundraising activities has been unclear. Nonetheless, a distinction can be drawn on the basis of a charity charging a fee for a service which is an integral part of what it exists for, as opposed to charging a fee for a service or good in order to raise

\textsuperscript{16}Grant-making trusts are almost invariably charities within the legal definition. A well known exception, however, which makes many large grants in England is the Gulbenkian Foundation. It is not a charity under English law because it was established in Portugal.

\textsuperscript{17}Until recently, several of the less popular diseases which charities have been unable to raise donations for, have been partly financed by the medical research councils in each country. However, since 1980 the budgets of these councils have declined in real terms. As we shall see in chapter seven section I. A, this has shifted a larger burden of the responsibility to charities for conducting medical research into these less popular diseases.
money. Britain’s National Trust is a good example: the Trust’s sale of jams and Christmas cards is undoubtedly commercial retail activity. However, it is less clear whether their charge on ‘non-members’ to visit their historic buildings is part of their ‘charitable activity’ or simply another means of raising money. It is not disputed that British charities, in particular many large ones, have increasingly relied on retail activities to generate income. Charities, like Oxfam, Save the Children’s Fund, War or Want and a host of other charities have opened clothing stores, held charity auctions and developed extensive mail order gift services. Charities have defended these retail activities by arguing that it reduces the inherent risks associated with fluctuating levels of voluntary donations. The data listed in Table 4.4 illustrates that among all British charities, retail income has increased by £6,570,000 from 1983 to 1986 but that in proportion to other sources of charity income it has remained constant. In the specific area of medical research, Table 4.5 illustrates that the total amount of retail income of the 14 British medical research charities appearing in the Charities Aid Foundation’s list of the ‘top 200 grant-seeking charities’ between 1982 and 1986 increased by £1,318,000. Among these organisations, retail income as a proportion of their total voluntary income fluctuated considerably between 1982 and 1986 but remained considerably below comparable sector-wide figures.

One of the best examples of a clear distinction between genuinely commercial activity and what are in effect solicitations
### Table 4.4

**Retail Income of British Charities as a Proportion of Total Voluntary Income: 1982-1986**

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<th></th>
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<tbody>
<tr>
<td>Retail Income (£000)</td>
<td>27,402</td>
<td>30,226</td>
<td>44,558</td>
<td>33,972</td>
</tr>
<tr>
<td>Retail Income as a Proportion of Total Voluntary Income</td>
<td>7%</td>
<td>7%</td>
<td>8%</td>
<td>6%</td>
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</tr>
</thead>
<tbody>
<tr>
<td>% of Income</td>
<td>3.6%</td>
<td>6.0%</td>
<td>2.9%</td>
<td>2.7%</td>
<td>3.9%</td>
<td>3.3%</td>
<td>3.2%</td>
<td>3.0%</td>
<td>3.1%</td>
<td>3.2%</td>
</tr>
<tr>
<td>% of Total</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
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<td>0.0%</td>
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</table>

**Table 4.5**

Retail Income of British Medical Association Members Included in the Charities Aid
for donations involves the sale of charity Christmas cards. In Britain, this is done through a non-charitable trading company called the Charity Christmas Card Council (CCCC). Charity Christmas Cards are a comparatively new form of retail fund raising in that they were distributed by individual charities in one form or another only on a small scale during the 1920's and 1930's. It was not until 1949 when Unicef produced a famous card that this form of fund raising became more widely embraced by a wide range of charities. During the 1960's a number of large charities recognized that it was not cost-efficient for each organisation to individually design, produce and market their own Christmas cards. As a result, in 1966 with the assistance of the National Council for Voluntary Organisations, the CCCC was formed. The CCCC is now comprised of 84 national and international charities which pay an annual membership fee. In doing so, charities are able to select a number of Christmas card designs from the CCCC's catalogue and have their names printed on the back. The cards are then distributed in three ways. First, they are sold in commercial stores owned and operated by the CCCC (see Appendix III for total sales figures for 1985). Second, they are sold in normal retail stores (including charity shops) and lastly they are sold through the post with the aid of a brochure. One of the initial stumbling blocks for the CCCC was that member charities were fearful of turning donors into traders. Prior to the introduction of Christmas cards an individual would donate £20 knowing that the entire amount would find its way to charity.
However, by introducing Christmas cards, charities feared the total amount of donations would decrease if individuals believed that of say a £20 gift, £10 was going to the card manufacturer. In an interview with the CCCC’s Executive Director the following explanation was offered:

"We originally feared that charity Christmas cards would turn donors into 'traders' and in doing so the level of donations would decline. However, as it turned out this was not the case; in fact the opposite was true in that charity Christmas cards carried the charities name on it. This has been proven through extensive marketing research to be an excellent source of advertising. In addition, people began to send charity Christmas cards in order to demonstrate that they were doing their charitable bit."  

A complex issue for charities engaged in retail activities involves their relationship with for-profit companies selling comparable goods and services. The tax advantage that the law confers on charities and its effects on the nature of competition between charities and commercial organisations is a subject outside the main focus of this chapter. However, from the sketchy information now available it can be postulated that commercial activities are reducing a charity’s risk of fluctuating voluntary donations and producing relatively constant incomes generated by retail markets.  

18 British Interview; Charity Christmas Card Council, 12 March 1987.  

19 The success of charities’ commercial activities is evidenced by the fact that the Cancer Research Campaign earned £143,934 net profit from its Christmas cards sales which
E. Individual voluntary donations

A charity whose income is derived substantially from voluntary, non-government sources is ideally thought to enjoy a good deal of self-governance and freedom from external interference. In reality, the situation is far more complex than this. For instance, the very need for a charity to raise voluntary donations can often limit its time and resources to pursue the main object for which the organisation was established. As illustrated in chapter five section IV. A, this has been a problem encountered by medical research charities representing 'unpopular diseases'. In many cases, a charity's preoccupation with fund raising has often meant that other important decisions like selecting eminent scientists to dispense research funds to scientific investigators has been neglected. Additionally, charities which are wholly dependent on voluntary donations, are often left vulnerable to the sporadic bursts of public benevolence towards other causes.20 This problem tends to be overcome by the

represented .08 per cent of its total income, an increase of .01 per cent over the previous year. Figure taken from Cancer Research Campaign, Annual Report, 1985. London: 1986, p. 19.

20The Ethiopian Famine of 1984-1985 was a cause taken up by many charities and celebrities working on their behalf. The vast sums of money raised through efforts such as LIVE AID, according to some analysts, served to re-direct charitable donations that would have gone to the other causes. However, this claim has been disputed by those who have argued that Band Aid clearly topped a new market for donations. The Charities Aid Foundation conducted a household survey which produced data showing that this 'new market' comprised two major groups; younger individuals (below 18 years) and non-professional socioeconomic groups. See, Charities Aid Foundation, Charity Statistics, 1985/86. Tonbridge: CAF, 1986, p. 130.
large well-endowed charities like the RSPCA and RNLI which can afford to employ professional fundraisers. These professional agencies use increasingly sophisticated techniques such as telethons to collect large amounts of voluntary donations over a short period of time. However, when small charities representing less popular causes hire professional fundraisers a major 'capital investment' is being made. Often this can carry with it the risk of failure, if there is a surge of public altruism towards a different, and seemingly more immediate cause. Furthermore, the competition between charities representing different 'causes' makes the reliance on voluntary donations even more unpopular among a donating public faced with inflation and high unemployment. In Britain, as opposed to Canada, charities are not only faced with competition among themselves for public donations, but sometimes with government agencies that also enjoy the statutory privilege to solicit individuals for such funds. For example:

When the Health Service Act, 1980 gave health authorities the power to raise voluntary funds there was much concern among voluntary agencies in the health and welfare field, lest the National Health Service (NHS) appeals cream off funds usually available for other more routine causes.

At the time, the National Council for Voluntary Organisations (NCVO) argued that this placed charities in direct competition

\[21\]

with the NHS for the public’s money, of which there was and continues to be an obvious limitation. The NCVO further argued that they were badly disadvantaged since the NHS had public funds provided to them for the start-up cost of their own fund raising efforts. However, in interviews with British medical research charities, not one respondent identified statutory fund raising as a source of ‘charitable’ competition. In interviewing a Medical Research Council official, it was commented that if the Council was forced to survive on voluntary donations instead of government grants, it would perform poorly alongside charity as people would hesitate to support something that resembles a quango.

The major draw-back for charities that rely on individual voluntary donations, as already mentioned in the discussion of corporate and trust donations, is that appeals for charitable giving rely on the public’s sympathy for a particular cause; sympathies that are notably volatile and sentimental. This again, is an argument that is much less convincing when applied to older well established charities that have a broad base of financial support. Nonetheless, charities in support of children have much more appeal than those for the elderly or the mentally ill; respectable causes such as blindness acquires more public support than do socially rejected groups like the single homeless and drug

22Guardian. 18 February 1981.

23British Interview; Medical Research Council, 2 April 1987.
In the area of medical research, a high profile disease such as herpes may, in fact, be over funded one year only to be left virtually bankrupt the next when public attention is turned to a higher profile disease such as Acquired Immune Deficiency Syndrome (AIDS) (see Chapter six section III. B).

F. Trends in voluntary giving

During the 1970's, public attitudes towards the financing of charities in Britain and Canada was supportive of voluntary sources of income rather than increased government funding of charities. Financial independence from the state was seen as crucial to a dynamic charity. However, in both countries the administrators of charities responded by pointing out that there were no substantial reservoirs of charitable resources waiting to be ‘tapped’. As a consequence, and as one British respondent lamented:

"the donating public has grown weary of charitable appeal after charitable appeal. There is a fine line between aggressive fund raising, where we can play on someones ‘duty’ to give, and outright bribery. Normally the latter scenario does not prevail, however, its frequency will no doubt increase as the need for non-governmental

As noted in chapter four, animal welfare charities have been much more successful in raising voluntary donations than other charities involved for example in helping drug addicts or those assisting the aged. In 1980-1981, the People's Dispensary for Sick Animals received almost as much income from voluntary giving as did the National Society for the Prevention of Cruelty to Children (NSPCC); and the Donkey Sanctuary, ranking in the top 200 British charities, received more income from voluntary sources than St. Christopher’s Hospice for the Terminally Ill. From, Charities Aid Foundation, Charity Statistics. 1980/81. Tonbridge: CAF, 1981, p. 60.
Statistical evidence in Canada indicates that during the 1970's and early 1980's there was a general decline in personal donations made to charities. In Canada, the best source of national data is derived from the statistical summary of all personal income tax returns published annually by Revenue Canada and the decennial survey habits of Canadians published occasionally by Statistics Canada. Because these studies are tabulated and published for a wide range of purposes, both studies have major defects as sources of data for rigorous analysis of personal donations and the underlying factors that motivate people to give. The statistical summary of personal income tax produces a particularly problematic data base for several reasons. First, it does not take account of donations of amounts less than $100 (£50) which do not qualify as tax exemptions according to the rules administered by Revenue Canada. Consequently, the data relating to total donations are grossly deflated since they fail to account for the many small cash donations made for example at garage sales, church bazaars and community car washes. Second, the statistical summary of personal taxation produces only raw data on the total amount of revenue donated, and in doing so fails to breakdown the figures into ‘donations per region’, ‘donations per age group and gender’ and other potentially useful categories for social scientists.

25British Interview; March 1987.
Despite these statistical shortcomings, one researcher has nonetheless concluded that in Canada, from 1946 to 1981, personal donations to charities declined in real per capital terms. However, as Martin himself remarked, "the evidence supporting that conclusion was reasonably convincing but I could offer very little to explain why." The study shows that the decline in donations was not significant during the Second World War or up until the mid 1950's when welfare services began to expand. Instead, the trend indicating a major decline in public support for charities became statistically significant in the late 1960's, as education, health care and culture became areas where state spending increased. This trend continued to accelerate throughout the 1970's leaving many charities with no other option but to 'wind-up' their operations. Table 4.6 illustrates this same point by comparing on a yearly basis the amount of donations per family (in real terms) to the percentage of donations per family income.

Another means of indicating whether voluntary donations by individuals have increased or decreased in Canada is to examine the number (and proportion) of Canadians claiming deductions for charitable donations on their income tax returns. In 1961, the first year that donations over $100 (£50) were tabulated, some 1.5

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27Ibid., p. 68.
28Ibid., pp. 41-46.
29S. Martin, An Essential Grace, p. 141.
<table>
<thead>
<tr>
<th>Year</th>
<th>Donations per Family</th>
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million Canadians made claims for tax exemptions - 25 per cent of all taxpayers. By 1970, the number of claiments had dropped to 1.1 million - 12 per cent of the total. In 1979, the number rose to 1.4 million - still 100,000 fewer but this still represented only nine per cent of all Canadians filing tax returns.30

In Britain, Falush's study in 1977 noted a general decline in personal donations made to charities. Like the Canadian cases, fewer households were making donations to charity and those who did, were not doing so at a level commensurate to the rise in their disposable income.31 In light of these results, the Wolfenden Committee (1978) was led to conclude that the failure of private giving to keep pace with inflation was so striking that there was an obvious need for charities to increase their reliance on statutory funding. It further warned that without such aid, some charities would have no other alternative but to discontinue their services.32 While fewer people were giving to charity during the early and mid 1970's, Figure 4.4 illustrates that the total amount of personal donations (not adjusted to inflation) has increased in every year since 1977. The more interesting point is that in relation to personal donations the aggregate level of all sources of income of British charities has increased more dramatically from 1977 to 1987. The 'levelling-off' of personal

30Ibid., p. 143.

31Falush, Trends in the Finance of British Charities, pp. 32-44.

Figure 4.4


donations from 1980-1982 was symptomatic of the economic recession that unfolded during that period. Between 1983 and 1985 the parallel upward trend of both personal donations and total charity income continued. However, data for 1986/87 indicates a 'levelling-off' in personal donations, while total income has continued to rise. Obviously, the sustained increase in total charity income in the face of levelling personal donations can be attributed to the strong performance of other fund raising techniques that have generated increasing amounts of income - for example from government sources. In the specific area of medical research, Table 4.7 illustrates that the total amount of personal donations of the 14 British medical research charities appearing in the Charities Aid Foundation's list of the 'top 200 grant-seeking charities', between 1982 and 1986 increased by £46,068,000. For these organisations, personal donations as a proportion of their total income fluctuated between 1982 and 1986 but averaged 67 per cent over this period - approximately 11 per cent higher than comparable 'sector-wide' figures.

Most studies examining the decline in voluntary donations (in real terms) in both countries during the early and mid 1970's list the rise of the welfare state as the most important contributing factor. It is argued by laissez-faire Libertarians like Friedman that individual donors felt less pressed to contribute out of their own pockets since the state had already assumed the major responsibility for social welfare and had increased the rates of
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Note: The table above shows the proportion of population in different age groups in the year 2016. The data is based on the latest available statistics.
personal taxation in order to be able to do so. However, this theory has been disputed by Obler who argues that in many domains of philanthropy, state assistance has not deterred private giving since the people who work for charity realize that private philanthropy can supplement rather than compete with state aid. As Obler himself remarked:

"The Libertarian position that state aid automatically precludes private giving is inaccurate. It is also naive. The Libertarians incorrectly assume that concern for others' welfare is the sole reason why people do charity work... many people become involved in charities not because they sympathize with the disadvantaged but also because they enjoy such fund raising activities as coffee mornings and strawberry lunches."

34

It is easily understood how the Libertarians' argument might explain a sudden drop in charitable giving in Britain and Canada in the late 1940's and into the late 1950's. However, it is less clear why the decline continued after the welfare state was more or less in place. For example, there have been many areas of activity since 1945 that have not been covered by the state - like recreational activities for the disabled - to which people could have given more generously. Alternatively, there may be a 'generational' type argument that people born into a welfare state are somehow less generous. However, testing this hypothesis with


empirical data - most notably in a comparative context - is extremely difficult. Another possible explanation for the decline in charitable giving since 1945 is related to increasing secularization in both Britain and Canada. What inspired people to donate their money during the 19th and early 20th centuries was a culture that viewed charitable giving as part of moral and religious duty. The decline of religious observance and religious practice since the 1950's has meant that these sorts of sentiments have declined correspondingly. In other words, there would have been a decline in giving anyway whether or not the welfare state had come into being.

At the time that voluntary donations were declining, one should also bear in mind that signs of a faltering welfare state began to emerge in both Britain and Canada. Precipitated by economic recessions at the beginning of the 1980's, it was not surprising that both the British and Canadian governments responded by cutting-back services provided for, or funded by, statutory agencies. An immediate result was that charities began to share an increasing burden of the responsibility for service provision in many areas such as medical research.35 Perhaps in recognition of this trend, and possibly for other reasons, the British and Canadian governments reacted similarly by increasing their amount of financial assistance extended to charities. As we shall see now in Section II, this assistance has taken two forms.

II. Government Financial Support to Charities

In Britain and Canada the financial interaction between charities and the state occurs in two distinct ways. When governments mention their interaction with charities they are normally referring to their financial aid to these organisations. However, there is an important distinction to be made between 'direct' and 'indirect' financial assistance. 'Direct financial aid' consists of grants and payments to charities for services out of the Treasury reserves in each country. 'Indirect financial assistance' consists of any legislative or executive act which stimulates the flow of money from private donors to charities by designing tax or other concessions for citizens, corporations or other private institutions. In effect, this type of state intervention gives individuals and institutions incentives to increase their assistance to charities whether in the form of time or in the form of direct financial contributions. Indirect aid may also take the form of legislative or executive acts which create tax concessions for charities which seek to lower their operating costs. This includes rate reliefs, preferential postal rates, and a number of other tax benefits.

There is one, fundamental, difference between direct and indirect government assistance that is worth explicating. In the case of direct financial aid, government itself decides whether to provide grants or some other payments to a particular charity or charitable cause in general. With indirect government financial
assistance, the decision whether to actually support philanthropic action rests with citizens, corporations and other private institutions depending on their generosity, their social concern, their wealth, and a host of other factors. The actions of government merely develop a more or less, favourable climate for this support. Again it is important to distinguish between two different kinds of 'direct aid': grants and fee payments (often called fee-for-services or contractual aid). Unlike instances of grants, it is less clear that a government's intention is to 'encourage' or support charitable activities when fees are paid to charitable organisations for the delivery of services to government. For example, local authorities often pay charities operating residential care facilities and hospitals for bed space. In the past, these charities have been critical of local government for being 'stingy' - for not reimbursing them at a fair rate when inflationary costs have been incurred. 36 In such cases it is difficult to view government fee payments as 'support or assistance'. While an extensive system of fee payments may make a charity financially dependent on government, this does not mean that the government's intention was to 'assist' them or promote their charitable activities. In such cases the government is able to save money by using charities as intermediary organisations as opposed to providing the service directly themselves. Nevertheless, some instances of payment for services

clearly do constitute state support for charities.

This section provides evidence that in both countries, indirect financial assistance is more important than is perhaps commonly perceived. An effort is made here to provide a more complete picture of how charities are financially supported both directly and indirectly by government and some of the inherent implications attached to each form of assistance. Of course the area of activity in which charities are operating largely determines how they will be financed by government. For example, in the case of medical research we see in chapter seven section I and II, that the governments of both countries have cut back their direct funding to their own research agencies - The British and Canadian Medical Research Councils. At the same time, both governments have indirectly increased their financial commitment to medical research charities by encouraging individuals through a number of tax reforms to donate more money to these organisations. In this peculiar way, both the British and Canadian governments have redefined their financial commitment to medical research, and in doing so have increasingly relied on charities to provide this service.

A. Indirect government financial assistance

In the attempt to reverse the decline in the level of voluntary donations in the 1960’s and 1970’s the governments of both Britain and Canada have taken steps to alter tax legislation in order to encourage people to make larger charitable donations more frequently. However, the tax policies in both England and
Canada that achieve this end are very different in the two countries.

In Britain, individuals are not able to deduct from their taxable income donations to a charity. Instead, charities, derive a large proportion of their income by way of covenants - by reclaiming the tax on the income paid by an individual donor. For charities, therefore, consistently high tax rates would, be preferred. In Canada, where the covenant system is not in place, lower levels of taxation generate more income for charities, since individuals have more disposable income from which to make charitable donations. In the remainder of this section we examine tax policies in relation to charities in more detail: we begin with Canada.

B. Canada

Canadian charity administrators have long realized the financial advantages that flow from government policies which encourage individuals to make charitable donations. Successive governments have been reticent to adopt sweeping changes to tax policies that would encourage people to donate more, since changes in the tax conditions for charitable giving involve trade-offs between what the government stands to lose in tax revenue and what charities stand to gain.37

The only scientific study of charitable giving in Canada is

37A good review of the trade-off between increased indirect financing of charities and lost government revenue is found in R. Bird and B. Bucovetsky, Canadian Tax Reform and Private Philanthropy. Toronto: Canadian Tax Foundation, 1976.
Samual Martin’s 1975 work entitled; *Financing Humanistic Services*. In it he concludes that as income rises, charitable donations increase in absolute terms, though not proportionately to the rise in income. In addition, tax incentives to individuals to donate more heavily to private charities do not necessarily produce increases in donations to those charities equal to the decrease in government revenue. Stated differently, taxpayers might keep some of the money saved on taxes for themselves depending on the tax scheme being used.38 Two of the most popular schemes currently being lobbied for are discussed below; namely a tax credit system and a matching government grant system.

(i) **Tax credit system**

An overall tax credit system would involve a deduction from an individual’s tax rather than a deduction when computing income to which the appropriate rate of tax is applied. Under such a formula, everyone’s cost in making a charitable donation would ostensibly be identical because the same amounts of credit would

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38S. Martin, *Financing Humanistic Services*. Toronto: McClelland and Steward, 1975, p. 140. It should be emphasized that the empirical data on which Martin bases his observations are not without flaw. His taxation data for example, only list those donations claimed as deductions for income tax purposes. Because tax laws concerning the deductibility of charitable donations have changed periodically since the end of the Second World War, the annual series is discontinuous. Annual comprehensive data for all donations made and claimed by Canadians are complete for 1946 through 1956. No donation statistics were reported for the years 1957 through 1960. Since 1961, the data only represents donations claimed by taxpayers provided the amount exceeded $100 (£50) per taxpayer. Since an optional standard claim of $100 (£50) was introduced in 1957, no listing has since been required for donation claims of less than $100 (£50) per taxpayer.
be made available to anyone despite their income. However, in fact, a tax credit system provides more real income to the low-income taxpayer. Both the Carter Commission on Taxation in Canada and the Filer Commission on Private Philanthropy and Public Needs in the United States, revealed that a tax credit system intended to stimulate philanthropy provides greater inducement to lower and middle income taxpayers than it does to higher income taxpayers. Their assumption was that if total giving remained constant - that is, if the lower and middle income earners increased their giving proportionately to the decline in giving by higher income earners - the result would be to increase support to the religious community and decrease support to cultural, educational and medical research charities. The former tends to be supported by those earning lower income; the latter by those with higher incomes. Martin corroborates this conclusion in his

39The number of studies on the feasibility of Canadian tax credits is voluminous. The best account as it relates to charitable giving is, W. Thrisk, 'Giving Credit where Credit is Due: The Choice Between Credits and Deductions Under the Individual Income Tax Act in Canada', Canadian Tax Journal, 28(1980), pp. 32-42.

1976 study and in his most recent work entitled; *An Essential Grace* (1985), arguing that charities heavily dependent on the wealthy would face much harder times.41

(ii) **Matching government-grants system**

Under this scheme, the government would have to match, in whole or in part, all charitable donations made to registered charities and pay them lump sums at regular intervals. The positive feature of this system from the viewpoint of both the government and certain charities, is that it can be adjusted easily by changing the ratio of government grants to other incomes. Taxpayers would, in effect, be directing government money to their favourite charity.42

The major drawback to the matching-grants system is that large support would clearly go to 'high-profile' successful charities, whereas little or no support would go to less visible causes, no matter how worthy. In effect, the less popular charities that often need increased support the most would likely find themselves further disadvantaged in comparison to the high profile charities because they have smaller incomes to begin with. The argument simply stated is that this system would not assist charities pursuing 'unpopular' but socially important causes, such


42The matching-grant formula has also been used widely in Federal financing of the provinces. They are normally given with 'conditions'; for example, the Federal government may try to place quality and administrative controls on a provincial programme being funded.
as half-way homes for battered wives or research into horrific afflictions like inflammatory bowel disease. Additionally, support would be given to more wealthy charities such as those involved in cancer and heart research which are already estimated by some to have more resources than they can spend responsibly.43

C. Britain

In Britain, a tax credit scheme has not been pursued by charities interested in tax law reforms. Instead their attention has been focused on other areas of tax legislation such as the covenanting scheme, Value Added Tax (VAT), and to a lesser extent, the matching grant scheme. All reforms in these areas are aimed at bringing about more indirect government assistance to charities.

The financial importance attached to major reforms of the tax laws governing charities can be gleaned from an overview of the gradual reforms in tax legislation that have already been made in Britain. As Schuster remarks:

"When the Conservative Party returned to power in Britain in 1979, its fiscal policies were designed to deemphasize the income tax and to

43See Carl Bakal, Charity USA. New York: Times Books, 1979, p. 401. Bakal points out that in the United States the American Cancer Society raises about 80 per cent more money for lung cancer research than the American Diabetes Association even though the latter disease is twice as widespread as cancer. The problem that arises for cancer research charities is that often they have more money than qualified researchers, therefore, the money is often expended on their infra-structure. The fear of a matching-grant formula is that charities involved in popular diseases such as cancer will become even more overfunded at the expense of these less popular diseases."
further exploit other sources of taxation, particularly the Value Added Tax (VAT). The Finance Act (1980) was a watershed for British charities because, in translating these Tory policies into law, it included several provisions that have had a direct financial impact on charities.  

For example, the Finance Act (1980) provided for 'higher relief' on covenanted contributions, an additional tax incentive for donors who pay more than the basic rate of tax. The 1980 Act also lowered the required minimum length for a charitable deed of covenant from seven years to four years. While this reform was strongly endorsed by British charities at the time, available data indicates that it has done little to influence individuals to donate more by way of covenants. In 1982, the Conservative government liberalized some of the existing tax exemptions in its Finance Act that included a fiscal package claimed at the time to be worth an extra £30 million. It was anticipated that most of this money would be generated from an increase in the upper limit of money that could be donated by way of covenant. Again, the data that is now available indicate that this was a far too


47Brenton, Voluntary Sector in British Social Services. p. 75.
optimistic calculation.

In its 1986 budget, the Conservative government continued with its commitment to extend more indirect financial assistance to charities. After the March budget was announced, the Institute of Charity Fund Raising Managers Trust, predicted that donations to charities would double as a result of tax concessions to encourage employees and individuals to support charities. The tax reforms were essentially a two-part relief package. First, it offered a series of concessions for companies and individuals, and second, it provided more relief for welfare and medical research charities from VAT.

The government proposed that it would abolish altogether the upper limits of £10,000 on covenants for individuals who wished to donate money over a four year period. At the same time, the government allowed companies to make single donations instead of having to covenant money over a number of years. Under the new legislation they were able to give up to three per cent of their annual dividends to charity and receive tax relief at the basic rate. Additionally, the government allowed any person on a company pay-roll to donate up to £100 a year with full tax relief to charity. Under this new programme, an employer would approach a charity to launch a scheme to give a maximum of £100 a year. The employer would then deduct the payment through PAYE. Deductions would then be made like pension arrangements, with the employee receiving tax relief. The concessions at the time of their announcement were valued at £60 million a year to charities.
which would double donations.48

The VAT concession made in the 1986 budget meant that charities would no longer pay for display advertising in newspapers and magazines, the provision of distress alarms and lifts for the handicapped, or the use of minibuses and cars to transport the disabled. This last concession was calculated by the VAT Reform Group as having a net worth of £12 million a year to charities.49

(i) Importance of indirect government financial assistance in Britain and Canada

No study has yet calculated the value of all the indirect government subsidies to charities in either country. However, in Britain one estimate, which included stamp duty, capital transfer tax and the covenant form of tax credits, but excluded other kinds of tax or rate relief, concluded the amount saved by charities equaled more than £200 million in 1980-1981.50 A more recent study suggests that this figure has doubled to an amount of £400 million in 1986.51 In Canada, one comparable study indicates that the federal government alone extends close to $395 million (£197.5 million) to charities by exempting them from

48‘Doubling of donations forecast to follow tax concessions,’ Guardian. 19 March 1986.
49Ibid.
50Brenton, Voluntary Sector in British Social Services, p. 75.
paying tax on their accumulated annual income. This figure is estimated to represent approximately 10 per cent of total charity income. In contrast, and as illustrated in Table 4.8, voluntary donations made up 44 per cent of all Canadian charity revenue in 1983, with government grants following at 23 per cent, the proceeds from the sale of goods and services made up 22 per cent and investment income comprised 11 per cent. However, among non-religious Canadian charities government grants were the most important revenue source, comprising 40 per cent of total revenues and donations fell to approximately 20 per cent whereas income from investments remained constant. In comparison to Canada, voluntary donations made up 54 per cent of all British charity revenue in 1983 with government grants following (similar to the Canadian pattern) at 26 per cent, followed by investment income at 13 per cent. However, in contrast to Canada, among non-religious British charities, personal donations as opposed to government grants remained the most important revenue source comprising 50 per cent of total revenue. Government grants increased moderately by three per cent whereas income from fees and investments remained constant.

A further, and closely related point is that charities are in effect increasing their income by not having to pay taxes on the donations they collect. This, of course, represents a net loss to


53Ibid., p. 1.
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the government through lost tax revenue. Gilbert and Specht describe this type of indirect subsidy as money that has escaped from the public treasury and which can be seen as a policy instrument used by governments to confer their blessing on certain types of activity and to deny it to others.54 Moreover, and as in our examination of medical research charities (chapter seven sections I and II), the governments of both countries have cut back the amount of direct funding to agencies while at the same time have increasingly relied on charities for research discoveries by indirectly increasing their income through various tax reform measures.

D. Direct government financial assistance

In both Britain and Canada, government grants to charities are given mostly on a selective basis to those organisations operating in a department's jurisdiction. Many departments have financial links with charities and it is frequently the case that charities combine grants from a number of departments to finance different aspects of their work if such work overlaps the sphere of interest of more than one department. For example, several smaller British medical research charities receive grants from the Medical Research Council (which is responsible to the Secretary of State for Education and Science) for experimental purposes, and from the Department of Health and Social Services (DHSS) which provides finance for patient service related projects; for

example, the provision of home nurses for terminally-ill cancer patients. Generally, the policy towards such subsidies is that they should go first to charities which engage in activities ‘supplementary’ to a department’s own area of concern. As noted in the Wolfenden Report:

Where departments have certain statutory responsibilities which must be met from the total amount of money available to them, only limited funds are left over for help to voluntary organisations which are not simply acting on an agency basis to fulfill statutory duties.

The data in Table 4.9 illustrate that among all British charities income from government sources has increased by £79,995,000 from 1983 to 1986 and that in proportion to other sources of charity income has increased from 17 per cent to 22 per cent. In the specific area of medical research Table 4.10 illustrates that the total amount of income from government sources (including central government grants and fees and local government fees) of the 14 British medical research charities listed in the ‘top 200 grant-seeking charities’, between 1982 and 1986 increased by £6,566,000. However, this figure is greatly skewed by the disproportionately large government grant flowing to one charity – the Spastics Society. In an interview with the Executive Director of this charity, it was learned that the entire amount of government support went to this one charity.

Table 4.9


<table>
<thead>
<tr>
<th>Total Amount of Government Funds given to British Charities (£000)</th>
<th>1983</th>
<th>1984</th>
<th>1985</th>
<th>1986</th>
</tr>
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<tbody>
<tr>
<td>148,499</td>
<td></td>
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<td></td>
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<tr>
<td>175,372</td>
<td></td>
<td></td>
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<tr>
<td>194,621</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>228,494</td>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Government Funds as a Proportion of Total Charity Income</th>
<th>1983</th>
<th>1984</th>
<th>1985</th>
<th>1986</th>
</tr>
</thead>
<tbody>
<tr>
<td>17%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.5%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22%</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>


Note: Data on government funds includes fees and grants made by central and local governments.
PAGINATION ERROR
support is directed towards 'patient services' as opposed to medical research. In removing the Spastics Society from the aggregate totals it is clear that government is not an important source of funding for medical research charities. For example, in 1986 not only did 10 of the remaining 13 charities not receive any government financial support but this source as a proportion of their total income dropped considerably from 16 per cent to a mere 1.7 per cent when the Spastics Society is excluded. In relation to the general policy that government limits its financial support to charities providing complementary services, the question arises whether there is any difference between charities and statutory agencies and whether the former has merely developed into a quasi-statutory agency. The argument frequently advanced is that charities deriving a large proportion of their income from government sources correspondingly deliver services on behalf of the statutory sector, as a glorified sub-contractor.57

A major difference between the financing arrangements between charities and the state in Britain and Canada relates to the existence of a special source of government money for charities in Britain namely, the Voluntary Service Unit (VSU).

The unit was established under the Conservative Government in 1973 and has acted as a focal point in government for relations with charities. A similar but much smaller co-ordinating unit had previously existed in the Cabinet Office under the Labour

57See, Brenton, Voluntary Sector in British Social Services, p. 39.
Government of 1964-1970, but had neither the resources nor expertise within its staff to co-ordinate effectively government involvement with charities. The VSU was originally designed to perform four roles: to act as a link between charities and government departments; to act as a focal point through a system of departmental liaison officers for departmental interests relating to charities; to stimulate the use of volunteers and encourage cooperation and coordination among charitable organisations; and to act as a financer of last resort in Whitehall. As is shown in chapter six section I, the VSU has not played a role in liaising between medical research charities and the Medical Research Council. Consequently, the potential for duplicated research has become an increasingly difficult problem for charities, government, the scientific community and the more prudent members of the donating public. In relation to its last function, the VSU has been largely responsible for funding charities whose activities are embraced by policies of more than one department or are not the direct responsibility of any one department. According to Brenton's estimations:

The VSU's grants to voluntary organisations in 1980-1981 amounted to just over £2 3/4 million. This total included grants of £500,000 or more to such agencies as Community Projects Foundation, Community Service Volunteers, and the Volunteer Centre and smaller grants to bodies like Gamblers Anonymous, the National Playing Fields

58Wolfenden Committee, The Future of Voluntary Organisations, p. 213.

206
As mentioned above, there is no comparable institution in Canada to that of the VSU. In the 1977 federal government report, *People in Action*, a major recommendation was that a central agency should be established to provide a wide range of grant-related information for charities. Additionally, it was argued that the Canadian government was inefficient, since departments had no central source of information regarding which charities had previously received public money and where in government it had emanated. Most of the Canadian charities surveyed for the report perceived government funding as largely uncoordinated and lacking an overarching policy to steer decision makers towards properly selecting worthy candidates for funding. In light of these problems, many charities have regarded direct financial aid from the federal government as a mixed blessing. While unquestionably most charities need government money, often acquiring it has been so onerous that charity administrators have debated whether it is a worthwhile exercise.60

While there continues to be no overarching government policy relating to the funding of charities, (despite efforts by the VSU) government departments in both countries nonetheless have their


own unique set of priorities for extending financial assistance to
them and for monitoring the activities of recipient organisations.
Each also has a distinct mandate and can set up programmes subject
to Treasury and Cabinet approval to provide grants and contracts
for needed services in light of those mandates. Once a programme
has been created, its operation is determined by the departmental
setting, the internal operations of the government, its past
relationship with charities, the attitude of particular ministers,
the political climate for its activities and a host of other
factors. There is, in short, little uniformity of policy within
the governments of both countries regarding the funding of
charities.61

The legal provisions under which the governments in both
Britain and Canada are empowered to give financial assistance to
charities are too numerous to list in their entirety. However,
even if all statutory powers were given it would not present a
full picture of the full range of funding; at least in so far as
the central and federal governments are concerned. This is
because:

The existence of specific statutory powers does
not necessarily mean the grants will be made and
conversely, the lack of statutory powers does not
mean the grants cannot be made; but if the

61The two best sources relating to government funding
structures in Britain and Canada are Brenton, Voluntary Sector in
British Social Services, chapter 4; D. Leat, G. Smoka and J.
Unell, Voluntary and Statutory Collaboration: Rhetoric or
Reality?. London: Bedford Square Press/NCVO, 1981, Chapter 2,
and the Report of the National Advisory Council on Voluntary
Action, People in Action, chapters 9-11.
assistance is substantial and continuing it is expected that covering legislation would be obtained.

62

An example of a statutory provision under which a central government department in Britain is empowered to make grants to charities is the Education Act 1944, S. 100, (1) (b): it states:

The Department of Education and Science may provide by regulation for grants to be paid towards expenses incurred in the provision of educational services or for the purposes of educational research. Regulations have been passed to enable grants to be made to special schools for training disabled persons, institutes for teacher training, adult education institutes and until recently, direct grant schools.

63

There are plenty of British and Canadian examples of the governments' offering of grants to charities covering all major fields of social welfare provision including education, relief of poverty, care for children, elderly people, health and even housing. Additionally, there are broad and flexible powers not expressly linked to recognized categories of social welfare. In Britain, these include the power under the urban aid scheme to support charities attempting to alleviate 'special social needs'.


63 Attached to the Home Office Voluntary Services Unit memorandum was a list of statutory provisions under which central government departments are empowered to make grants to charities. See Wolfenden Committee, The Future of Voluntary Organisations. p. 233.
in urban areas, and in Canada the power of the federal government to finance charities involved in promoting bilingualism and biculturalism.

To gain some perspective on the importance of these statutory provisions some data indicating the actual amounts of capital given to charities are listed below. Large sums of money, for example, have been dispensed to charities in Britain out of central government coffers under the job creation programme (£31.2 million between October 1975 and March 1977) and to charitable associations chiefly via the Housing Corporation (some £6 million in 1975-1976). Besides these amounts, £1.9 million was paid to charities under the Urban Aid programme in 1976-1977 and £4.5 million paid out in the same period by VSU in its role as a stimulator of charitable activity. Likewise, the Canadian Opportunities for Youth programmes (COY), administered by the Secretary of State, sought to alleviate the high employment rate among Canadian youth by providing opportunities for worthwhile community work during the summer months. Much of the £190 million budget for the programme went to local charities whose responsibility was to provide students with summer jobs. The employment created under this programme sought to develop technical and trade skills and to complete projects that benefitted local communities.

64 These data are drawn from the Wolfenden Committee, The Future of Voluntary Organisations. Appendix 6 B.

The extreme diversity of both the Canadian and British governments' policies and programmes renders it difficult to acquire information comparing grants made by different departments or even different programmes within the same department. For example, it is difficult to acquire general information relating to available grants, grants' criteria, the procedures for dealing with grants, rules for reporting by grant recipients and the evaluation of grant recipients and their programmes. The lack of any central source of information in both Britain and Canada, on grants to charities, presents a serious obstacle to anyone investigating this area.

E. Government funding policies

There are many examples where governments have relied on charities to deliver certain kinds of services instead of relying on their own agencies. Some have argued that this symbolizes government's belief in a pluralistic supply of services. Others claim that governments have relied on charities to deliver new programmes or services because establishing new departmental agencies for this purpose has proved expensive. Lastly, some writers have argued that governments use charities because their labour is cheaper.66 This is partly true since charities use volunteers and their employees are normally paid less than public sector employees performing comparable tasks.

At the partisan level in both countries, the policy aspects

of government-funded charities vary between departments; nevertheless some general patterns may be identified. The summary supplied to the Wolfenden Committee by the VSU divided government support into three categories:

These are where it is considered that voluntary provision is preferable to a statutory service; where the voluntary organisations can provide an alternative to existing statutory provision, providing an element of choice for users of the service concerned; or where a statutory service can be supplemented or are extended by voluntary means.

The breakdown in government support in Canada is virtually identical to Britain. However, one Canadian study stresses the importance of the first category; namely where charity provision is preferable to that of the state. This is the case since government assistance is often extended to charities to promote activity in areas that would otherwise be politically embarrassing to government. Such has been the case of government's financial support for the Women's Shelter, which provides temporary homes for distressed pregnant women as well as offering information concerning the availability of therapeutic abortions. Since the issue of abortion is a highly politicized issue, the government has favoured the use of charities as an intermediary body to

Given the general policy of the government in each country towards charities, they would, for example, support an organisation where a need was relatively small and specialized or where a case for statutory provision has previously failed. Alternatively, for specific groups like drug addicts, alcoholics or the single-homeless, the authoritarian image of a state agency is often deemed not appropriate. Some kinds of services lack popular appeal so that, on the one hand, statutory provision is not viewed as legitimate, and on the other, alternative voluntary provision has difficulty gaining financial support. Consequently, a publicly funded charity has been a happy compromise.

The typical departmental response in both countries to a charity seeking financial aid since funding began has been described as being 'reactive' and 'arbitrary'. The reason being that the previous austerity measures imposed on government expenditures have prevented individual departments from tailoring a comprehensive grants policy aimed at charities in general. According to Martin, the imposition of expenditure controls on every Canadian department, save the Ministry of Defence, has contributed to a grants policy popularly described as being 'ad-


69Brenton, Voluntary Organisations in British Social Services, p. 73.

hoc' and 'systematically unfair' for three decades.\textsuperscript{71} The economic constraints have also had an effect on the duration of grants. In Britain, government subsidies are normally given for one year, whereupon they are re-negotiated.\textsuperscript{72} In Canada, one report averages the normal contract to last approximately two years, however, this figure fluctuates considerably given the type of government assistance under discussion.\textsuperscript{73}

There are two important but largely ignored facts concerning these developments that are worth noting. First, the difficulties faced by charities in renewing their grants may not necessarily rest on government's evaluation of the service being financed, but instead upon the vicissitude of public expenditure policies. Second, the popular belief that governmental sources of income facilitate charities to conduct long-term financial planning is challenged by the fact that government grants are not necessarily renewed automatically on a yearly basis.

Government policies relating to the conditions under which funds are customarily granted and the extent of their control over the activities of charities in receipt of funds is also remarkably similar in both countries. Both the VSU report in 1978 and the Canadian study conducted by the National Advisory Council on

\textsuperscript{71}Ibid.. p. 203.

\textsuperscript{72}One exception is the DHSS which announced a change of policy in 1984, setting grants on a two to three year basis, to give greater stability to charities. Brenton, Voluntary Organisations in British Social Services. pp. 63-64.

\textsuperscript{73}National Advisory Council on Voluntary Action, People in Action. p. 167.
Voluntary Action in 1977, agreed that the primary determinant for government funding of charities must be that the organisation work to a policy which is in accordance with that of the departments involved. The formal conditions which attach to grants differ depending on their amount and the proportion they represent of a charity's gross income. For example, government policy in both countries demands that charities in receipt of relatively small grants must reciprocate by providing public officials with some form of annual report and audited accounts. For charities whose grants are large, or which constitute a substantial proportion of their total income, the designated status of 'controlled fringe body' applies, and the organisations become subject to governmental location policy and to public sector norms regarding conditions of service and levels of pay. As Brenton points out:

The number of charities that fall into this category are relatively few, instead most are open to less direct forms of government control and accountability for their expenditures of public funds.


75Brenton, Voluntary Organisations in British Social Services, p. 74.

76Ibid., p. 74.
The theme widely discussed in the existing literature. The purpose here, however, has been to summarize both the British and Canadian government's policies and general attitudes towards the funding of charities.

F. Types of direct government financial assistance

Three main types of direct government funding are discussed below: namely, project grants, sustaining grants and fee-for-services. Also discussed are other schemes for funding charities and types of funding relationships each providing both government and charities with a unique blend of opportunities and problems. It should be noted at the onset of our discussion that the three funding arrangements are identical in Britain and Canada, although instead of using the term fee-for-service, British charities in receipt of this kind of government assistance are said to be receiving 'contractual aid'.

(i) Project grants

Project Grants are payments provided to charities to carry out a specific activity, programme or a series of activities and programmes. In Canada, these grants may be given to provincial governments, private institutions as well as to charities. Likewise, in Britain this type of government assistance may be given to local governments, city councils as well as to a range of organisations including trade associations, mutual or self-help groups and charities. For example, the Canada Council has provided funds to a children's museum in London, Ontario, so that
it could develop further displays for exhibits and programmes.77

In Britain, the Department of Health and Social Security has given financial aid to charities like 'Welcome House' that provides homes to children who are without adequate parental supervision and that have been in trouble with the law.78

In both countries, the government usually sets up broad programmes under which the projects of individual charities will be funded. This initiative for developing specific projects utilizing the funds under the government programmes rests with the individual charities, though a department often can and does take the initiative. The department running the grants programme then assesses whether specific projects are complimentary to the objectives of the programme and its own interest and mandate.79

In both countries, new grant programmes have been initiated, particularly job creation schemes which have created a variety of new relationships between government and charities. For example, in Britain one of the earliest programmes, and one entirely designed for charities, was the Community Industry Scheme, set up as a temporary measure in 1972 under the direction of the National Association of Youth Clubs. The programme provided aid to "help socially and personally disadvantaged young people prepare for


permanent employment by providing them with practical work or community benefit.80 Financed by the Department of Employment, the programme provided job opportunities for thousands of youths who worked on community projects and workshops as well as in social service institutions. In Canada, the Student Community Service Programme administered by the Department of Secretary of State is an excellent example of a programme which gave project grants exclusively to charities to provide an opportunity during the summer for young persons to carry out activities which the employment charities themselves lacked the resources to perform.81 The programme was also subjected to yearly scrutiny to determine whether it was still meeting the needs of both charities and those of the students. When conducting this annual assessment, the government considered that, in order to accomplish something worthwhile in a single summer, it was necessary to impose on charities a host of management and administrative procedures. Because such arrangements can be unnecessarily burdensome to charities, the question has been raised about the value of this type of funding. The initial negative reaction to the use of project grants in the context of job creation took two forms. First, the programmes were seen by non-charitable organisations as being disruptive to community priorities since they by-passed established agencies already providing similar services. Second,


government officials themselves were uncertain as to whether the charities which received the grants would be able to account properly for their expenditures. The response, at the time of these concerns, was to set up constituency advisory boards composed of local citizens nominated by the area Member of Parliament and appointed by the minister in many federal ridings to select and oversee projects. In a few ridings the local M.P. made the selections and administered these projects himself.82 D. Blake has made the controversial argument that, because of this last arrangement, political considerations frequently affected the selection of projects and the groups who were assigned to administer them.83

(ii) **Sustaining grants**

Sustaining grants are payments by government into the general core budget of a charity. In other words, the grants are designed to do what their name implies; they sustain a charitable organisation. In both countries, the evidence suggests that these payments have not resulted in the direct involvement of the funding department in determining how the money should be spent. In providing this direct financial assistance, government officials first assess whether a potential charity will provide a sufficient contribution to the overall national interest. Thus in comparison to project grants, the government’s focus shifts from

82Ibid., p. 53.

supporting a specific activity or project to funding a charity's entire range of activities.

In Canada, in the last few years the Welfare Grants Section of the Department of National Health and Welfare has developed, a Sustaining Grants policy for charities registered at the federal level. The policy was designed generally to assist five areas of charitable activity that are complementary to departmental interests. First, the department supplements charities engaged in citizens' action within a specific area of need; such groups include the Canadian Rehabilitation Council for the Disabled and the Canadian Association for the Mentally Retarded. Second, the department supports charities with limited resources as a means of equalizing their provision of services in each region of the country. Such groups include the National Anti-Poverty Organisation and the Canadian Council on Children and Youth. As discussed in more detail in chapter five, 20 Canadian medical research charities presently receive this type of government support. Third, the department supports charities dedicated to training and developing social welfare manpower, such as the Canadian Association of Schools of Social Work. Fourth, it supports Canadian affiliates of international social welfare groups. The fifth type of activity supported by this department is unique in that it is also available to non-charitable non-

84For example, in Canada, the Department of National Health and Welfare, through the use of sustaining grants has supported the overall activities of the Canadian Rehabilitation Council for the Disabled and the Canadian Association for the Mentally Retarded.
profit organisations having professional qualifications; such
groups include the Canadian Association of Legal Aid Workers and
the Canadian Institute of Chartered Accountants. These
organisations provide feedback on government proposals and make
suggestions relating to social policy in general. Charities have
limited participation in this particular area of activity since
legal rules restrict them from openly participating in the policy
formation process.85

An important aspect of this type of direct funding is worth
mentioning. The Department of Health and Welfare argued publicly
that in order for a charity to meet community needs effectively,
it should assess its own internal operations thoroughly and
evaluate—either independently or with government assistance—
the relevance of its goals and objectives. In the case of
sustaining grants, as opposed to project grants, the overriding
concern was not necessarily that the goals of the charity should
always converge with departmental objectives but rather that the
charity itself become aware of how to improve the services it has
offered. In short, it appears that the department's intention was
that Sustaining Grants be utilized by individual citizens be
directed into socially useful projects.86

85 National Voluntary Health Agencies Committee, 'The Role of
the National Voluntary Health Agencies', Discussion Paper to
Delegates attending the Second National Voluntary Meeting.
Ottawa: NVHAC, April 1979, pp. 5-6.

G. Fee-For-Service or Contractual Aid

As previously stated, the Canadian term ‘fee-for-service’ and the British term ‘contractual aid’ have the same meaning. They are simply payments given to an organisation in direct exchange for goods or services required by government.

When the government enters into such arrangements with a charity it is to some degree recognizing and capitalizing upon the special expertise of that particular charity. Contractual aid is therefore, normally initiated by the government and involves the payment of an agreed upon fee for services rendered. The government’s focus is upon ensuring that the service is adequately provided; the nature of the charity providing the service is secondary. Contractual aid, like project grants, support specific activities instead of a charity’s general programme of action. The types of activities often supported by this type of government funding include, among others, research, education, community development and cultural programmes.87

The debate continues as to whether contractual aid should be viewed as support by the central and federal governments for charitable activity or the reverse. On the one hand under such contracts, charities accumulate income but on the other hand government receives a precisely defined service for the money expended. If charities did not provide the services, they would have to be delivered by for-profit corporations or by government

itself, possibly at greater expense and at an uncomparable level of quality.

Charities in both countries often use this last argument in pleading with government to amend tax legislations in order to create a more opportunistic financial environment for themselves. Furthermore, in the sense that charities receive capital, and with it recognition of the value of the service they provide, they eventually do receive some 'non-financial' gains from contractual aid. As the 1977 Canadian government report on charities stated:

The learning of business methods, the hiring of administrative personnel and the adoption of its structures to a bureaucratic system can also strengthen the independence of a charitable organisation by improving its efficiency.

H. Other funding relationships: centralized funding and matching-grant formulae

(i) Centralized funding

One of the unique features of the state system of financing charities in Britain is that there exists a central government agency - the VSU - which is responsible for co-ordination and funding. In Canada, the absence of a similar agency was identified in the 1977 government report *People in Action* as a major weakness and potential drawback to a healthy and dynamic charitable non-profit sector. There were several problems and

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concerns that charities felt could be eliminated by a centralized funding agency comparable to the VSU. Many charity administrators were suspicious of political bias concerning the selection of grant recipients. Other charities expressed concern that the 'closeness' or 'directness' of the present funding relationship between themselves and government departments meant that it was too easy for the funding agency to force its objectives on charities. Still, others complained that the scattering of funding throughout the Federal government meant that there were too many different sets of granting criteria for grants.90

However, the recommendation of People in Action for centralized funding departed from the British model in that it proposed all federal money to charities be funded through this new agency, whereas the VSU has always extended grants to charities only as a last resort to those unable to secure funding elsewhere.

In Canada, evidence was submitted to the National Advisory Council on Voluntary Action when drafting its report, stating why a centralized funding scheme was impracticable and virtually impossible to implement. These recommendations were likely acted upon given that no agency described above has emerged at the federal or provincial level of government in the eight years that have passed since the report was published. Perhaps one of the most persuasive recommendations was that a central funding agency would have to possess final say over the dispensing of grants and contracts to charities. However, this authority has long been a

90Ibid., p. 193.
vital component of many deparmmental programmes and, therefore, it would be likely that a new agency would meet serious resistance from departments on this issue. A parallel can be drawn between the likely future of this agency and a similar agency that failed to provide inter-departmental co-operation; Information Canada. The latter was set up to collect and cross-index information regarding, among other things, governmental expenditures, but soon after failed to do so because of its inability to secure the full support and co-operation of government departments. Government departments saw Information Canada as an encroachment into their own activities in the information field.91

(ii) Matching-grant formulae

Over the last ten years in Canada, and only recently in Britain, charities have called on government to be more innovative in their funding policies towards charities. One scheme strongly advocated by 'certain charities' is a matching-grants formulae. As previously stated, this scheme operates by government providing money to a charity in some proportion to the money they collect from private donors. For example, the government might give a charity one pound for every pound collected from private donors. But these proportions could be varied. In fact, the argument has been made that the proportion of government grants to private donations - the matching-grants formulae - should be varied in

accordance with the needs of a specific charity receiving the grant.92

A Canadian study conducted by H. Cooperstock assessed the reactions of charities to a matching-grant formulae as a new means of government support. Fifty-seven per cent of Cooperstock's respondents said they opposed any overall matching formulae which might be imposed on them by government. The respondents pointed out that the matching-grants system could work against many types of charitable activities. For example, the arts, anti-poverty organisations as well as senior-citizen groups argue that they would be poorly served by this type of granting system. Conversely, it should be noted that 43 per cent of Cooperstock's respondents favoured matching grants on the grounds that it would "improve the autonomy and initiative of volunteers and provide assurance that the community really supported a project".93

III. Non-Financial Government Support to Charities

Charity-state relations in Britain and Canada are diverse most notably when one considers the broad picture and not just financial matters. In this section of the chapter, we focus on the main categories of 'non-financial' support given by the state to charities. These include 'general support', the 'bestowal of


recognition' and the 'release of information'.

A. General support

The most obvious form of non-financial assistance is 'aid-in-kind'. This includes access to government facilities, premises, resources, efforts to improve the responsiveness of government personnel to charitable activities and various types of non-financial support services.94

At the present time in Britain and Canada, the provision of aid-in-kind is extended by governments without clear guidelines. Instead, their provision now depends upon the goodwill of governmental personnel at all levels and on the ingenuity of charities in seeking-out this assistance. In Britain, and perhaps more so in Canada because of its vast geographical size, national charities have lobbied government to provide support to overcome the high costs of communication and travel. Specifically, the governments have been requested to offer their own communication facilities such as WATS telephone lines and telex to charities free of charge or at a reduced charge.

In the area of transportation, demands have been made for government to ensure that the economies of charter and excursion flights on government owned airlines - such as Air Canada - be made available to members of charities attending their annual conventions and meetings. Another proposal has been for the government to set up a system of grants which could be used in

reimbursing members of charities for part of the transportation costs incurred when travelling to such meetings.95

Most charities depend extensively on the circulation of printed materials to their membership because, unlike government and business, charities cannot afford expensive phone-calls. Thus in order to maintain adequate and efficient communications with their members, charities have had to resort to the post - this has been a particularly severe problem in Canada because of the long-standing inefficiency of Canada's postal system. The effects of continually rising postal rates in both countries, charities claim, have had a serious financial impact. As a result, repeated demands on the government of each country have been made to create specially reduced postal rates for the information materials and publications of charities.96

B. Recognition

The granting by government of a charitable registration number, the disbursement of a grant and the provision of facilities or services are not just sought by charities as a means of support. They are also appreciated as a symbol of recognition by the government of the worth and credibility of charitable organisations. There are other special measures which charities in both countries seem to agree the government could take as a

95Ibid., pp. 61-66.

96Sim, Government Grants to Voluntary Organisations, pp. 15-17. Canadian and British charities have cause to be optimistic since American charities do enjoy preferential postal rates.
means of bestowing recognition on charities. One is for the
government to make a greater effort to publicize the value of
charitable activity. One such scheme that has been proven
successful in Canada has been to send leaflets promoting
charitable activities along with cheques emanating from the
Department of National Health and Welfare. The existing ‘cheque-
insert’ programme has reached close to 5 million people monthly
across Canada who receive government assistance through Family
Allowance, Old Age Security or the Canada Pension Plan.97 As best
can be determined, no comparable scheme has or does exist in
Britain.

Other forms of recognition by government of charitable
involvement includes the bestowal of the Order of Canada for
voluntary achievements and in Britain the distinction of honours-
from MBEs upwards. Additionally, the issuing of special stamps
commemorating achievements, as well as public mention of
charitable activities by politicians and senior civil servants are
looked upon favourably by charities. One form of recognition of
charitable activity that has been proven successful in Canada is
the Life-Style Award programme administered by the Department of
National Health and Welfare. This award honours volunteers who
contribute outstandingly to the creation of healthy life-styles in
their communities. Local branches of national charities,
municipal governments and local citizens all share in the

97Ibid., pp. 30-31.
C. Information

Another important source of non-financial support from government for charitable activities involves the preparation and circulation of government information. The belief of many British and Canadian charities is that governments have traditionally been unwilling to provide 'information' at their disposal. The defence of government policy has been that information potentially valuable to charities has been held back for reasons of national security, defence and especially to protect the infringement on the privacy of individuals.

One Canadian study has estimated that a considerable amount of information falling outside the above categories has remained secret because it has become customary to classify most government information. In fact, it has been estimated that over 80 per cent of Canadian government documents are classified. As a result, many charities have found it difficult to obtain information relating to government investigators of charities where embezzlement or other accounting irregularities have been alleged to have occurred. This is a particular concern of foundations which do not wish to disburse grants to grant-seeking charities that have been involved in administrative improprieties.


Another related problem for charities concerns the collection and organisation of information on government programmes. The relative autonomy of government departments has meant that information has been scattered between different departments and different programmes within single departments. Charitable activity has historically been such a minor governmental concern that there is no centre located in any department for the collection and dissemination of grant information to assist charities. As the Canadian government report; People in Action concluded:

The council discovered that there were no uniform reporting procedures or commonly accepted definitions of granting activities for charitable activities for use in obtaining such hard data. In addition, the Treasury Board did not act on a Cabinet directive to produce an annual report on Federal support to charities and little has been done to resolve this problem.

Charity administrators in both countries complain that they need more accurate and up-to-date information regarding government programmes and policies which affect them. This information can often be quite general; for example, charities may demand to know where they can best go for assistance given their own programmes and objectives. At other times, their information needs may be quite specific. For example, many charities often have detailed questions requiring equally detailed answers—such as, the

100National Advisory Council on Voluntary Action, People in Action, p. 271.
precise criteria required for charitable registration. One recommendation put forward by the National Advisory Council on Voluntary Action was that the Federal government directs every department and agency with programmes of assistance for charities to allocate sufficient resources and personnel for the preparation and annual updating of directories identifying these programmes. The Canadian government's response to this recommendation has been that departmental resources are better applied by distributing grants to charities instead of spending a portion of that money on their publication.

IV. Conclusion

In Britain and Canada, we now know that charities derive their income from a wide variety of government and non-government sources. For charities that are financially independent from the state there are problems of fluctuating levels of public benevolence which make long-term planning difficult. However, these charities nonetheless enjoy the freedom and independence to expand their resources as they see fit. Government financed charities normally tend to enjoy the benefits of large and more secure incomes; possibly however at the expense of government influence on their administration.

With our knowledge that the state welfare system has begun to falter we are able to make some sense as to why both the British and Canadian governments have increasingly relied on charities to

101 Ibid., p. 272.
deliver important social services. The manner in which
governments have done so can be classified in two distinct ways. 
First, they have directly financed them through the extension of 
project grants, sustaining grants and service contracts. 
Government's selection of which charities should receive direct 
financial assistance and the type of aid depends largely on a 
charity's area of activity and whether its existing programmes 
coincide with government policy. Second, governments have also 
indirectly increased their financial commitment to charities by 
ammending tax legislation to encourage individuals and 
corporations to make larger donations. Where charities have been 
successful in raising voluntary donations because of these recent 
tax amendments, as in the case of medical research, governments 
have in turn cut back their own financial commitment to these 
areas of activity.

By examining some of the problems encountered by charities 
dependent on non-government financial sources such as voluntary 
donations, corporate donations, retail income, trust grants and 
self-generated income, we are able to discuss in the following 
chapter, how effectively they are able to function as surrogate 
institutions to statutory agencies. In this next chapter we 
focus on charities involved in medical research. By doing so we 
are able to examine the nature of government's reliance on 
charities, some of the advantages and disadvantages of this 
arrangement and the likelihood of it being applied to other policy 
areas.
Chapter Five

History of Charitable and Government Support for Medical Research

This chapter is the first of four chapters focusing specifically on charities which collect, and spend, voluntary contributions on medical research. The object here is to gain an understanding of how and over which issues, medical research charities interact with government and where possible, more general conclusions are made about charity-state relations.

British and Canadian medical research charities have become increasingly active in lobbying their respective governments on a host of issues, ranging from government cutbacks to the British Medical Research Council (B)MRC to government legislation affecting the Canadian tobacco industry. As an introduction to this discussion, it is first necessary to offer a short history of the role of medical research in changing public health. While the history of scientific investigation into the cause and cure of disease dates back many centuries, the organized response to funding medical research in both countries is less than a century old. Indeed, medical research charities as a community of charitable organisations are one of the most contemporary types of philanthropic bodies when compared to those dating back to Elizabethan times established for the 'relief of poverty'. Most
medical research charities were established during the 1960's and 1970's and registered under the second category of the Macnaghten classification as 'educational charities'.

After placing medical charities in their proper historical context, section II describes the impetus behind the establishment of the first medical research charities at the turn of the century. Explanations are offered as to their enormous popularity 60 and 70 years later - as witnessed by the large number of new charities established and their success in attracting voluntary contributions. From this, we focus specifically on the internal dynamics that have shaped the way in which these charities organize and operate themselves. Here, close examination is made of the organisational features which have made charities representing certain diseases more successful than others. Indeed, arguments are formulated suggesting that the nature of the disease represented by a charity is a significant factor in determining its fund raising capabilities. In both countries, this provides useful background information for understanding why there are disparities between the incident rates of certain diseases and the availability of both government and charitable funds for their research. Appreciating this disparity lends understanding to why British and Canadian charities have lobbied their respective governments to increase research funds specifically earmarked for the disease they represent. These two issues are discussed in greater detail in chapter six. In addition to charities as a potential source of funding for bio-
medical researchers the role of government as an alternative source is discussed below.

I. Role of Medical Research in Public Health

It is scarcely contentious to claim that modern medical practice developed during the last two centuries and that during this period life expectancy increased (in the Western World) at a rate not witnessed before. The reliable identification of disease began in the 19th century, as did the first accurate understanding of disease processes. The ancient physicians had always blamed the development of disease on the defective mixing of the humours in the body but in 1761 an Italian, Giovanni Battista Morgagni published a book entitled *On the Seats and Causes of Diseases* based on a greater number of post mortems in which he showed convincingly that different diseases involve different organs. Forty years later the Frenchman, Marie Francois Xavier Bichat, showed that organs are made up of many different kinds of tissue and that different tissues are responsible for different disease processes.1

In 1833 a German, Johannes Muller, published the first volume of his *Handbook of Human Physiology* which led the move away from philosophical medicine towards a more scientific approach. The final and perhaps most important step in the creation of the basis of modern medical thought was taken in 1855 by another German,

Rudolf Virchow, who used microscopes to study cells and who introduced the idea of cellular pathology. His book called *Cellular Pathology as based upon Physiological and Pathological History* was published in 1858 and many historians believed that it marked the beginning of modern medicine.2

The fight against infection was also fought with great enthusiasm in the 19th century. Jan Ignaz Semmelweis, an assistant in the Obstetrics Unit in Vienna, believed that puerperal fever, an infection which affects women who have just given birth, was caused by a 'poison' of some sort from dead bodies. He was scorned, and his theories were rejected at first, but later in the same century he was proved right. Robert Koch discovered the tubercle bacillus in 1882 and in 1883 found the organism which causes cholera. Meanwhile, in the 1860's Pasteur developed his theory of the cause of infectious diseases, and it was in 1865 that Joseph Lister, the British surgeon, developed the antisepsis principle which helped save patients on the operating table. Before Lister, surgeons used to wear their oldest and dirtiest clothes in the operating theatre and their instruments were rarely if ever rinsed.3

The basis of modern anaesthesia was also developed in the 19th century. Horace Wells, an American dentist, introduced the use of nitrous oxide (laughing gas) in 1844; another American W. T. Morton, first used ether in 1846, and a Scottish doctor, Sir

2Ibid., p. 37.

3Ibid., p. 37.
James Young Simpson, introduced chloroform as a general anesthetic in 1847. He complained that "... the man who lies on the operating table in one of our hospitals runs a greater risk of dying than did the British soldier on the Battlefield of Waterloo".4

The compound microscope, which enabled Virchow to study cells and Pasteur to study micro-organisms associated with different diseases, was developed during the 19th century. In 1895, at the end of this scientifically progressive period, Roentgen discovered x-rays and made the greatest single contribution to diagnostic medicine. Like a good many of the inventions later to prove so vital to doctors, the x-ray machine was developed by someone who had no interest at all in medical practice or medical research.5

Undeniably, then, the 19th century saw the introduction of many ideas and techniques which are so crucial to the modern medical practitioner. Through the efforts of researchers, medical men had learned a great deal about the function and structure of the human body. Never before had a single century seen a greater increase in the amount of medical knowledge made available. Science commentators like Wilson and Rosenberg have even debated


5Fielding, An Introduction to the History of Medicine, p. 26.
whether a similar ‘information explosion’ will ever occur again.  

During that same century when Virchow, Pasteur and Koch were making their great discoveries, the expectation of life improved significantly. A baby born two centuries ago would on average live only to the age of 25. By the end of the 19th century, however, the newborn baby had a far better chance of reaching his ‘biblically allotted three score years and ten (70 years old)’. In 1901, the one-year-old male would stand an average chance of living to the age of 55; the 45 year old could expect another 23 years of life. During no other century had life expectation improved so dramatically.

However, in retrospect there is considerable debate over whether these improvements reflect the contributions made by medical researchers or by better public health standards ushered in during the late 19th century. Coleman argues that the decline in infant mortality and the increase in life expectancy was a direct result of an increase in the supply of good nutritious food, an increase in the supply of pure water and the improvement in the quality of available housing. Cholera, for example, one of the biggest ‘killers’ of the 19th century, was brought under control by hygienic measures 10 to 20 years before Koch discovered the existence of the cholera vibrio. Furthermore, writers, including Coleman argue that the decline in the incidence of tuberculosis was due not to the discovery of the 'tubercle

bacillus' but to improved nutritional standards.\footnote{7} According to McKeown and Lowe,

"... it seems right to conclude that in descending order of importance the main influences responsible for the decline in mortality - our best index of improved health since deaths were first registered in 1838 have been: a rising standard of living, hygienic measures and specific preventative and curative medicine."

8

Interestingly, a World Health Organisation (WHO) publication entitled *Life Expectancy in the Year 2000* adds stable government, progress in road building and better education to the above list.\footnote{9}

From the middle of the 19th century, improvements in available food, in the quality of water supplies, in sanitation, in living accommodation and other environmental factors were largely responsible for typhoid, scarlet fever, dysentery and infective diarrhoeas being brought under some sort of control. These diseases had been important 'killers' and their environmental control led to a decline in mortality rates. Some writers, like Coleman, argue that the many technically important discoveries of the 19th century were of far more importance to the academic than to the busy practitioner struggling with the


practical problems of how to treat disease. Vaccination against smallpox was one of the very few medical measures to have any real effect in the 19th century and the disease was of relatively small importance in statistical terms. For example, in 1878 only 1.2 per cent of the total number of people admitted to British hospitals were diagnosed with smallpox.10

During the 20th century medical intervention did play a much greater part in the improvement of life expectancy. By far the greatest contribution to medical care came from the researchers developing drugs. At the end of the 19th century the pharmaceutical industry was still in its infancy (the first aspirin tablet was made in 1899) but during the next three to four decades great advances (many of them accidental) were made in the development of drugs. The discovery of the hormone insulin by Banting, Best and Murphy at the University of Toronto in 1922 brought about a revolution in the treatment of diabetes. The development of potent diuretics and drugs to control hypertension meant that patients with cardiovascular disorders could be treated. In 1914, Wenchebach discovered the usefulness of quinidine for patients suffering from arrhythmias of the heart. In addition there were, of course, tremendous advances in the development of the sulphonamides, the penicillins and so on meant that those infectious diseases which still remained were no longer

10Coleman, Paper Doctors: A Critical Analysis of Medical Research, pp. 11-12.
The resultant more effective treatment of infectious diseases helped to ensure that life expectancy rose from 50 years at the beginning of the century to about 70 years today. As indicated by Figure 5.1 there were over 70 deaths per 100,000 from tuberculosis in England and Wales in 1930 but only about three per 100,000 in 1970. There were over 6,000 deaths from whooping cough in 1925 but only 15 in 1970. More than 5,000 people died from measles in 1925 but by 1970 the annual mortality rate had dropped below 50. The mortality from gastro-intestinal infections dropped by 80 per cent in the United Kingdom from 1930 to 1975 and the number of deaths from chest infections dropped by 70 per cent during the same period.

Interestingly, the improvement in life expectancy which we have enjoyed in this century has been largely due to the dramatic decrease in the number of children dying. In 1900 about 150 children in every thousand born in England and Wales died within one year. By 1950 this had declined to 30 per thousand. Adults, however, have benefited far less from the pharmaceutical revolution. If we consider their life expectancy, we find that it has hardly changed in the last three-quarters of a century. The 45-year-old male could expect another 23 years in 1901 and only 25 years in 1980. While the improvement in standards of nutrition

11Ibid., p. 11.

Figure 5.1

Mortality Rate From Tuberculosis in England and Wales 1900-1980.

Annual Deaths per 100,000 population

and in living standards greatly affected the life expectancy of
the middle-aged man in the second half of the 19th century, the
first half of this century saw comparable improvements in the
survival rates of infants but not of adults.13

While great strides in the field of basic bio-chemistry were
being made by the pharmaceutical industry during the first half of
this century far less was directly accomplished by government and
charity financed researchers during the same period. In 1919,
under a provision of the Ministry of Health Act the British
government established the Medical Research Council [(B)MRC]. The
first provision of a comparable state mechanism for funding
Canadian medical research was established in 1936 as the National
Research Council later to be known also as the Medical Research
Council [(C)MRC]. Table 5.1 lists the level of government funding
of both the (B)MRC and (C)MRC from the time of their
establishments to 1986. The Medical Research Councils in both
countries gave government officials a greater say as to what type
of research they wanted conducted. In addition to this, funds for
medical research also became available for the first time from
private charity but were limited exclusively to the area of
cancer. This was primarily a response to economic arguments as to
the need to preserve an able-bodied workforce and to maintain
healthy armies to defend the country during periods of war. The
first organisation to collect voluntary donations specifically to

# Table 5.1

## Level of Government Funding of the British and Canadian Medical Research Councils, 1926-1986

<table>
<thead>
<tr>
<th>Year</th>
<th>British - Medical Research Council (£)</th>
<th>Canadian - Medical Research Council (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1926</td>
<td>135,000</td>
<td>-</td>
</tr>
<tr>
<td>1931</td>
<td>139,000</td>
<td>-</td>
</tr>
<tr>
<td>1936</td>
<td>195,000</td>
<td>26,500*</td>
</tr>
<tr>
<td>1941</td>
<td>195,000</td>
<td>27,000</td>
</tr>
<tr>
<td>1946</td>
<td>415,000</td>
<td>90,000</td>
</tr>
<tr>
<td>1951</td>
<td>1,626,500</td>
<td>110,000</td>
</tr>
<tr>
<td>1956</td>
<td>2,680,000</td>
<td>500,000</td>
</tr>
<tr>
<td>1961</td>
<td>5,884,000</td>
<td>1,103,000</td>
</tr>
<tr>
<td>1966</td>
<td>11,831,000</td>
<td>6,504,000</td>
</tr>
<tr>
<td>1971</td>
<td>23,469,000</td>
<td>11,300,000</td>
</tr>
<tr>
<td>1976</td>
<td>37,357,000</td>
<td>23,000,000</td>
</tr>
<tr>
<td>1981</td>
<td>101,523,568</td>
<td>40,000,000</td>
</tr>
<tr>
<td>1986</td>
<td>122,310,000</td>
<td>80,000,000</td>
</tr>
</tbody>
</table>

*Note: From 1936 to 1960 the Canadian federal government channelled its 'grants-in-aid' to medical research through the National Research Council (NRC). As discussed in Chapter five section V. C, this changed in 1960 when the Medical Research Council - which from 1936 had operated as a 'division' of the NRC - became fully autonomous.

**Source:** British and Canadian data compiled from the Annual Reports of the Medical Research Councils in Britain and Canada for the years listed above.
fund research into the 'cause, cure and prevention of disease' was founded in 1902 in Britain (The Imperial Cancer Research Fund) and in Canada in 1934 (The National-Cancer Institute of Canada). The rapid increase in the number of medical research charities in other disease areas did not begin until after the Second World War.

From the beginning, charity (and government) financed research has been executed in university science departments. After the First World War the specialization of certain fields of medicine and medical research was a natural consequence of the broadening field of scientific knowledge. At that time, it became increasingly obvious to scientific investigators that no one person could adequately or efficiently cover the entire field of medical knowledge as had previously been the case. As a result, a number of disciplines and sub-disciplines such as bio-chemistry, physiology and neurology were defined. Furthermore, advances in science necessitated larger, and better equipped, laboratories. No longer was it feasible for researchers to work in the basement of their homes, or in ill-equipped laboratories. Therefore, universities were the obvious forum for scientific investigations to proceed on a much larger scale, and the creation of new university science departments was a natural outgrowth of this increasing sophistication in medical research.

Despite the increasing funds made available to Canadian and British medical researchers, improvements in life expectations up to the end of World War II were again arguably due to better
living conditions, better techniques of preventive medicine, improved surgical techniques and greater availability of drug therapy. Consequently, there are many who now believe that, with the important exceptions of drugs for the treatment of infectious diseases like syphilis, tuberculosis, pneumonia, and poliomyelitis, medical research had surprisingly little effect on life expectancy. In other words, improvements in human health in the late 19th and 20th centuries was largely due to changes in environment and modification of human behaviour.

While the evidence presented by writers such as Coleman indicate that the pharmaceutical industry contributed the most to improved public health conditions up to the end of World War II, it is curious why public support for medical research charities increased dramatically shortly thereafter. In answering this question and in addressing more general themes concerning the interaction between charity and state we begin our comparative case study of British and Canadian medical research charities.

II. History of Charitable Involvement in Medical Research

Most British and Canadian medical research charities, (excluding those involved in cancer) are only 20 to 30 years old. The list of medical research charities and the dates of their establishment given below (see Table 5.2) indicates that British and Canadian organisations representing comparable diseases were created at virtually the same time; in seven instances Britain took the lead, in two cases medical research charities representing the same disease were established in the two
## Table 5.2

**Dates of Establishment of British and Canadian Medical Research Charities**

<table>
<thead>
<tr>
<th>BRITAIN</th>
<th>CANADA</th>
</tr>
</thead>
<tbody>
<tr>
<td>2) British Diabetic Association - 1934</td>
<td>2) Canadian Diabetes Association - 1952</td>
</tr>
<tr>
<td>3) British Digestive Foundation - 1971</td>
<td>3) Canadian Foundation for Ileitus and Colitis - 1974</td>
</tr>
<tr>
<td>4) British Heart Foundation - 1961</td>
<td>4) Canadian Heart Foundation - 1961</td>
</tr>
<tr>
<td>5) Cancer Research Campaign - 1923</td>
<td>5) Canadian Cancer Society - 1934</td>
</tr>
<tr>
<td>7) Cystic Fibrosis Research Trust - 1964</td>
<td>7) Canadian Cystic Fibrosis Foundation - 1964</td>
</tr>
<tr>
<td>10) Imperial Cancer Research Fund - 1902</td>
<td>10) Canadian Cancer Society - 1934</td>
</tr>
<tr>
<td>11) Mental Health Foundation - 1972</td>
<td>11) Canadian Mental Health Association - 1950</td>
</tr>
<tr>
<td>13) Multiple Sclerosis Society - 1953</td>
<td>13) Multiple Sclerosis Society of Canada - 1948</td>
</tr>
</tbody>
</table>

*Source: The list is derived from interviews with British and Canadian medical research charities where identical organisations exist in both countries. The closeness in dates of establishment of "like" British and Canadian charities after 1950 is partially attributable to the formation of international associations representing specific diseases - their aim being to create new charities in other countries. In many disease areas, associations were formed first by British and American charities and successfully assisted in establishing, charities in places like Canada, and a number of other European countries.*
countries in the same years, and in seven instances, medical research charities appeared first in Canada. It is interesting to note that after 1950, the average period of delay in establishing a new charity in the one country after it had been established in the other was only five years.

The growth in the number of medical research charities in both countries during the late 1950's, 1960's and early 1970's can be attributed to the tremendous advances made by science in identifying new diseases. Certain afflictions such as cystic fibrosis and muscular dystrophy were identified by medical researchers only after the Second World War. While other diseases such as cancer, diabetes, and arthritis were identified by scientists in the early part of the century, the economic vicissitude imposed by two world wars and the Great Depression of the 1930's precluded a greater response by an altruistic public to these afflictions. Furthermore, the financial resources made available to medical researchers at that time were usually for solving more 'dreaded' diseases like tuberculosis, polio and cancer. The economic prosperity associated with the era after 1945 generated enormous faith and optimism in science to rid people of all diseases. With the introduction of television and the development of a more educated and affluent middle class, people became better informed about many of the less popular diseases. In response, charities were established with a view to raising money for research into their cause, cure and prevention.

British and Canadian medical research charities created in the mid
1970's were also symptomatic of a society disenchanted with the welfare state, for it was acknowledged that the state through its own apparatus [(B)MRC and (C)MRC] could not solve all the problems posed by disease. Not only did the increasing number of diseases identified by scientists place a burden on the resources of the Medical Research Councils in each country, but the type of research which the public demanded was different from that which the Medical Research Councils were prepared to fund. As is discussed in greater detail in chapter six, section I, the research bias of the Medical Research Councils in Britain and Canada is, and has been historically to support basic, non-disease-related research. To the British and Canadian public of the 1960's and 1970's, charities offered an alternative and complementary approach to government sponsored research by funding more 'applied-disease-related investigations'. The post war increase in the number of medical research charities can be attributed to the increasing willingness of people to support this type of charitable cause. The public and volunteers working for these charities wholeheartedly believed that if only enough money was raised, a cure would be found very shortly. In the late 1980's volunteers and the donating public appear to be better educated and more realistic about how science progresses, since they have 20 to 30 years of largely 'non-discovery' to reflect upon. While during the 1950's and 1960's the 'man in the street' was deluded, by previous successes in the field of tuberculosis and poliomyelitis and pneumonia, that same man has developed more
realistic expectations as to the ability of science to generate miracle cures and wonder drugs. This view is affirmed by the sparse number of medical research charities created after the mid 1970's despite the discovery of many diseases which have been identified by researchers since that time; for example ... Kleinfelter syndrome, cerebellar disease and certain new strains of encephalitis. Clearly, the absence of a charitable response in many of these new disease areas is due to the relatively small number of people affected. In addition, the risk of mass epidemic has normally been low. However, where newly identified diseases, like AIDS have shown their potential to become a growing public health problem, a charitable response has been displayed (in Britain the Terrence Higgins Trust and in Canada The Canadian AIDS Foundation).

It was stated earlier that British and Canadian cancer research charities have a much longer history in comparison to charities representing other types of maladies. When the (B)MRC was founded in 1919, cancer was the one field of medical research for which there was already, by the standards of those days, ample financial provision. This was the result of voluntary contributions from the public towards a cause that had always made a strong appeal to the charitably minded since the beginning of this century. The Imperial Cancer Research Fund (ICRF), established in 1902 was the principal body engaged in raising funds, primarily for the maintenance of a scientific staff in
laboratories in London. The ICRF is the only British and Canadian charity that funds and administers its own 'in-house' laboratories; all subsequent medical research charities in both countries distribute their funds to university or hospital based researchers.

At the turn of the century, cancer research was also richly endowed in the United States and in countries of continental Europe. In Canada, it took a full 32 years after the creation of the ICRF to establish a comparable cancer research charity. By this time, Canada had begun to sever its colonial ties with Britain by signing the Balfour Declaration in 1926 and was becoming much more economically integrated with the U.S. The shifting influence on Canadian affairs from Britain to the United States manifested itself in the financial assistance which the latter gave in helping to establish the Canadian Cancer Society in 1934. A study of funding sources of Canadian researchers conducted much later in 1949 showed that all sources contributed .75 million dollars of which .1 million emanated from the United States. In the early years charitable trusts, such as the Rockefeller Foundation, were particularly supportive of Canadian


15This agreement allowed the Government of Canada to exercise its own independence in foreign and domestic policy matters without having to first consult London. The impetus behind this document was Canada's disgruntlement over Britain's treatment of the Dominion during the First World War, whereby all key decisions were made in London without consultation with Canadian Officials.
bio-medical research.16

In 1923, another cancer research charity was established as the British Empire Cancer Campaign (now the Cancer Research Campaign). Its programme differed from that of the ICRF in that all monies collected from the public were, and continued to be, allocated to outside researchers. Criticism of the multiplicity of appeals has always plagued cancer charities in Britain. In addition to the two previously mentioned cancer charities in Britain, there are four other, smaller, ones: the Tenovus Cancer Fund, Marie Curie Memorial Foundation, Yorkshire Cancer Research Campaign and the Institute of Cancer Research. In Canada, the only charitable source of funds for cancer research is the National Cancer Institute of Canada which is the legally associated research arm of the Canadian Cancer Society. The presence of more than one charity in a particular field of research has been problematic from a fund raising perspective (see section III of this chapter), as well as from a scientific perspective because of possible wasteful duplication of research.

At this point, it is useful to make a distinction between two different legal forms adopted by medical research charities operating in Britain and Canada. On the one hand, there are those charities which collect money directly from the public and spend it on medical research, patient services or public and professional education campaigns. On the other hand, in both

countries, there are charities such as the Wellcome Trust and Leverhulme Foundation which derive all their income from endowments and which tend to support one programme at the exclusion of others.

In the field of British medical research donative charities are clearly more prominent than foundations: of the AMRC’s 35 members, only four can be classified as endowed medical research charities. However, the term ‘foundation’ is only loosely defined in a strict legal sense, the result has been that you get charities which are not endowed using the word Foundation in their title; for example, the British Heart Foundation and the Foundation for Age Research, both of which solicit the public for funds. Like foundations, the Medical Research Councils in Britain and Canada are not susceptible to the same sorts of constraints placed on the more traditional, unendowed, medical research charities. First, because a foundation’s aims and objectives are normally defined by a testator in a will, the trustees may have little flexibility in shifting emphasis from patient services to research, this makes internal division over expenditure priorities superfluous. Second, foundations have traditionally been insulated from criticism by the scientific community over the quality of research they have supported. This is true for two reasons; first, trusts do not have to account to the public for their donations and therefore are in a position to fund very ‘basic’ or ‘fundamental’ research that may have no clear connection to any specific disease. The scientific community has
traditionally preferred this type of research over the more 'applied' disease-oriented research. Second, trusts have the flexibility to fund inter-disciplinary research that may cut across two or three different disease areas, something unendowed charities have been reticent to do for fear of alienating volunteers and confusing the donating public.

A distinct pattern in the creation and development of British and Canadian medical research charities is that most were founded by individuals suffering from the diseases for which the organisations were set up to represent. Consequently, many medical research charities had a dual purpose to help those suffering from a disease and to help fund research into its cause, cure and treatment. Additionally, some charities which represent diseases like cancer where a 'cause' is known (such as smoking in the case of cancer), a third objective has been to develop public and professional education campaigns. The annual reports of 44 medical research charities interviewed (18 Canadian and 26 British) shows that 14 Canadian and 25 British charities were established by sufferers, or their friends and families; the impetus for the creation of the remaining five charities came from the scientific community.

Medical research charities that adopt a 'three-pronged' programme encounter both advantages and disadvantages over charities pursuing just one programme, whether it be research, education or patient services. On the one hand, comprehensive medical research charities have a broad base of support since they
are ‘doing something for everybody’; they are helping people in the future, by funding research and prevention through education, and they are helping people today by funding patient services. On the other hand, this type of charity encounters two problems; first, it must spread its resources thinly between each programme and, second, it must arrive at a formula for doing so which appeases the volunteers, who traditionally support patient services, and the donating public which normally responds more when its money is earmarked for research. The Medical Research Councils in both countries fund only research; in Britain patient services are a responsibility of the Department of Health and Social Security (DHSS) and in Canada that of the Department of Health and Welfare (DHW).

Another observable pattern which emerged from the interviews was that the larger and more sophisticated a medical research charity becomes, and hence the more money it raises, the more it spends on research and the less it spends on patient services or public and professional education. As the budgets of medical research charities increased, particularly during the affluent 1960’s and early 1970’s, the greater the need became to replace volunteers (who were normally disease sufferers) with paid staff (non-disease sufferers). These professional administrators were swayed less by emotion, and they tended to be more eager to support research rather than caring for those already afflicted. Most charity executives interviewed admitted that their own organisation had experienced ‘growing pains’ and that a tension
between volunteers and paid staff remains a constant irritant. The tenor of this complaint can be gleaned from the following statement offered by one paid staff member of a medium-sized Canadian medical research charity.

"I feel I really don't fit in as a paid staff member because I am not suffering from (disease x), especially since they run the operation. Our entire executive are sufferers and are so involved with their emotional problems that they have no sense of business. When our volunteers and executives get together at our annual meeting they are so involved with their condition that their main concern is expressing ideas relating to their physical condition instead of discussing business. They do not understand private sector concepts, like profits, cost-benefit budgeting and zero-based budgeting. Furthermore, while I would like to see more spent on research it is understandable that they skew their budgets in favor of patient services since a disease like the one we represent is passed on genetically to their sons and daughters."

17

Transforming a medical research charity's emphasis from patient services to research has been difficult for some organisations since the articles of association of several of them require that a certain proportion of board members must be actual sufferers. In cases where research has gained more prominence over patient services the shift has often been precipitated by a gradual education of the volunteers of the necessity to invest in research for the benefit of future generations. For many charities, increasing annual incomes has made it relatively easy for charity executives to appease their volunteers, by sustaining

17Canadian Interview; December 1986.
the level of patient services while increasing expenditure on medical research. However, even when most volunteers are disease sufferers, or their relatives, there are pressures to give priority to research.

For charities representing less popular diseases (often called ‘orphan’ diseases) where there is an absence of government commitment to research, volunteers have been apt to embrace the philosophy ‘if we don’t fund research into disease x nobody will’. Thus there has been a natural inclination of medical research charities over the years to place a greater premium on research as opposed to patient services despite some opposition from volunteers. As one respondent explained:

"If the state has one hundred units of money to spend how much do you think it will give to a disease like muscular dystrophy which affects 20,000 people in comparison to what it would spend on cancer which affects millions? If the state was the sole provider of research funds it is clear that many less popular diseases would not be funded at all."

This tendency for organisations to support research over patient services is illustrated in Figure 5.2. First, the total income of medical research charities (indicated on the graph as AMRC 1) has increased dramatically from £82 million in 1979 to £137 million in 1981 representing a 67 per cent increase over a five year period. However, breaking this figure down into the total charitable expenditure, specifically on medical research (indicated on the

18British Interview; Muscular Dystrophy Group of Great Britain, 19 February 1987.
Figure 5.2

Association of Medical Research Charities’ Income and Research Expenditure, (1979-1984)

AMRC-1 = Total income of AMRC member Charities
AMRC-2 = Total expenditure on research by AMRC member charities

The difference between AMRC-1 and AMRC-2 represents the total expenditure on patient services and public education by AMRC charities.

AMRC-1 figures represent total income after administrative costs of AMRC member charities are subtracted.

Comparable statistics are not available for Canadian medical research charities since there is no national association similar to the AMRC. However, interviews with executives of Canadian research charities revealed a similar pattern.

it is revealed that this amount jumped from £37 million in 1979 to £115 million in 1984 representing a 210 per cent increase. In other words, while the incomes of British medical research charities have been rising steadily, far more has been spent on research as opposed to other programmes such as patient services and education.19

Converting charities into research-support agencies has produced some problems. For charities in both countries which have increased their commitment to research, the criticism has often been made that there is not a proper scientific infrastructure to review research grant applications made by university-based scientists. The result of this has been a lack of consistency and lower quality of research in comparison with bio-medical research supported by the Medical Research Councils in each country. One British respondent pointed out that a charity he knew of had recently appointed to their grants-review committee a past Director of the British Steel Corporation who had no previous medical training.20 However, it is necessary to point out that in Britain, attempts to standardize and improve decision-making procedures relating to grants by medical research charities have been made through seminars. These have been held in conjunction with the (B)MRC where most charities have been encouraged to adopt the former's grant-making procedures. The


20British Interview; February 1984.
seminars have been organized by the Association of Medical Research Charities (AMRC) - the interest association representing 35 British medical research charities. In Canada, where no comparable association exists, the improvement of a charity’s grant-review committee has been left to the individual organizations.

A further problem with charities making a transition from patient services to research is the tension between administrators and their scientific advisors. In both countries, top-flight scientists are seconded from universities to work for a charity on a part-time basis which involves reviewing grant applications between one and four times a year, depending on the size of the charity. Normally, these scientists are supervised by a permanent scientific advisor whose main job is to coordinate their research with that supported by other medical research charities and the Medical Research Council, as well as to communicate the results of this research to the charity’s executives and volunteers. However, in Britain, where a peculiarly large number of executive directors are ex-servicemen, scientists have found it difficult convincing them to pursue certain lines of research. The resulting tension between the scientific advisors and senior administrative staff can be appreciated from the following comments made by one scientist:

"The real problem with the charities is that the people in control are retired military types who are great fund raisers but know very little about science. They bring their military way of thinking to these medical research charities and
are convinced that you can find the cure for a disease by throwing money at it. I often hear them say "We've got to attack this problem with both barrels". As a scientist I would let our Executive Director fly me to America any day of the week but when it comes to medical research his judgement I respect not".

III. **Structure of Medical Research Charities**

Generalizing about the way in which medical research charities are organized in Britain and Canada is difficult for a number of reasons. First, the annual incomes of these organisations differ dramatically: in Britain of the AMRC's 35 members, the largest is the ICRF with £24.7 million, the smallest is the Back Pain Association with £121,789. Comparable figures from Canada indicate a similar disparity between the largest medical research charity - the Canadian Cancer Society with $3.5 million (£17.5 million) and the Canadian Foundation for the Study of Infant Deaths the smallest charity with $102,000 (£51,000). Figure 5.3 illustrates the distribution of British and Canadian charities expenditure on medical research. The difference in income between the two largest British and Canadian charities can be partly attributed to the population levels of each country. In Britain there are 31 million more donors.

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21 British Interview; February, 1984.


23 Income Tax Returns of Canadian Charities for the year 1982. Supplied by Revenue Canada upon request.
Figure 5.3

Income of Selected British and Canadian Medical Research Charities as a Proportion of Total Income

A. Britain

- Imperial Cancer Research Fund 20%
- Wellcome Trust 21%
- Cancer Research Campaign 28%
- Arthritis and Rheumatism Council 4.1%
- British Heart Foundation 10.4%
- Others 14.2%

B. Canada

- Canadian Cancer Society 33%
- Canadian Heart Foundation 22%
- Kidney Foundation of Canada 6%
- Canadian Diabetes Association 10%
- Other 27%

In light of this income disparity between small and large charities, many organisations have only a local presence in London or, in the case of Canada, a presence in Toronto or Montreal. However, of the 18 Canadian medical research charities interviewed, 13 had established branches throughout the country whereas all 26 British charities interviewed had representation in virtually every region of the country. However, in both countries, a national presence was facilitated through a three-tier structure that included local branches, regional offices (in the case of Canada known as provincial offices) and national offices. Given that most medical research charities were created by people actually suffering from the disease, many were established first at the local level. As the fund raising capacity of these branches increased, and as public awareness of the diseases they were representing grew, it was natural that many more local branches were created. As the number of branches increased and as research gained prominence over patient services, it became necessary to create regional offices to coordinate local fund raising campaigns and a national office to disperse systematically funds for research. Without a national office, local branches raising and distributing grants for research ran a greater risk of funding lower quality work, since each branch would not have the resources to second first-rate scientists to review grant applications. They also ran the risk of duplicating research funded by other branches, since communication among them would be poor. Thus, for British and Canadian medical research charities
whose main emphasis has been on research, the role of the national office has been to collect money raised by the local branches and to assemble a committee of experts to distribute funds to scientists.

It is interesting to note that some charities, like the British Spastics Society, which devote only a small proportion of their income to research, funds flow in the opposite direction - from the national office down to the local level (see explanation provided of Table 4.10). Sir John Cox - the Executive Director of this charity explained that there is a better understanding at the local level of how money can best be spent on those already suffering from cerebral palsy. However, the obvious question is why have predominately patient service oriented medical research charities adopted a 'national office' structure at all when presumably this would detract from local appeals? The same respondent answered this by explaining that a national office does perform several useful functions including helping to establish new local offices and negotiating government grants for individual branches from the central and local governments. Again, many national offices have lobbied government for legislative reforms on issues related to patient service (see chapter eight). Furthermore, since a national office of a predominantly patient service oriented charity disperses its funds to the local level, national fund raising appeals have not posed a threat to the

24British Interview; Spastics Society, 23 February 1987.
25Ibid.
autonomy of individual branches.

Canadian and British respondents were asked what advantages and disadvantages there were in adopting a three-tier structure. In both countries, there was a clear consensus that this type of structure greatly enhanced a charity's fund raising capabilities by giving them representation at the grassroots level. Most money is collected at the local level through sponsored walks, coffee mornings, garage sales and a host of other fund raising events. Surprisingly, though, a number of disadvantages were identified with this type of organisational structure. For example, the executive directors of several British and Canadian charities remarked that they had received criticism from the local and regional wings of their organisations when national direct-mail fund raising campaigns were launched. In several cases, the national offices were asked to discontinue these campaigns on the grounds that they were detracting from local appeals. In both countries, this type of complaint is symptomatic of strong affiliations that people have with the region in which they live. For example, Canadians tend to see themselves first as Maritimers, or as Quebeckers or as Westerners. With this type of mentality, it is difficult for national organisations to forge a consensus out of all the regional interests. The national wing of a Canadian medical research charity must position itself within the hierarchy of its member bodies, as its role is often defined in terms of dismantling the consolidated power of one region and sharing it with others. The tension between jealously guarded
local organisations and the national organisation reflects the same federal-provincial tensions which have been characteristic of Canada's political system since Confederation. Similarly, in Britain, a number of respondents spoke of a 'tartan curtain' and the difficulties encountered in administering a national fund raising effort that embraced Scotland, Northern Ireland and Wales. In both countries, problems have manifested themselves when national organisations have collected money from local branches and have been perceived to have distributed them disproportionately to researchers in those regions which 'house' a greater proportion of the scientific talent and research facilities. In Britain, these facilities are located in London, Oxford, Cambridge and several other large urban centres in the south. The thriving scientific communities in Canada are located almost entirely in Toronto and Montreal, to the exclusion of eight other eastern and western provinces. Despite the obvious point that, say, a cure for cancer found in London would benefit equally a person living in Wales or Scotland, strong pressure is nonetheless exerted on charities to fund research in all regions where money has been raised. As the following statement implies, at least one charity has succumbed to this pressure, and it would run the risk of being criticized if in the future it continued to fund research in a less prosperous region of the country should the quality of such investigations prove sub-standard.

"I think the (charity) would be reluctant to move away from a situation where there was no research
being funded within the University of Wales and its various colleges. This is not a problem now because there is some very good research being done there. However, if this last point were not true there would be a requirement to keep some research going. It is important for fund raisers in places like Wales and Northern Ireland to see that some of their money is going back locally." 26

Funds are also redirected back to the regions by charities to discourage the public from making donations instead to their local hospitals, which often administer their own research funds. Several of the larger British cancer research charities have been vocal in their criticism of the quality and cost-effectiveness of research funded in this way, since research projects tend not to be screened by peer review. The British Heart Foundation has had the added problem of getting local branches to raise money for research, since collecting funds for medical equipment, like defibrillators earmarked for a local hospital, has often been more popular. Other charities, like the Cancer Research Campaign (CRC), have avoided this problem by stripping local branches of their autonomy by making them remit their total annual proceeds to the national office and by enforcing strict regulations on the amount they are allowed to keep for their own fund raising activities. This arrangement has effectively limited the amount of pressure that local branches can place on national offices to fund research on a regional basis. Volunteers unhappy with this arrangement have had no legal recourse and consequently have

26British Interview; Cancer Research Campaign; 11 March 1987.
normally resorted to withdrawing their services. However, for the large cancer and heart research charities, the number of volunteers lost as a result of such disputes has not had a great impact on their overall operations.

While many medical research charities support research in certain localities to appease fund raisers, it is interesting that the Medical Research Councils in both countries also have the same policy but for very different reasons. Since the (B)MRC and (C)MRC derive their income from their respective Treasury each are tied to government policies aimed at reducing regional disparities. Consequently, in Britain the (B)MRC maintains units in universities located in every region (see Appendix III). When the (B)MRC failed to maintain one of its research units in the north west, during the Council's 1984 budget cutbacks, strong criticism by the media, succeeded in re-establishing this research centre. However, spokesmen from the Research Councils in each country emphasized that; "in determining what research should be funded, the question of quality of research has always dominated over the issue of where it should be conducted."²⁷ In Canada, proof of this statement lies in the fact that of the (C)MRC's 1986 budget totalling $161 million (£80.5 million) all of which is spent on grants to university based researchers $80 million (£40 million) of that went to the University of Toronto where the

²⁷British Interview; Medical Research Council, 2 April 1987; and Canadian Interview; Medical Research Council, 28 January 1987.
country's best scientists are employed. Having said this, it is nonetheless true that the (C)MRC's mandate is to provide funding for research in all of the 16 universities with medical schools. This policy is based on the premise that a good medical training involves research experience. In response to regional interests during the 1950's and 1960's, the federal government established a number of smaller universities through a series of transfer payments to the provinces. This allowed people to be educated within their own region instead of travelling to the older, more established, universities which are located in the larger urban centres like Halifax, Montreal, Toronto, Ottawa and Vancouver.

However, the problem with medical research, in which every country it is conducted is that the very best researchers gravitate towards the more established schools where salaries are higher, research facilities better and prestige more attainable. Since the early 1960's the (C)MRC has tried to counter this by offering 'development grants' to the smaller schools like Lakehead University located in Thunder Bay. In some isolated cases, (C)MRC officials admitted that this has been successful in luring 'top-notch' researchers away from the larger schools. One Canadian scientist was critical of this type of (C)MRC grant on the grounds that it tended to destroy 'centres of excellence'.

"If a researcher investigating heart murmurs working in a Dalhousie university laboratory leaves his colleagues and takes up a post in Saskatchewan it is impossible for economic

28 Canadian Interview; Medical Research Council, 28 January 1987.

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reasons to collaborate closely with him. Indeed, it would be easier to collaborate with him if he moved to Britain since he'd be closer."

The (B)MRC has been able to side-step this criticism, since, unlike the (C)MRC, the (B)MRC not only provides grants to university researchers but also maintains its own laboratories and research units housed in university science departments. As a result, the (B)MRC has the ability to shift entire teams of top-flight scientists to less prosperous regions of the country.

While the British and Canadian governments have both attempted to utilize their Medical Research Councils to help narrow the regional disparities in their respective countries, the Canadian government has gone one step further by offering grants to medical research charities enticing them to adopt a national profile. This is in sharp contrast to British medical research charities which are left to their own devices to establish a presence in all regions.

Through its Department of Health and Welfare the federal government initiated a programme in 1960 called 'Sustaining Grants for Voluntary Health Organisations'. The main thrust of the programme has been to encourage medical research charities to adopt a truly national perspective by establishing local branches and provincial offices in every region of the country. To alleviate regional disparities, the sustaining grants were

29Canadian Interview; McMaster University Medical School, 19 January 1987.
designed to allow medical research charities to ‘free-up’ some of their administrative budgets to create new local branches or get the services in ‘have not’ provinces like Newfoundland up to levels available in prosperous provinces like Ontario and Quebec. The maximum value of these grants can only equal 50 per cent of the medical research charity’s administrative costs – up to a maximum of $125,000 (£62,500). However, in the past, several newly established medical research charities have received grants equalling 70 per cent of the administrative costs, after it was decided they were providing essential services. This was justified on the basis that the value of the grant would be reduced to 50 per cent and ultimately to 20 per cent when the charity had established its own fund raising base.30

In 1982, the budget for this programme received a large increase, from $400,000 (£200,000) to $3 million (£1.5 million). This rapid expansion was indicative of the government’s recognition that medical research charities were providing a service that would otherwise have to be offered by government itself. At present, 20 medical research charities receive this grant, including charities that have overlapping aims and objectives such as the Canadian Alzheimer’s Society and the Huntington’s Society which both fund research into the neurological sciences.31 Of the 13 national charities interviewed


31 Ibid.
10 were in receipt of this grant and those that were not, were asked why. Three explanations were offered; first, large charities such as the Canadian Cancer Society and Canadian Heart Foundation had already developed a national presence and were therefore ineligible for the grant. Second, the charities commented that deriving income from government took an 'edge-off' their appeal to the public for voluntary donations. The extent to which charities publicize their financial independence from government further illustrates their belief that government money tarnishes an organisation's 'saleability' to the public. Third, the charities were reluctant to accept this government grant on the grounds that Health and Welfare demanded too much in the way of control and accountability. Surprise on-site visits were made by departmental officials and extensive annual reporting were required. In terms of control, the Department of Health and Welfare has refused in the past to renew grants when charities have failed to demonstrate 'suitable progress'; this may involve a charity failing to create new local branches, fund national conferences or fund a national information magazine. As one executive director pointed out;

"These are all very expensive ways of showing progress - sometimes more expensive than the dollar value of the government grant itself. For a $100,000 (£500,000) grant we may find ourselves developing new research programmes that cost us $250,000 (£125,000) simply to appease Health and Welfare officials in Ottawa. While we appreciate the availability of these funds the fact remains that government officials can indirectly determine our expenditure priorities through
The Canadian Government is active in influencing the national affairs of medical research charities through another programme—the ‘Promotion of Official Languages Programme’—administered by the Secretary of State. This government grant scheme which helps to defray the cost of translating a charity’s literature into English or French, had its origin in the ‘official languages policy’ formulated by the Liberal government in the early 1970’s. The only organisations qualifying for this assistance are registered charities with a national agenda, which operate in either of the two official languages and want to provide services to the public (normally fund raising campaigns) in both English and French. As an added condition, recipient charities must have a bilingualism clause as part of their articles of association. This protects against the possibility of a new administration taking over a charity and abandoning a bilingual policy thereby wasting previously invested government money.

After completing interviews with Canadian medical research charities the data revealed that of 13 national organisations interviewed eight held grants in tandem from the Department of Health and Welfare and the Secretary of State. Throughout the interviews, an effort was made to ascertain the degree of co-ordination between these two government departments; that is, whether a charity in receipt of one government grant was in a

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32Canadian Interview; January 1987.

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favourable position to receive funds from another. Officials from both departments acknowledged that each programme operated independently from the other, but that it was natural for officials dispersing grants to be biased towards supporting charities that had already received the financial 'blessing' of another government department. Departmental spokesmen from each agency also admitted that historically there had been little contact between the two, despite the fact that the raison d'être of both programmes has been to encourage the growth and development of nationally focused charities. However, it was added that during 1986, a movement in the direction of more inter-departmental coordination had been spawned through the creation of a committee designed to liaise between the Programme Directors of each department.33

When comparing British and Canadian medical research charities it is important to argue that, while the level of government subsidies to Canadian charities is much higher, they must be viewed in terms of the problems they seek to address—namely, the presence of two cultures, as well as the economic disparities between each of the ten provinces. Given these two features, the economic costs incurred by Canadian charities seeking a national presence are clearly greater than their British counterparts. In other words, the higher level of federal government support to Canadian medical research charities in

33Canadian Interview; Department of Health and Welfare, 30 January 1987, and Canadian Interview; Secretary of State, 29 January 1987.
comparison to the complete absence of comparable support offered by the British government must be understood in the context of Canada’s distinct culture and geographic size.

IV. Fund Raising Capabilities of British and Canadian Medical Research Charities

The amount of money that individual medical research charities are able to collect from the general public depends on a number of different factors. For example, whether the disease is contagious, affects children, or is confused with other diseases. Appreciating how British and Canadian charities market themselves to the public sheds some light on why there is a disparity between the incident rates of specific diseases and the amount of money both charities and government commit for research purposes. Furthermore, by examining the reasons for this disparity, we can understand why British and Canadian medical research charities lobby their respective governments to increase research expenditures into the specific disease they represent. The examination of how medical research charities raise funds is divided into two sections. The first section considers a charity’s organisational features, while the second takes account of the advantages and disadvantages of the ‘nature’ of the disease being represented.

A. Organisational features

As discussed earlier, charities adopting a three-tier structure are more successful in raising funds since they have representation at the local, regional and national levels.
Furthermore, the more success a national office has in creating local branches the more money it is likely to raise. Finally, a charity's income is normally directly proportional to its number of volunteers; for example the Canadian Cancer Society with 130,000 registered volunteers has a far greater fund raising capacity than the Parkinson Foundation which has only 1,000.34

When comparing the fund raising efforts of British and Canadian medical research charities it is clear that each enjoys both advantages and disadvantages in relation to the other. For example, in Britain medical research charities, indeed all charities, are restricted from advertising on television.35 In Canada, not only is this permitted but often advertising companies and television networks will donate their services free of charge as a 'corporate gesture of goodwill'. In 1985, the Canadian Mental Health Foundation increased its income by 22 per cent after launching a six week television advertising campaign. Because the cost of producing the commercial and showing it on television were largely covered by corporate sponsors, the Foundation claims it spent only three cents to raise one dollar.36


35Both the Charities Aid Foundation (CAF) and the National Council For Voluntary Organisations (NCVO) have lobbied for this law to be relaxed. Both organisations are optimistic that by 1989 the Central Government will consider lifting a partial ban on charity television advertising.

36Canadian Interview; Canadian Mental Health Association, 18 December 1986.
The main advantage that British medical research charities enjoy over their Canadian counterparts is the absence of any legal restriction on the amount of money that can be expended on administration. In Canada, charities are permitted to spend a maximum of 10 per cent of their annual income on 'administration'. Clearly, this gives smaller British charities the flexibility to spend more money on advertising, particularly during the early years of their existence when it is critical to develop a public profile. Even larger, more established, British medical research charities can benefit from having annual capital expenditures in excess of 10 per cent. For example, they are able to finance large projects like the purchase of a new administrative building independently of a bank or a building society. In Canada, a charity wishing to purchase a comparable facility would have to do so by taking on a long-term mortgage whereby a maximum of 10 per cent of its total annual income could be directed at paying this mortgage off. This is a disadvantage to those Canadian charities which have the resources to fund large projects in a given year, because instead they must pay interest on a loan in order to comply with charity law. The rationale for this law is that it deters charities from spending large proportions of their income on non-charitable purposes such as administration.

One fear expressed by a number of British medical research charities concerns permissible television advertising. Organisations might spend exorbitant amounts in order to stay competitive with other charities vying for the donations, and
could do so because there is no ceiling on administrative costs they may incur. However, the counter-argument offered by one British charity executive was that expenditures on items like advertising are closely monitored by volunteers, the media, consumer interest groups and by the donating public.37

Throughout interviews conducted in Britain, several respondents suggested that there was a far more serious fund raising problem. This involved medical research charities that did not spend a large proportion of their income on charitable purposes, but rather invested money in the stock market and in term deposits to generate future income. Volunteers and the donating public have always objected - sometimes by withholding further services or donations - when money has been directed into savings accounts instead of being expended immediately on charitable purposes.38 This has not been an issue in Canada since Income Tax laws require charities to disperse 90 per cent of their annual receipted income on their charitable purposes. This last

37British Interview; National Fund for Research into Crippling Diseases, 4 March 1987.

38In interviewing a spokesman from the Cancer Research Campaign (CRC) it was explained that in 1980 the charity had been the target of a media campaign on the issue of abuses of publicly donated funds. The main criticism levelled at the CRC was not that it was in efficient or wasteful but that it was not immediately applying the money it had collected to address the ‘so-called’ urgent problems associated with cancer. One of the main promises appearing in the CRC’s fund raising literature was that ‘money would be spent to ensure that cancer patients would benefit from the fruits of research as speedily as possible.’ When it was publicized that this was not the case, the number of people willing to donate their voluntary services to the CRC decreased. British Interview; Cancer Research Campaign, 11 March 1987.

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regulation, is aimed at ensuring that Canadian charities spend
donated funds ‘immediately’ on the charitable projects for which
the public is often prompted to support on the understanding that
a particular ‘need’ is current. The most frequent complaint made
by Canadian charity executives is that this rule makes long-term
budgeting and financial stability problematic.39

In reviewing the Charities Aid Foundation’s 1984/85 Annual
Report it is clear that the above criticism is not simply directed
at British medical research charities. For example, in the area
of third world relief, Bob Geldof’s Band Aid Trust which spent
only one-third of the £69 million raised in 1985, has deliberately
held back money to fund longer term development. This has been
justified on the grounds that the aim was not only to relieve the
current famine but to prevent future ones. Save the Children’s
Fund has given similar reasons for the fact it spent only 61 per
cent of the £42 million it raised in 1985.40

Beyond the area of medical research and third world relief,
the NSPCC spent only 57 per cent of its £21 million income.
Though its income rose £7 million between 1984 and 1985, spending
went up by only £500,000. The National Trust’s income exceeded
its spending in 1984 by £14 million, the Salvation Army’s by £13
million, Doctor Barnardo’s by £6.3 million and the Royal National
Lifeboat Institution by £6 million. Table 5.3 provides a rank

39Canadian Interview; January 1987.
40Charities Aid Foundation Charity Statistics, 1984/85.
Table 5.3

Expenditure Record of the Lowest-Spending British Charities listed in the 'Charities Aid Foundation's Top 200 Charities'

<table>
<thead>
<tr>
<th>CHARITY</th>
<th>1985 INCOME (£m)</th>
<th>% OF INCOME SAVED OR INVESTED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Band Aid Trust</td>
<td>69.0</td>
<td>66%</td>
</tr>
<tr>
<td>National Society for the Prevention of Cruelty to Children</td>
<td>21.2</td>
<td>43%</td>
</tr>
<tr>
<td>Save the Children</td>
<td>42.7</td>
<td>39%</td>
</tr>
<tr>
<td>Salvation Army</td>
<td>43.3</td>
<td>30%</td>
</tr>
<tr>
<td>Imperial Cancer Research Fund</td>
<td>32.4</td>
<td>26%</td>
</tr>
<tr>
<td>Royal National Life Boat Institution</td>
<td>25.8</td>
<td>24%</td>
</tr>
<tr>
<td>Dr. Barnardo's</td>
<td>42.8</td>
<td>23%</td>
</tr>
<tr>
<td>National Trust</td>
<td>70.2</td>
<td>20%</td>
</tr>
<tr>
<td>Royal National Institute for the Blind</td>
<td>23.1</td>
<td>20%</td>
</tr>
</tbody>
</table>

ordering of the lowest spending British Charities in 1985.41

B. 'Marketing' disease

Organisational features are just one dimension in understanding the fund raising success of charities. In the context of medical research charities, another important dimension is the 'nature' of the disease being represented. In many cases more money is raised by charities on behalf of 'socially popular' diseases where incidence rates are lower than for 'socially unpopular' diseases where, conversely, incidence rates are high. The argument is made in the following chapter that the level of government support for research is determined in a broadly similar way. Thus popular diseases such as 'cancer' and 'heart' receive more funding when compared with more prevalent, yet less popular and horrific diseases, like schizophrenia or bowel disease. Additionally, it is because of this disparity that medical research charities have increased their lobbying activities to encourage more government-sponsored research into the disease areas they represent. Some of the arguments developed by political economists might shed some light on why people make voluntary contributions. For example, Becker suggests that the act of giving may be only apparent charitable activity motivated by a desire to avoid the scorn of others or to receive social acclaim.42 Similar suggestions have been made by Johnson and

41 Ibid.

Olson, yet neither can explain why some kinds of charitable activities attract voluntary contributions more easily than others. It is the purpose of this section to explain why, for example, the cancer research charities are able to raise twice the amount that heart research charities can, despite the fact that far more people die of chest, heart and stroke diseases than do from cancer.

Charities representing diseases where the 'cause' is known, such as certain types of cancer, are able to launch public education campaigns which not only provide a valuable service but are also a tremendous fund raising tool. For charities representing diseases where the cause is unknown and public education campaigns are unable to be organized, the level of public understanding of the diseases is diminished. As a result, charities representing diseases like multiple sclerosis, muscular dystrophy and cystic fibrosis are commonly confused with each other. To increase their fund raising capabilities these types of charity have made their first priority that of assisting the public in differentiating between what are incorrectly viewed as closely related maladies. But knowing what causes a disease, and being able to educate the public about how it can be prevented, has its own limitations as demonstrated by the early response to the AIDS problem. With AIDS, its 'causes' and 'prevention' were

known yet because the disease was originally thought to be confined to homosexual men the level of charitable support for research into AIDS was limited. It was only after further epidemiological studies\textsuperscript{44} revealed that heterosexuals, haemophiliacs and drug users were susceptible to the virus that charitable giving to organisations like the Terrence Higgins Trust in Britain garnered stronger public support. Indeed, the British and Canadian governments' protracted delay in responding with funds for AIDS research indicates that governments are influenced by similar factors.

The 'class of people' affected by a disease can pose serious problems for fund raisers, as in the case of AIDS. It is also true that this factor can be used to a charity's advantage, as is evident in the extensive use of children as a fund raising tool by British and Canadian medical research charities. The British Heart Foundation, which actually supports coronary research for those aged 35 and over, nonetheless used a picture of a baby on the cover of its 1985-1986 Annual Report. However, charities collecting money for research into cot-death do not advertise the suffering of the child in their fund raising campaigns. An interesting explanation for this was offered.

\textsuperscript{44}Epidemology is defined as "the science which investigates the cause and control of epidemic diseases". Through empirical methods epidemiologists factor into their study of diseases many different variables in order to determine its cause and spread. For example, with AIDS, the sexual orientation, diet, region, occupation and social habits (such as drug addiction) of those already infected, helped scientists to better understand the 'cause' and 'prevention' of this virus.
"With cot-death a child will die suddenly in his/her sleep; it is seldom that any will recover ... therefore all that is left is a grieving family. Where many cancer and heart patients live for a protracted period of time and are often cured, multiple layers of people surrounding those patients are affected including friends and family. However, cot-death strikes quickly and invariably kills every time, so where the cancer and heart charities can sell the 'suffering' we are left selling 'death' or the grief of stricken parents - something we have adamantly rejected. Instead, we have raised far more money by launching positive campaigns."

The standard advertising formula adopted by most Canadian and British medical research charities, particularly in the daily newspapers, is to demonstrate first the scope of the problem, by providing figures on the number of people suffering from the disease. This is done to impress in people's minds the seriousness of the problem. During interviews it was suggested by respondents that the advice given to medical research charities by marketing agencies is to frame their disease as a 'public health problem'. Charities benefiting most from this strategy are those representing diseases that are 'contagious', those that inevitably result in death, and those that involve long periods of suffering and diseases with incident rates which are already high or are increasing. It is these factors, individually or in combination, which determine a charity's success in 'shocking' the public to

45Canadian Interview; Canadian Foundation for the Study of Infant Deaths, 8 January 1987.
respond with their pocket-books. But 'scaring' the public into believing that they could be the next to contract, say, kidney disease or cystic fibrosis is only one part of their message. Equally important is the idea that the disease is not insurmountable, and that with money donated for research the disease can be conquered. Hence, there are slogans that 'cancer can be beaten' and 'where there's a will there's a way'. Despite this marketing strategy, there are diseases that still encounter difficulties attracting public support. A disease such as mental health, which affects many more people than cancer, and which involves longer periods of suffering (often leading to death), nonetheless encounters problems raising voluntary contributions for research. Despite the large number of sufferers, inflammatory bowel disease, and other gastroentological diseases have similar debilitating effects are viewed as being so horrific and unappealing to discuss that public financial support is limited.

One hypothesis to explain this is that people associate themselves with a disease when making a contribution in aid of research. This argument is better understood by looking at the fund raising history of the cancer research charities. It has only recently become evident that people are able to speak publicly of having cancer without embarrassment. In other words, cancer has been promoted to a 'legitimate disease'; it has been demystified through vigorous education campaigns with the result that people are not afraid to contribute to this cause. The success of the cancer charities has been in striking the right
balance between fear and hope in the minds of the public. Medical research charities like the one representing bowel disease have not progressed this far, since the public is uniformed of how the disease is caused and the possibility of finding a cure. As one respondent noted:

"It will probably take a famous movie star to come forward and talk publicly about their bowel disease or schizophrenia before the public feels comfortable with these causes. After all it worked with Patricia Neil with stroke, Rita Hayward with alzheimer’s, and most recently Rock Hudson with AIDS".

Again, diseases like leprosy affect millions of people yet because it is perceived correctly to be confined to people living in developing countries its appeal to the British and Canadian public is diminished. The diabetes research charities encounter special problems: people incorrectly believe that insulin represents the ‘cure’ for diabetes, rather than a means of containing the disease, and that money donated for research is therefore wasted. While diabetics must suffer through daily injections of insulin — often developing other medical complications because of this — charities in both countries are unable to market this suffering since thousands of diabetics live long, and relatively normal, lives and object to ‘shock advertising’. One in five blind people in Britain became blind as a result of diabetes, but the public is unaware of this since the

46Canadian Interview; Alzheimer Society of Canada, 10 February 1987.

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British Diabetic Association and Canadian Diabetes Association refrain from publicizing this as part of their fund raising campaign. In the words of the Executive Director of the British Diabetic Association:

"Of our 110,000 volunteers, the vast majority are diabetics who repeatedly insist that our advertising campaigns should avoid shocking those afflicted, particularly children suffering from juvenile diabetes."  

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These charities are less successful in producing the 'trauma' that makes people frightened of contracting diabetes, and hence they are less successful in raising voluntary donations. The 'genetic' nature of diabetes has meant that the British and Canadian diabetes research charities have developed into self-help groups for family (and the extended family) with a single mission — to save the lives of their children.

Another factor to consider when assessing a medical research charity's fund raising potential, is whether or not other charities are funding research in the same disease area. The multiplicity of appeals by British cancer research charities has confused the donating public. Proof of this lies in the number of vague bequests made in wills for 'cancer research' which end up tying the six cancer research charities in litigation over the titlement of these funds. While there are several Canadian charities with slightly overlapping research objectives, such as

47British Interview; British Diabetic Association, 2 March 1987.
the Canadian Geriatrics Research Society and the Canadian Institute of Gerontology, all nonetheless have very different research foci. In Britain, the problem of competition among charities representing the same disease is slightly greater. Apart from cancer there is another disease area where there are several charities with overlapping aims; there are two organisations that collect funds for heart disease research: the British Heart Foundation and the Chest, Heart and Stroke Association. In interviews, the executive director from each of these organisations made the point that having two charities funding identical research, does tend to limit the fund raising capacity of both charities.48

In 1961 the British Heart Foundation was formed as an offshoot from what was then the Chest and Heart Association. After 15 years of direct competition between the two charities in the area of ‘mainstream heart research’ the Chest and Heart Association decided to redirect its focus by funding stroke research. To make a clearer distinction between itself and the British Heart Foundation it was re-named the Chest, Heart and Stroke Association. While this move has limited the possibility for the duplication of research, it has done little to lessen the confusion in the minds of those wishing to donate money for heart research, since both charities retain the word ‘heart’ in their title. Correcting the public’s perception of duplicated research

48 British Interview; Chest, Heart and Stroke Association, 20 February 1987; and British Interview; British Heart Foundation, 3 March 1987.
has been a priority of both organisations - as the Research Director of the British Heart Foundation stated:

"We must advertise the special qualities of the British Heart Foundation; this is critical since the public are getting wiser and more prudent with their donations; they simply do not want to give to a cause where duplication of research is a possibility."

Both charities admitted that careful coordination of national fund raising campaigns was absolutely essential to avoid further confusing the public. As a result, the Chest, Heart and Stroke Association avoids sponsoring fund raising events during the British Heart Foundation's London to Brighton annual bike ride which normally raises £500,000. While direct competition between charities is limited to the disease areas of cancer and heart, the following chapter illustrates the need for cooperation and coordination, between all medical research organisations and the Medical Research Councils in each country.

V. History of Government Involvement in Medical Research

Presently, the British and Canadian governments' direct involvement in medical research is executed entirely through the Medical Research Councils in each country. The (B)MRC and (C)MRC are charged by their respective governments with the promotion of research aimed at advancing knowledge in the bio-medical field. They also advise the government departments on matters requiring

49British Interview; British Heart Foundation, 3 March 1987.
special investigation. Furthermore, their members are appointed in a manner that largely ensures their status as an independent scientific body, but members are nonetheless susceptible to some political influences in special disease-related research programmes such as that involving AIDS. A review of their origin, development, financing and present structure facilitates an examination of charity-state interaction in the area of medical research.

A. Medical Research Council in Britain [(B)MRC]

It was not until the 20th century in Britain that, following the 1911 National Insurance Act, the Medical Research Committee (1913-1920) was created. As immediate antecedent of the (B)MRC, the formation of the Committee was the single most significant step in the formation of the structure supporting a modern research community. After the First World War the Ministry of Health Act (1919) provided the basis for the formation of both the (B)MRC and the new Ministry of Health. A central facet of the relationship between the two was the Haldane – Addison principle that scientific research should be free of immediate ministerial direction (a provision at the start ensured by the fact the (B)MRC operated under the aegis of a Committee of the Privy Council).

In 1965 this arrangement was changed in that responsibility for the funding of the (B)MRC was placed in the hands of the


51Ibid., p. 6.
Secretary of State for Education and Science. But the (B)MRC has never been controlled by the Ministry/Department of Health. The two bodies have retained distinct roles defined in a mutually acceptable concordat. Appendix IV shows the first version of this agreement, privately drawn up in 1924 between Sir Walter Fletcher and Sir George Newman. However, the agreement was not made public until 1928.

To many commentators, the achievements of the (B)MRC appear to justify fully the independence it was given initially and has retained. This confidence is reflected in the fact that it served as the model for the formation of other research management agencies: the Agricultural Research Council (ARC), the Science and the Engineering Research Council (SERC, formally the SRC), the Natural Environmental Research Council (NERC), and the Economic and Social Research Council (ESRC, formally SSRC). The Research Council's total proportional U.K. spending in 1979-80, including funds from all sources is given in Figure 5.4. The purpose of the (B)MRC has been to promote the balanced development of medical and related biological research in Britain. It is advised by a Neurological and Mental Health Board, a Cell Biology and Disorders Board, a Physiological Systems and Disorders Board and a Tropical Medicines Research Board. The (B)MRC's grant-in-aid from the government for the year 1983-84 was £113.5 million out of a total allocation to the Research Councils of £500 million. It is the recipient of the second largest sum; the highest grant in aid
Figure 5.4

The Research Councils' Total Proportional UK Spending in 1979-1980

The financial allocations for research recommended by the boards of the (B)MRC are of three types. First, the Council awards project or programme grants to non-council employees, almost exclusively university employees, in response to applications submitted to it. This accounts for 36 per cent of the expenditures in support of research. Second, the (B)MRC employs full-time staff to work in (B)MRC units located within a university campus. This accounts for a further 30 per cent of the (B)MRC's research expenditure. Finally, the (B)MRC supports work undertaken by its own full-time employees in its own institutes and units located outside the universities. These include the Institute for Medical Research at Mill Hill, the Clinical Research Centre, Northwick Park Hospital and several other smaller establishments. Together they consume some 34 per cent of the Council's research expenditure. Prior to 1960, the (B)MRC made the decision to establish its own research centres since the existing facilities for university-based scientific research were inadequate. However, when university facilities were improved and expanded in the 1960's, the need for separately controlled and financed (B)MRC facilities decreased. In comparison to Britain, the (C)MRC does not have its own 'in-house' research facilities. Consequently, all Canadian government support for bio-medical


53British Interview; Medical Research Council, 2 April 1987.
research funded through the (C)MRC is conducted in universities. In light of the (B)MRC having its own in-house laboratories it enjoys a number of advantages over its Canadian counterpart. First, scientists working in these laboratories can devote all of their time and energy into high quality research since they have no teaching responsibilities. Second, the (B)MRC utilizes its own laboratories to support outstanding individual researchers to free them from other commitments. Such appointments are often designed to offset the emigration of top-flight scientists to countries like the U.S. where salaries and laboratory conditions are better. The problem with 'brain drain' in the field of medical research is discussed in chapter seven section I. Third, research conducted in a (B)MRC laboratory is more 'directed' than that funded in universities or hospitals. Indeed, the (B)MRC can exert greater control over a scientist's research programme if that person is employed directly in one of its three research establishments. As outlined in chapter six section III. A, this has given the (B)MRC a tremendous advantage over the (C)MRC in responding to the AIDS crisis.54

In interviews, officials at the (C)MRC offered an explanation for the absence of in-house facilities. It was argued that the (C)MRC's history has prevented it from emulating the British model, since the (C)MRC has been enormously successful from a cost perspective in providing university researchers with various types of grants. As one (C)MRC respondent stated;

54Ibid.
"If we started opening our own laboratories, as they have in Britain, then we would have to bear the cost of laboratories, technicians, equipment, researchers and an entire administrative staff to manage these in-house facilities -- this is simply not realistic given the present political climate which would like to see the private sector assume more responsibility for medical research."

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The reason why a similar structure to the (B)MRC was not adopted by the (C)MRC is symptomatic of Canada's federal system. Because Health and Education are provincial responsibilities, the federal government [through the (C)MRC] must utilize provincial institutions like universities and hospitals in its funding of medical research. If the federal government had adopted the British model entirely, by making provisions for (C)MRC laboratories, it would have been viewed as encroaching into the provinces responsibility for 'health'. Canada's federal system has also affected the 'type' of medical research which the federal government is able to support through the (C)MRC. In Britain, a very small proportion of the total work conducted in (B)MRC laboratories is 'applied research' such as the work done in their Common Cold Unit which has the potential to yield immediate results affecting the health of British citizens. In Canada, the (C)MRC is precluded from funding 'applied research'; instead, it must limit itself to funding very 'basic or fundamental' biomedical investigations. For example, the (C)MRC supports

55Canadian Interview; Medical Research Council, 28 January 1987

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scientists conducting basic research in the neurosciences and those examining protein structure and function. This 'basic or fundamental' research does not encroach into the provincial domain of 'health care', since any discovery would not immediately affect the health of people living in the province. While the Canadian federal system gives the provinces considerable responsibility for applied research, very little is actually funded by the ten governments. Instead, this type of bio-medical research has been funded primarily by the medical research charities.

Understanding the British government's present commitment to scientific research in universities via the (B)MRC, necessitates an explanation of the 'dual support system'. This system is not unique to medical research; it is the primary means by which all academic research is undertaken in Britain. The two components of the dual support system are the universities and the research councils; both operate in the public sector.

All universities now obtain their primary funding from government. The government department accountable for this expenditure is the Department of Education and Science. However, money does not pass directly from the department to individual universities. There is an intermediate agency, the University Grants Committee (UGC). The terms of reference of the UGC, established in 1919, are:

"to inquire into the financial needs of university education in Great Britain; to advise the government as to the application of any grants made by Parliament towards meeting them; to collect, examine and make available..."
information relating to university education throughout the United Kingdom; and to assist in consultation with the universities and other bodies concerned, that preparation and execution of such plans for the development of the universities as may from time to time be required in order to ensure that they are fully adequate to national needs."

As the terms of reference imply, the UGC advises the Secretary of State for Education and Science, on the financial needs of the universities. It also has the responsibility for dividing the budget provided by government and notifying the individual universities of their allocations.

The chairman and members of the UGC's main committee are academics, the Chairman being on secondment. The Secretariat is provided by the civil service. To assist it in its work, the UGC has a number of sub-committees, one of which is the medical sub-committee. Whilst the UGC has the responsibility for allocating funds to each university, it does not indicate how those funds are to be used. Each university has a degree of autonomy in the use of its 'grant-in-aid' yet is required to make annual returns outlining how the grant has been spent. In the year 1982-83 the UGC divided £1,250 million amongst all universities in the U.K. The 19 universities having medical schools spent £130 million on their clinical and preclinical departments where the vast majority of university-based medical research is conducted. Of this

56 Buller, The Organisation of Medical Research. p. 189.
amount, 70 per cent represents the cost of staff salaries. The remaining 30 per cent is available for the recurrent teaching and research costs during the year. 57

A basic tenet of the dual support system is that the universities should, by means of the grant in aid, provide 'well-found' laboratories - that is, the physical plant, including modern equipment and consumables, support staff, (both technical and secretarial, and academic staff with time available to permit them to undertake research). The second arm of the dual support system is the group of five research councils. Like the others, the (B)MRC receives its income, from the Department of Education and Science. Again, rather like the UGC in the case of universities, there is a buffer between the government department and the (B)MRC. This is the Advisory Board for the Research Councils (ABRC). According to the DHSS' Chief Scientist from 1977-81 the ABRC was established in 1972 with the following terms of reference.

"A) To advise the Secretary of State of its responsibilities for civil science with particular reference to the research council system.

B) To advise the Secretary of State on the allocation of the science budget among the research councils.

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57 Association of Medical Research Charities, Annual Report, 1986, p. 5.
C) To promote close liaison between councils and the users of their research."

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The ABRC determines the distribution of the science budget between the research councils. Each research council is accountable to the ABRC for the use to which it put its money, though it has considerable autonomy in determining expenditure priorities. This system contrasts with Canada in that the three councils in that country all report directly to the federal Parliament without passing through an intermediary agency. The distribution of funds among all the Canadian research councils is left to Cabinet to decide. This decision is ultimately influenced by advice received from the Treasury Board and other government departments where scientific research overlaps with departmental mandates.

In Britain, the Department of Education and Science, and succeeding Secretaries of State, have always paid lip-service to the maintenance of the dual support system for medical research. During the early stages of the reduction in UGC funding to universities (1980), it was stated that this reduction would be counter-balanced by continuing growth in the sum made available to the ABRC and hence the research councils. However, that growth has not continued. Since 1983 the (B)MRC has faced a serious financial situation (see Figure 7.4). Due to an insufficient

increase in the grants-in-aid, the effective spending power of the Council was reduced by £2 million in 1983 from what would have been required for level funding. The (B)MRC has been forced to place stringent financial constraints on its own institutes and units; its support for medical research in the universities has also declined substantially. It is apparent that with a decrease in real terms of the grants in aid to the universities and the (B)MRC, the support for medical research provided by the dual support system is under great strain. Indeed, when interviewed the (B)MRC spokesman stated that it can no longer fund some of the applications submitted to it, even though these have been scored 'alpha' by referees and grant committees. Consequently, medical researchers have turned to alternative sources of funding such as medical research charities to sustain existing research programmes. This shift in support of medical research from the public to the private sector has inspired medical research charities to become more vocal in criticizing government cutbacks to the dual support system. In chapter seven section I. A and B, we examine the increasing lobbying activities of British medical research charities on this issue.

B. Department of Health and Social Security (DHSS)

There is presently only one major source of public sector funding for medical research in Britain, however this has not always been the case. For many years a small sum of money has

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59 British Interview; Medical Research Council, 2 April 1987.
been available annually to the Chief Medical Officer at the DHSS (formally known as the Ministry of Health) to be used for research at his discretion. However, this money has always been too small for Departmental officials to organize a major research effort around their own interests. In an effort to change this, Lord Rothschild as head of the Central Policy Review Staff (the 'Think Tank'), urged the government in 1971 to adopt a customer-contractor relationship with the research councils for its R & D programmes. Lord Rothschild's report recommended the transfer of money from the civil science vote to the budgets of government departments so that the recipients would become more able to influence the work done by the research councils. Among scientists, its publication evoked considerable debate concerning the utility of the 'customer-contractor' principle.60 The (B)MRC, in particular, stated that the method was inappropriate for the prosecution of bio-medical research. The DHSS, unconvinced by this argument, enumerated a list of topics (prepared in 1972) including arthritis, rheumatism, hearing, heart disease and stroke, mental health and low back pain in which they had been unable to obtain an adequate research effort, as perceived by themselves, from the (B)MRC. In July 1972 a government White Paper was published.61 It reaffirmed the government's intention of extending the customer-contractor approach to all its applied

60 British Interview; Blonde McIndoe Centre for Medical Research - Research Scientist, 26 February 1987.

research and development. The White Paper described the intentions of the DHSS to set up a Chief Scientist's Organisation and indicated that, after a transition period, the DHSS would acquire control of approximately 25 per cent of the (B)MRC's previous income from the science vote.62 Rothschild's proposals were first put into practice in 1974 but were dismantled in 1981. For a variety of reasons the DHSS never became an effective customer, certainly not in the bio-medical field. In an interview with the government's Chief Scientist (1978 - 1981) an explanation was offered as to why the Rothschild agreement failed.

"It was apparent to all that this arrangement just simply was not working - because there was nobody in the DHSS who could tell the (B)MRC sensibly what it wanted done. Stated differently the (B)MRC knew its job better than did DHSS. When I was Chief Scientist I had the embarrassing job of forwarding research request from DHSS to the (B)MRC of the kind which included statements like 'we would like a cure for schizophrenia' - but who at that time didn't want a cure ... it was ridiculous since these requests didn't help the (B)MRC at all. It soon became evident that money had to be transferred back from the DHSS to the Department of Education and Science - it had to go from one government department to another, it being done on the understanding that the DES would put this money into the civil science budget, and that having being given to the ABRC it should be rescheduled back to the (B)MRC from whence it came."

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In Canada, the parallel government department to the DHSS-

62Ibid., p. 6.

the Department of Health and Welfare (DHW) - has never experimented with anything comparable to the Rothschild's customer-contractor principle. By returning to the pre-Rothschild arrangement in 1981 whereby the (B)MRC was free to set its own research priorities, the British government's organisation of medical research became virtually identical to Canada's. The only two major differences now are that the (B)MRC is responsible to the Department of Education and Science through a buffer body (the ABRC), whereas in Canada the (C)MRC is directly accountable to the Department of Health and Welfare. In addition, there is a lack of uniformity between the two countries in the government departments overseeing the Medical Research Council in each country. In Canada, there is no federal government department for 'education' since this remains a provincial responsibility.

C. Canadian-Medical Research Council (C)MRC

The history of the (C)MRC is similar to that of the (B)MRC. Indeed, in interviewing a (C)MRC official the idea was supported that the (C)MRC was modelled closely on its British counterpart; the similarity of names was no accident. Its formation in 1960 was a culmination of a series of events dating back to 1921. In that year, the major discovery of insulin in a Canadian laboratory opened up research possibilities in virtually every field of biomedical research. In 1925, the National Research Council (NRC) established a special joint committee with the Department of Agriculture, which had been spending large sums annually on bovine tuberculosis, to study, both the relation of this to Human
tuberculosis and also the means by which they might be mastered. For many years funds were provided for trials of a vaccine undertaken in several Canadian research centres. The next major step towards federal support for Canadian medical research was not taken until 1936. General A.G.L. McNaughton, president of the NRC, supported by the Canadian Medical Association and the Royal College of Physicians and Surgeons of Canada, established an Associate Committee on Medical Research (ACMR) with the NRC. This committee was chaired by a leading British scientist of the day—Sir Frederick Banting; its Secretary was Dr. Chester B. Stewart, and it had a meager budget of $53,000 (£26,500) that was distributed mostly for research grants.64

The 'adolescence' of medical research in Canada ended abruptly with the outbreak of World War II. The newly formed ACMR had to suspend the federal programmes then being planned for medical research in the universities. Furthermore, the ACMR divided itself into several sub-committees, each devoted to solving specific medical problems confronting the various branches of the Armed Forces. As in most other Western countries during this period there followed a great surge of activity in the field of medical research.65

As was the case in Britain, the need for war-related research forced the Canadian government to rely upon university professors to conduct investigations into new areas of medical research—

64Medical Research Council, Newsletter, p. 5.
65Ibid., p. 6.
most notably, areas that addressed injuries suffered in modern warfare.

"University professors made up most of the various committees and directed the researchers; they were assisted by colleagues who had joined the services and were seconded to investigative work. University laboratories and their personnel were used for most investigations. This focus on research in the universities was continued after the war. In both countries, peace brought freedom to the universities to resume more basic and fundamental research activity. Much new equipment had been installed for war researchers, technical personnel had been trained in its use; young medical graduates who had been in the services clamoured for graduate training; there remained only a need for increased financial support."

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In 1948, the Department of National Health and Welfare instituted a system of health grants, part of which could, with provincial approval, be used for the promotion of university research in specific areas such as child and maternal health, mental health, and cancer. In that same year the Defence Research Board was established and through its medical section, the government began to increase the amount of federal funds channelled to the universities in support of medical research that was related to defence problems. Two years later, the Department of Veterans' Affairs established a programme for the support of special areas of medical research to be carried out in its own hospitals across the country, and often under the direction of investigators who at the same time held university appointments.

66Ibid., p. 6.
As mentioned in section II, the growing public interest in the advancement of medicine at that time was reflected in the establishment of a number of medical research charities. Substantial sums raised from public campaigns by societies concerned with cancer, heart disease, arthritis and rheumatism were devoted to research in these special areas. While these charities, both large and small, made an important contribution in providing funds for service and research, they also made another type of contribution, which was just as important as the financial one. They stimulated public interest in research which brought many to a realization of its value in achieving a better standard of health for Canadians.67

The definitive steps towards the formation of an autonomous (C)MRC were taken in 1957. Dr. D.H. Copp writes,

"The Association of Canadian Medical Colleges sent to the newly elected Prime Minister, the Right Honorable John Diefenbaker the following resolution; that the Association of Canadian Medical Colleges, representing, through their deans, the twelve Medical schools of Canada, finds that federal support for medical research is alarmingly inadequate to support those investigations which are now in hand, and those which, in the public interest, should be undertaken, and asks the Prime Minister to increase the funds available to the Medical Division of the National Research Council in his first budget, by at least $500,000 (£250,000)." 68

67 Canadian Interview; Medical Research Council, 28 January 1987.
According to the (C)MRC's 1969 Annual Report, this letter was followed by direct representation to Cabinet by a delegation from the ACMR. The response was prompt; the budget of the Division of Medical Research was increased by $628,000 (£314,000) to $1,523,000 (£761,500) in 1958, and the Honourable Gordon Churchill, in his capacity as Chairman of the Committee of the Privy Council on Scientific and Industrial Research, set up a special committee in February 1958.69 After consulting experts at the (B)MRC, which at that time had already been in existence for 39 years, a report was submitted that included the following recommendations:

"A) That a Medical Research Council be established under terms similar to those of the National Research Council.

B) That the budget of the Medical Research Council be $4 million (£2 million).

C) That funds be made available for the construction of urgently needed research buildings and facilities in the medical schools of Canada and affiliated institutions." 70

On 4 July 1960, the (C)MRC was established as an autonomous subsidiary of the NRC with a budget of $2,206,000 (£1,103,000). At the end of the 1960's the (C)MRC became a crown corporation. During the early summer of 1968, the federal government announced its decision that the (C)MRC should report to Parliament through

69 Ibid., p. 3.
70 Ibid., p. 4.
the Minister of National Health and Welfare. Royal assent was received on 28 March 1969, bringing an end to the NRC's 32 year period of support and guidance.

At this point both Britain and Canada paralleled each other in terms of the structures in place for funding medical research. Both governments had established their own medical research funding agencies that functioned at arms-length from elected and non-elected officials. The (B)MRC and the (C)MRC provided governments with structures to facilitate state involvement in the search for knowledge leading to the eradication of various diseases. In each country, this came in response to public pressure on elected officials to actively participate in this area of science. Similarly, while governments responded to public pressure and provided more research funding, the public also began to support medical research voluntarily through charities. We now turn our attention in chapter six to the interaction between charity and state in the area of medical research. In doing so, we focus on several issues: how charity and government coordinate their research efforts and how charities attempt to influence the state's research priorities.
Chapter Six

Relations Between Medical Research Charities and the State:
Co-ordination and Collaboration

This chapter seeks to understand the nature of interaction between medical research charities and government within the context of public goods theory. Section I describes the limited degree of collaboration between charity and state in their effort to avoid duplicating bio-medical research. Interviews with charity and government officials reveal that no formal coordinating mechanisms exist but instead ad hoc procedures whereby only limited technical information is traded. Section II provides examples of successful charity-government collaboration in funding joint research projects. This contrast makes it difficult to assess whether medical research charities and government view each other as partners or competitors in this policy area. Section III describes how the British and Canadian governments divide their research budgets among the various diseases. Like their charitable counterparts, it is clear that the governments are susceptible to public and interest group pressures (including

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1 The limited extent of collaboration applies to all disease areas in Britain and Canada with the exception of cancer research in Britain. In this case, there is a special agency known as the United Kingdom Co-ordinating Committee on Cancer Research (UKCCCR) whose membership includes the (B)MRC and the six British cancer research charities.
charities) to fund 'popular diseases'. Consequently, it is natural for governments too to also ignore funding unpopular but prevalent diseases. In response to this imbalance, most British and Canadian medical research charities have begun to lobby government despite legal limitations on the political activity—limitations which we discussed in chapter three. Consequently, the public policy role played by medical research charities in influencing government research priorities is a central theme of this chapter.

I. Charity-State Co-ordination of Medical Research

Section I of this chapter reviews the impetus behind charity-state co-operation (or lack of co-operation) at the state and international level in the context of public goods theory. It does so by examining the factors that motivate British and Canadian medical research charities and the government funded Medical Research Councils in each country to co-operate and co-ordinate their research programmes to avoid wasteful duplication.

To begin with a basic understanding of public goods theory we turn to Mancur Olson's notable contributions to this strand of political economy literature. Olson tells us that the most important type of organisation is the 'nation-state' and that patriotism is probably an individual's strongest non-economic motive for supporting it. Many nations draw additional strength and unity from ideology, such as democracy or communism, as well as from common religion, language or cultural inheritance.
However, the state is also important economically in that it provides its citizens law and order which is a prerequisite of all civilized economic activity. Despite the force of patriotism, the appeal of the national ideology, the bond of a common culture, and the indispensibility of the system of law and order, no major state in modern history has been able to support itself through voluntary dues or contributions. As Olson explains:

"Philanthropic contributions are not even a significant source of revenue for most countries. Taxes, compulsory payments by definition, are needed. Indeed, as the old saying indicates, their necessity is as certain as death itself."

The reason the state is unable to survive on voluntary contributions, and instead must rely on taxation, relates to its provision of fundamental services that must be available to everyone if they are to be available to anyone. The most obvious examples are national defence, police protection and the system of law and order which benefit everyone in a nation. For example, it would be infeasible to deny the protection provided by the military, the police, and the courts to those who did not contribute voluntarily to pay their share of the costs—consequently taxation is necessary. The common or collective benefits provided by governments are usually called 'public goods'.

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3Ibid., p. 13.
by economists and can be defined as any good such that, if any person \( X \); in a group \( X_1 \ldots, X_2 \ldots, X_n \) consumes it, it cannot be withheld from the others in that group. In other words, those who do not purchase or pay for any of the public or collective good cannot be excluded or kept from sharing in the consumption of the good, as they can where non-collective goods are concerned.

Just as the state supplies public goods so do many charities. However, the application of conventional economic theories of public goods are woefully inadequate in providing explanation as to why this is true of charities. The problem is that many charities are principally engaged in the provision of

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5Not all charities supply public goods: the ‘public good’ component of a soup kitchen is rather small. Some charities therefore are supplying goods for individuals which others have paid for out of ‘altruism’. Other charities (like medical research charities) are suppliers of public goods. Finally, because of the legal peculiarities in the development of charity law (discussed in chapter two section I. A) some charities such as public schools provide private goods to those who pay for them.
public goods, to an extent that is inconsistent with the public

good literature since theorists have no means of accounting for

the voluntary input of labour and money to produce such goods.

This is a critical problem since the standard theory of public
goods is adopted in most economic discussions of the proper role

of the state in providing goods and services. These theories

advance the notion that public goods will not be supplied in

economically efficient amounts unless individuals are compelled
to contribute towards the cost of supplying them. Naturally, it is

because of this line of argument that most political economists

argue that public goods should be provided by the state as opposed
to by charities.6 In many cases it is reasonable enough for a

political economist to ignore the possibility of private-

charitable provision of public goods by simply viewing them as

anomalies. The problem arises when we seek to understand the

nature of charity-state relations in an area like medical research

where both participants are supplying a 'like' public good-
namely scientific research. Consequently, we are unable to

analyse properly what might motivate charities and government to

co-operate and co-ordinate their activities in an effort to supply

the public good most efficiently (that is by avoiding wasted

resources on duplication).

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6Robert Sugden, 'Voluntary Organisations and the Welfare
State', in Julian LeGrand and Ray Robinson, Privatisation and the
A. Medical research as a public good

In adopting Olson's definition of a 'public good' we see that both charitable and governmental provision of medical research is a classic example of a pure form of such goods from which many people simultaneously benefit in direct and indirect ways. For example, Jenner's discovery of the small-pox virus leading to the development of a vaccine has benefited not only those who contributed but equally those who did not. In addition, there is no 'crowding-out' effect in that the 'consumption' of small-pox medicine by one person does not exclude others from benefiting from this technology. Like other public goods, medical research can be contrasted with private goods. The supply of public goods cannot be restricted to those who pay for them. For example, cleaning up polluted air is a public good since you cannot restrict the clean air to those who have paid for it just as you cannot restrict it to those who are actually responsible for the polluting. One important feature of medical research as a public good, in contrast to many public goods, is that there are no special or geographic constraints. For example, if the British government funded the establishment and maintenance of a park in London users of that good would obviously be required to be located (if only temporarily as tourists) in that city. However, in the case of medical research, the results of scientific investigations are usually published in journals and thereby freely available to scientists and individuals of other foreign countries. Indeed, medical research charities are required by
their charitable status as 'educational' organisations to make their discoveries publicly available to everyone in order to be of 'benefit to the community', [one -of the important features of charity law discussed in Chapter two section I. B. (ii) ]. As a result, there is an incentive for the governments of other countries to act as 'free riders' by utilizing the benefits that flow from medical research without levying taxes to finance their own contribution to improved public health.7 Given the free-rider dilemma why do governments and charities continue to supply this public good? Interviews with (B)MRC and (C)MRC officials revealed three reasons. First, governments fund medical research out of partisan political interests in response to public pressure (governments publicly perceived to be 'caring' have normally improved their electoral fortunes). Second, governments frequently hold the view that other countries may not be doing a good job in researching a particular health problem and, therefore, the opportunity to 'free ride' does not occur. Lastly, there is often great prestige, in the form of Nobel prizes and like honours, that flow to governments who have supported research.

7There is no necessity that a public good to one group in a society is necessarily in the interest of the society as a whole. Just as a tariff could be a public good to the industry that sought it, so the removal of the tariff could be a public good to those who consumed the industry's product. This is equally true when the public-good concept is applied only to governments; for a military expenditure, or a tariff, or an immigration restriction that is a public good to one country could be a 'public bad' to another country, and harmful to the rest of the world.
yielding major discoveries. Medical research charities have garnered public support for the provision of the public goods they supply for different reasons. First, there is the obvious explanation that some individuals are altruistic and are concerned with supporting public goods, even goods which 'spill-over' national boundaries. Second, some individuals are not impeded by the free-rider issue since their motivation for giving to research is grounded in the superstition that if they 'give to a disease' they might somehow be immunized from contracting it. Other reasons for giving that ignore the free-rider problem are synthesized by Ware and include:

"... laziness (the failure to stop a bank's standing order for a charity in which the donor has long since lost interest); convenience (it is sometimes easier to give donations than to argue with the person soliciting funds); social conformity (a desire not to be in the minority that is not wearing a charity flag); peer group pressure (social ostracism because of a failure to support a particular cause); social esteem (at Jewish charitable functions in the U.S. the donor often has to announce how much he is prepared to pledge, a device which helps to increase contributions); informal tit-for-tat ("you contribute to my fund raising drive and I'll contribute to yours later"), [and] habit ("I've always given to this cause...")

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To get to the more central issue of what motivates, or fails to motivate charities, to co-operate with other foreign and

8British Interview; Medical Research Council, 2 April 1987, and Canadian Interview; Medical Research Council, 28 January 1987.

domestic charities and with governments to avoid duplicating research we must explain why the state provides this public good alongside charitable provision. The orthodox theory of public goods demonstrates that charitable activities will be undersupplied if individuals are free to choose how much they contribute towards them. It is argued that economic efficiency can only be achieved if the free-rider problem is solved through coercion. This argument is often used to justify the provision of welfare services by the state. It has been used to justify both income support schemes and public provision of certain welfare services, particularly health care. This line of argument can also easily be extended to explain governments' commitments to medical research despite the increasing numbers of medical research charities established in Britain and Canada after 1960. The problem with this theory of public goods is that it does nothing to illuminate the special relationship between charity and the state once both are actively involved in supplying like goods and services. An alternative theory that resolves this

10Individuals might consent to their being co-erced as part of a kind of social contract but what they consent to is nonetheless coercion.


problem starts from the idea that individuals derive some kind of private benefit when they contribute to charities; since non-contributors are excluded from these benefits, the free-rider problem is eliminated. The 'private benefits' theory rests on the notion that individuals who contribute to charities receive direct benefits in return, the value of which does not depend on any private or social morality and from which non-contributors are excluded. In the more general context of public goods, Olson has argued that many pressure groups and trade unions work on this principle: they supply public and private goods as joint products, and the private goods - which are supplied only to paid-up members - are sufficient to induce individuals to join. For example, trade unions and professional associations often provide specialized information to their members and organize social functions. It can be argued that the same principle explains how medical research charities - especially those with patient services programmes - operate. Historically, British and Canadian medical research charities were founded by disease sufferers and have subsequently come to rely on them for voluntary inputs of both labour and money. In return, these disease sufferers have not only contributed to the provision of medical research (a pure public good) but have also received private benefits. These


benefits have come in the form of specialized medical information relating to their disease conditions, the opportunity to interchange with other disease sufferers (self-help benefits) and benefits accruing from charitable organisations lobbying government on their behalf for disability payments, mobility allowances and the like. The logic of this theory is that a charity supplying a public good has two components. One component works essentially like a private firm, providing some excludable service (information, social functions, personal advocacy) in return for contributions of money and labour. The profits of this firm are then used to finance the other component of the organisation, which supplies some public good – medical research.

While the private benefits theory sheds light on why disease sufferers establish and support charities it also explains the role of volunteers in seeking to protect their interests. In the context of medical research, it helps to explain why disease sufferers and their families, who are often volunteers or financial contributors, pressure charity administrators to avoid wasting funds on duplicating research. Duplication can occur in two ways: there is duplication involving domestic and foreign charities, and then there is duplication involving charity and government.

B. Co-operation and co-ordination of charity supported Research

The need for co-operation and co-ordination in the field of medical research is especially important given the nature of those
who are actually involved in developing this public good. As one scientist explained:

“Scientists are a fiercely competitive lot possessing enormous egos. Consequently, there is little co-operation within the international scientific community and certainly not among scientists from the same country doing identical work. There is an ongoing race to cross the finish-line first ... for example, for a scientist to be able to put his/her name behind new disease, drug, or innovative surgical technique.”

A glaring example of wasteful duplication stemming from a lack of co-operation among charity-funded scientists involved fierce competition between France and the United States in identifying the AIDS virus. Even after its discovery, there continued a long battle between researchers in both countries over the naming of the virus. This international rivalry involved Professor Gallo from the U.S. and Professor Luc Montagnier at the Institut Pasteur in Paris. As early as 1979, Gallo discovered that a virus claiming the lives of homosexual men was related to a family of viruses called HTLV(1) and HTLV(2). When Professor Montagnier discovered the AIDS virus in March 1983 - a full year before the Americans - the French called it Lymphadenopathy Associated Virus (LAV) because they had isolated it from a gland (Lymph node) of a young male homosexual. After long and bitter public, and private, debate between the rival investigators, it was agreed to make

15Canadian Interview; McMaster University, Medical School, Department of Pathology, 19 January 1987.
HTLV(3)/LAV the technical designation for AIDS. In retrospect, scientific commentators have concluded that the Gallo-Montagnier race mitigated against discovering the virus rather than accelerating the process. Moreover, it is agreed that, in clamouring for more funding, fame, patent rights and possibly a Nobel prize, not only delayed the discovery of the virus, but also a lack of international co-operation, delayed the formulation of a public education campaign, which in turn might have saved thousands of lives.

While AIDS exemplifies the potential for international competition, there are instances where remarkable co-operation has been displayed. In the case of muscular dystrophy, three


17 Ibid., pp. 30-39. Duplicated research should not be confused with research that verifies other scientific results. A recent case highlighting the need for verification involved the muscular dystrophy research charities in Britain, Canada and the United States. In 1982, a British researcher claimed publicly that a 'compound' he had discovered was effective in curing those afflicted with muscular dystrophy. He did this for several years despite strong opposition mounted by the international scientific community. As a result of his claims - which marshalled strong support among optimistic parents of muscular dystrophy sufferers - the issue had to be resolved at an emergency international conference held in New York City. Of the 39 participating scientists in attendance, 38 rejected his evidence based on the results of their own independent studies. When reflecting on this unfortunate event, the British and Canadian muscular dystrophy research charities agreed that; 'the results should have been duplicated immediately so as to avoid the disgraceful waste of time and money spent on the New York rendezvous. Moreover, it would have spared those suffering from the disease and their families, from the enormous let down they later experienced', from Canadian Interview; Muscular Dystrophy Association of Canada, 5 December 1986; and British Interview; Muscular Dystrophy Group of Great Britain, 19 February 1987.
researchers, (Dr. K. Davis from England, Dr. B. Walton from Canada and Dr. P. Loucunkle from the U.S.) exchanged blood samples and information over a three year period in their search for isolating the muscular dystrophy gene. Though the American team discovered the gene in 1984, credit was also accorded to the British and Canadian scientists:

"My counterpart at the U.S. Muscular Dystrophy Association contacted me three days prior to the press conference they staged to announce their discovery. He reassured me that they would be very generous in their literature about the help they received from this charity and the one in Canada."

Global co-operation between different medical research charities (and the scientists they fund) is largely aided by international associations representing specific disease areas. These include the International Diabetes Foundation, the International Cancer Research Society, the International Society and Federation of Cardiology. These organisations arrange and finance conferences attended by leading scientists from a variety of research fields. In doing so, they attempt to foster greater collaboration among scientists from different countries and to encourage a multi-disciplinary research approach. According to one charity executive; "The financing of these meetings has been supplemented by pharmaceutical companies who aim to keep their

18 British Interview; Muscular Dystrophy Group of Great Britain, 19 February 1987.
finger on the pulse of scientific progress". The multinational Interfalf drug company from West Germany has long been a financial supporter of international conferences dealing with gastroentological diseases and is a leading manufacturer of synthetic drugs for these afflictions. According to one respondent, "These conferences are a useful means for the pharmaceutical companies to do some of their major networking".

The suspicion might arise that a Canadian researcher flown to Venice for a two week, all-expense-paid, conference, would feel some allegiance to the sponsoring company if he discovered a compound worthy of further drug development. One pharmaceutical spokesman argued, though, that scientists are not legally bound by contract to turn any of their major discoveries over to the sponsoring company. However, it was added that this is what most scientists would likely do since the company would certainly be a leader in that particular research field.

After completing interviews with 44 different British and Canadian medical research charities, it became evident that some organisations are more concerned about the issue of duplication than others. For example, there are charities like the British Diabetic Association that have reduced the probability of international duplication by holding memberships in several

19Canadian Interview; National Cancer Institute of Canada, 28 November 1986.

20Canadian Interview; Canadian Foundation for Ileitis and Colitis, 12 January 1987.

21Canadian Interview; Connaught Laboratories, 11 February 1987.
associations, including the United States Juvenile Diabetes Association, the World Health Organisation (WHO), the European Association de Societe pur Diabetes-(EASD) and the International Diabetes Federation. Conversely, there are charities like the Parkinson Foundation of Canada, that are less concerned about duplication and appear to be isolationists even though there are five different American organisations collecting voluntary donations for Parkinson's research as well as two international co-ordinating agencies. In Britain, the Chest, Heart and Stroke Association (CHSA) acknowledged the potential for duplicated stroke research programmes since an international co-ordinating agency does not exist for this disease. Although the CHSA has heard of other stroke research charities operating in Canada and the U.S., no effort has been made to contact them to establish an association. As the Executive Director of the CHSA freely admitted:

"In the area of stroke research, there is no means of co-ordinating research conducted in other countries - so the potential for wasted resources is enormous. This is sad given that I know of the American Stroke Association located in Denver, Colorado as well as the Ontario Heart and Stroke Association in Toronto."

The question remains why an international association for stroke research has not been formed, given that other charities have responded to pressures from volunteers to avoid duplication.

22 British Interview; Chest, Heart and Stroke Association, 20 February 1987.
One possible explanation might be that creating an association is beyond the financial means of a charity like the CHSA. It is conceivable that the establishment and maintenance of an international co-ordinating body could be a function of the income levels of its member charities. However, in examining the membership of existing international associations, this appears not to be the case. For example, the CHSA’s 1985 income of £939,110 is more than double that of the Asthma Research Council, an active member of the International Asthma Federation. Similarly, the Cystic Fibrosis Research Trust in Britain, which has an income level comparable to that of the CHSA, holds dual membership with WHO and with the International Cystic Fibrosis Association (ICFA). Appendix V lists the ICFA’s points of contact with researchers around the world.

An alternative explanation of why the CHSA has isolated itself from the international research community involves the sparse distribution of their research funds to cover stroke and coronary heart research as well as a host of other chest ailments. The reason for doing this can be understood in the context of the rather peculiar history of this charity. The CHSA, which began as the National Association for the Prevention of Tuberculosis (NAPT), switched its research focus to heart disease when Tuberculosis mortality rates declined sharply after World War II. From a scientific viewpoint, it is not entirely clear how NAPT was

able to make a connection between tuberculosis research and heart research. Indeed, it can be argued that during the 1950's the NAPT was a charity in search of a disease. As was discussed in chapter five section IV. B, the newly established Chest and Heart Association decided in 1976 to further extend its activities by tacking-on 'stroke' to its title. Consequently, the CHSA's remit now embraces all chest, heart and stroke related illnesses. As one scientist commented, "the number of diseases falling within the CHSA's ambit is almost limitless; it is not surprising that their scope of international contact is non-existent. It would cost them a fortune to hold memberships with associations in order to represent all the diseases embraced by their remit".24

In considering charity's role in the international co-operation and co-ordination of bio-medical research, special reference must be made to the Ciba Foundation. This British charity is the only organisation in the two countries whose specific purpose is to promote international dialogue between biomedical researchers. The Ciba Foundation - established by the Swiss pharmaceutical company, Ciba Geigy - was registered by the Charity Commission in 1947 as an educational charity. The Foundation operates independently from other charities or corporations in London and is internationally known for the symposia it organizes at its premises in London. The Ciba Foundation makes contributions towards research by holding eight

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international symposia each year. The proceedings of these meetings are then edited by the Foundation’s staff and published as hard back books. As Dr. David Evered, the Foundation’s Executive Director, explained:

"Scientists are competitive and their work is often fuelled by it. I am convinced that this is not inherently bad. Although duplication stemming from this competition is vital for the verification of results, there is often unintentional duplication resulting from limited communication networks. The aim of the Ciba Foundation is to resolve this problem by bringing researchers from around the world together under one roof and in doing so, to break down the barriers created by scientists by virtue of their selected areas of expertise."

C. Co-operation and co-ordination of charity and government-sponsored research

The ‘private benefits’ argument to explain why charities co-operate internationally with other charities does not seem to be applicable to charity-state co-operation and co-ordination of research. Here, the degree of co-operation to avoid wasteful duplication does not appear to hinge on volunteers seeking to protect their own interests by pressing charity administrators to apply research funds efficiently. Instead, motivation for co-ordination at the state level seems to reflect the relative size of a charity’s research commitment to a particular disease area vis-à-vis that of the government. In Britain and Canada, the problem of duplication is precipitated by multiple sources of

funds available to scientists, regardless of their research focus. For example, there are the research councils which fund research into a wide range of disease areas and which overlap with research supported by one (or more) charities. However, in the peculiar case of British cancer charities an effort in co-ordinating research has been demonstrated.

In 1974, the British government, in collaboration with the six cancer research charities, established the United Kingdom Co-ordinating Committee on Cancer Research (UKCCCR). Membership of the UKCCCR now includes the (B)MRC, the Cancer Research Campaign, the Imperial Cancer Research Fund, the Tenovus Cancer Fund, the Institute of Cancer Research, the Leukemia Research Fund and the Marie Curie Memorial Foundation. The aim of this 'umbrella' organisation is to disseminate scientific information among its members in order to eliminate duplication. The committee's executive meets twice a year, attended by the directors of the member charities, senior (B)MRC officials and observers from the DHSS. A permanent Secretary, housed at the (B)MRC's headquarters in London, is responsible for routine administrative matters including the collection of information relating to who receives funding for cancer research, how much is granted, what problems

Pharmaceutical companies represent a third source of funds for bio-medical researchers. However, most of their research differs from that funded by charity and government. Drug company research is more commercially-oriented, towards developing new synthetic compounds to treat disease, rather than investigating the cause and cure of disease. The role of the British and Canadian pharmaceutical industries in shaping charity-state relations in each country is examined in chapter eight.
the project seeks to address, and where the investigations are conducted. The UKCCCR has also been used by its members to lobby government on medical-related issues—such as increasing taxes on cigarettes as well as banning 'skullbandits'—a new type of oral tobacco.27

In contrast to cancer research in Britain, attempts to control duplication in all other disease areas in the two countries is left to more informal and ad-hoc mechanisms. British and Canadian charity executives were asked what procedures were in place to ensure that duplication of research into their particular disease was avoided. Fourteen of 18 Canadian respondents explained they were aware of what the (C)MRC was funding in their disease area since their reviewers performed a similar task for the (C)MRC (referred to as a cross-appointment). Likewise, of the 26 British charities interviewed, 24 described a similar arrangement in Britain. With the exception of one respondent, the cross-appointment system was deemed a sufficient mechanism for deterring unnecessary duplication. The following statement by the Executive Director of the Heart and Stroke Foundation of Ontario typifies the attitudes of most British and Canadian charities towards this arrangement:

27As a member of the UKCCCR and as an agency deriving 98 percent of its income from government, the (B)MRC encountered 'political difficulties' when it was later learned that a factory built to manufacture skullbandits in Scotland had received a large government grant. The (B)MRC was therefore trapped in the confusion between the government's health policy and regional economic development policy.
"To say that we check with the (C)MRC every year over every grant we make would be a fallacy. But the people who are grant reviewers for our organization are likely to be reviewers for the (C)MRC or a part of that network. They would have a pretty good feel for what research has been done and what needs doing."

The vast majority of British and Canadian charities have not made 'cross-appointments' with the (B)MRC/(C)MRC a formal policy. Instead, as one respondent commented; "There might be some crossing over but it would almost be accidental". There is an important explanation as to why charities have avoided making it a firm policy to use (B)MRC/(C)MRC scientists to review their grant applications. First, 'territorial protection' of their disease area, means that charities are reluctant to give any of their responsibilities away to the (B)MRC/(C)MRC, even to help avoid duplication. Charities have historically relied entirely on their own in-house expertise for reviewing grants, involving complex bureaucratic and administrative structures. By hiving-off all of their own peer-review responsibilities to (B)MRC/(C)MRC scientists, it is argued that the autonomy of these charities might be threatened.

In contrast, there are a small minority of charities like the Canadian Cancer Society and British Heart Foundation that require either (B)MRC/(C)MRC officials to participate in their granting

28Canadian Interview; Heart and Stroke Foundation of Ontario, 11 December 1986.

29Canadian Interview; Multiple Sclerosis Society of Canada, 3 December 1986.
process or that there be a formal exchange of technical information between them. This may lead to the design of a charity's research programme around government interests rather than an integration of the two programmes. This distinction may seem inconsequential but is nonetheless an important consideration for charities whose fund raising success depends on being seen by the public as independent from government. In recognizing this, the (B)MRC commented: "When we have our scientists sitting on a charity's scientific review board, we understand the need to avoid stepping on their toes".30

Understanding what motivates British and Canadian charities to co-operate and co-ordinate their activities with government to avoid duplication involves distinguishing between at least three different funding policies adopted by charities. First, there are a few smaller charities, like the Canadian Alzheimer's Association (CAA), that limit themselves to providing supplementary grants to researchers whose main support comes from the (C)MRC. With this arrangement, the charity will liaise closely with government officials as a means of determining the appropriate funding level. These types of charities freely acknowledge the (C)MRC/(B)MRC as the leading funding agency hence communication and co-ordination of research is not problematic normally.

Second, there are a few charities like the Multiple Sclerosis Society of Canada and the British Heart Foundation, that refuse to support scientists receiving (B)MRC/(C)MRC funding. In the words

30British Interview; Medical Research Council, 2 April 1987.
of one respondent; "if a scientist receives funding from the
government, we ask them to choose between us and them; we simply
refuse to adopt a 'dual funding policy'". 31 These charities do
not recognize the (B)MRC/(C)MRC as a senior partner in funding
bio-medical research but rather covet this role themselves. Here,
the likelihood of duplication is greatest, owing to poor
communication and co-operation between the two. In their own
defence of this policy, one Canadian charity spokesman claimed:

"there is no formal mechanism to protect against
duplication or over-funding but there are a
number of surreptitious ways of knowing what the
(C)MRC is up to. We prefer this arrangement
because it gives us greater flexibility in
determining what projects we want funded". 32

A criticism of this approach is that charities may fund some lower
quality research since good investigators, who are made to choose
between charity and government, will normally opt for the latter,
presumably more prestigious, option. As one scientist remarked;
"if a charity gave me an ultimatum, there is no doubt that I would
choose the (C)MRC even if the awards were commensurate in value
and tenure". 33

Third, the vast majority of charities, including the British

31 Canadian Interview; Multiple Sclerosis Society of Canada, 3
December 1986.

32 Canadian Interview; Muscular Dystrophy Association, 5
December 1986.

33 Canadian Interview; McMaster University Medical School,
Department of Pathology, 19 January 1987.
Diabetic Association and the Canadian Geriatrics Research Society, have a funding policy which is a compromise between the two approaches already described. These charities fund investigators who are both independent of and yet closely associated with the (B)MRC/(C)MRC. These charities normally like to carve-out a scientific reputation of their own but this does not preclude them from collaborating with government on ‘alpha’ research projects worthy of dual support. Most respondents did not view a trade-off between their collaboration with government and any loss of freedom or flexibility in determining their own research priorities.

D. The role of the Association of Medical Research Charities (AMRC) in eliminating duplication

In Britain, duplicated research is partly avoided through the role played by the Association of Medical Research Charities. Founded in 1972, the (AMRC) operated for many years as a loosely structured unincorporated organisation. During this time, discussion among the member charities centred on issues of mutual concern relating to the administration of their organisations. In 1981 this changed when the AMRC began to realize the total contributions of its 35 member charities towards research was approaching the amount spent by government via the (B)MRC. Consequently, in 1982, the AMRC initiated plans to reconstitute itself, apply for charitable status and create a permanent

34 Canadian Interview; McMaster University Medical School, Department of Pathology, 19 January 1987.
secretariat; a process that has lasted five years. It was believed this would give British medical research charities a forum with which to lobby government on issues of collective concern for example, government cutbacks to the (B)MRC and to the number of senior registrars employed in DHSS hospitals (these issues are examined in chapter six section I). The newly constituted AMRC is expected to operate as an 'information house' by collecting and disseminating information on research projects supported by member charities. Additionally, it is anticipated that the association will help to set standards of practice in grant assessment and performance evaluation. With regard to the first objective, the AMRC has already made considerable progress by implementing new granting policies aimed at correcting problems of nepotism that have plagued many smaller charities. In doing so, charities like the Arthritis and Rheumatism Council in Britain have created their own 'research policy committee' which ensures that their grants' review committee is distanced from the community of researchers who apply for support. With smaller charities representing less popular diseases, there are comparatively few scientists investigating in these disease areas. Consequently, as one respondent remarked; "it is frequently the case with small charities to have the monkeys guarding the bananas".35 In instances like this, the AMRC's policy has been to encourage charities to second eminent scientists from different,

35British Interview; Association of Medical Research Charities, 4 March 1987.
but closely related, disease areas. For example, the Multiple Sclerosis Society's recently-appointed grants' review chairman is a leading expert on Parkinson's disease.

The newly constituted AMRC will also encourage members to use the association as a forum to arrange collaborative research ventures. Anne Luther, the AMRC's Secretary, explained that the association will eventually develop very flexible sub-groups, made up of charities with overlapping research programmes. For example, one sub-group representing neuro-muscular diseases might embrace the Spastics Society, the Muscular Dystrophy Group of Great Britain and the National Fund for Research into Crippling Diseases. Since the AMRC was registered by the Charity Commission during the final preparation of this thesis, it is difficult to assess its performance in fostering greater co-operation among member charities. For the same reason, the AMRC's interaction with the (B)MRC over the issue of duplication is also difficult to assess. However, when asked how the (B)MRC had received the news of the AMRC's intention of re-constituting itself, Luther explained:

"We haven't had a formal response from the (B)MRC. To be quite honest I think our new presence will be a little bit daunting for them. In terms of eliminating duplicated research, I am positive the (B)MRC will welcome us with open arms. However, on other issues, where the AMRC intends to make strong representations to government, the (B)MRC may feel that we are going to be usurping some of their traditional advisory
In Canada, where there is no comparable association, the problem of duplication will continue to plague both government and charities. In the light of this, Canadian respondents were asked why a national association has not been created and what possibilities exist for the establishment of one in the future. In addressing the first part of the question, several explanations relating to Canada's federal system were given. Most charities feel that the combination of Canada's geographic size and small population, and the resulting economic costs, are not conducive to bringing people together under an umbrella organisation to discuss problems of mutual concern. Second, and a much more persuasive argument, is that charities are unsure of the federal government's power to influence the 'execution' of bio-medical research, since the institutions where research is conducted (universities and hospitals) fall within provincial jurisdictions. It was agreed that a national association, comprising medical research charities, might successfully lobby the federal government to increase its funding of the (C)MRC, but any subsequent input into the way in which 'research dollars' are spent would have to be negotiated with ten separate provincial governments. As one respondent remarked:

"powers."

36

36 British Interview; Association of Medical Research Charities, 4 March 1987.
"In England, I can see why an association for medical research charities has been successful since they can go to Whitehall for everything ... they can ask for more money and see the expenditures of these monies right through to their end. In Canada, an association would have to lobby in Ottawa for 'research dollars' and if successful, it would then have to lobby from St. Johns to Victoria."  

The absence of a national association could also be attributed to the bilingual nature of Canada. The Psychiatric Research Society felt that it would be difficult to bring together francophone medical research charities from Quebec under an umbrella organisation dominated by charities from nine other anglophone provinces. An attempt to organise a coalition of Canadian mental health research charities failed because the Quebec-based La Foundation pour La Recherche sur Melad Mental (FRMM) refused to collaborate with anglophone charities operating either inside or outside of Quebec. FRMM adopted this policy in the belief that anglophone mental health researchers from Quebec had previously received too much support at the expense of their francophone counterparts. Consequently, the FRMM funded the establishment of a research institute exclusively for francophone mental health investigators.  

The absence of a Canadian interest association can also be explained by a difference in public awareness in each country of  

37 Canadian Interview; Canadian Mental Health Association, 18 December 1986.  
38 Canadian Interview; Canadian Psychiatric Research Foundation, 8 January 1987.
the government's involvement in funding medical research. In contrast to the situation in Canada, the (B)MRC has a very strong standing in the minds of researchers, the public, and elected government officials. Because the (B)MRC maintains its own laboratories, and has a long and distinguished history of achievement, its public profile is firmly entrenched. Furthermore, British scientists reaching the pinnacle of the research community are publicly referred to as 'B)MRC scholars'. In Canada, the same phenomenon does not exist, principally because the (C)MRC does not fund and administer its own laboratories. As a result, any recognition of the achievements made by (C)MRC - funded scientists tends to flow to the universities and hospitals where the research is actually conducted. Canadian medical research charities have benefited from this in so far as the public perceives them as being the only source of funding for medical research. As a spokesperson for the (C)MRC noted:

"Medical research charities have not created an association because they do not want to attract attention to the (C)MRC. To do so would dissipate their presence in the public's mind and perhaps limit their ability to raise voluntary donations."

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The major drawback to this strategy - if indeed it can be correctly described as a strategy - is that Canadian medical research charities are unable to negotiate collectively when dealing with the federal government. From the government's

39Canadian Interview; Medical Research Council, 28 January 1987.

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viewpoint, the absence of a national association is preferable as they would rather negotiate with relatively weak individual charities as opposed to a strong association. This is particularly important since an association representing Canadian medical research charities and their volunteers might come to represent a coherent 'political vote'.

The fragmented lobbying effort in Canada is in sharp contrast to the highly co-ordinated activities spearheaded by the AMRC in Britain. Since most of the British public are aware of two sources of medical research funding - one public and one private - British charities have had nothing to lose, and everything to gain by drawing public attention to an issue such as cut-backs to the (B)MRC. In acknowledging government’s shared responsibility for funding bio-medical research, British charities are also able to define their responsibilities vis-a-vis the (B)MRC’s. For example, distinctions between British charities and the (B)MRC are easily drawn in relation to the type of research each funds, the type of support each provides and the duration of their research awards. These distinctions are highlighted in AMRC publications where it is argued that medical research in Britain is serviced best through a division of responsibility between government and charity. In doing this, the AMRC have argued that cutbacks to the (B)MRC translate into an increasing burden on charity to deliver a service historically defined as a shared responsibility. In Canada, a similar distinction between the respective role of the different bodies is blurred in the public’s mind, principally
because charities are mistakenly viewed as the sole provider of bio-medical research funds.

Lastly, Canadian medical research charities are ambivalent about the idea of a national association since they perceive Britain's AMRC as co-ordinating its member's fund raising campaigns. However, this is not the case; the AMRC's articles of association prevents the organisation from publicly campaigning for voluntary donations on its own behalf or for its individual members. In clarifying this point to Canadian charities, many respondents agreed that a Canadian association, comparable to the AMRC, would be a good vehicle for improving charity-state relations.

E. Duplication and scientific accountability

A universal problem for charity and governments dedicated to the efficient supply of medical research has involved making scientists fully accountable for the financial support they receive. This includes making sure that scientists use charitable and government funds for the same investigations as those proposed in their grant application. To determine how this is enforced, 44 British and Canadian charities were asked what control and accountability mechanisms were in place to ensure scientists utilized research grants for their intended purposes. The responses varied enormously. Only six charities (four Canadian and two British) admitted that the only guarantee that proper research had been conducted was the honesty and integrity of the scientists concerned. The remaining 38 charities required
scientists to submit a number of progress reports during their investigations, and to publish final results in a recognized scientific journal, acknowledging their charity as the funding source. Publication of final reports in scholarly journals is an effective control device since scientists would be unable to submit a report on the project for which they received funds if they had substantially altered their research focus. Although initially it may seem an insignificant deterrent, an investigator seeking future grants could ill-afford a reputation for failing to do research as outlined originally in a grant application.

Many charities, like Britain’s Multiple Sclerosis Society, enforce very strict accountability regulations to deter the misapplication of funding and to assess whether funding should be terminated or extended. On this point, the Executive Director of the Multiple Sclerosis Society stated:

"If a scientist fails to make satisfactory progress, then that person is required to appear before our sub-committee and also normally receive an on-site visit from people who sit on our Medical Advisory Committee."

Enforcing accountability also gives a charity current information to report to its volunteers and donating public. The annual reports of virtually all British and Canadian charities include progress reports on research completed or in progress. Obviously, volunteers who are family or friends of those afflicted

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40British Interview; Muscular Dystrophy Group of Great Britain, 19 February 1987.
by a particular disease would look unfavourably upon a scientist who changes the focus of his investigation. (A scientist funded to investigate Alzheimer's disease, who later changed his focus to a related disease like Huntington's disease or Parkinson's disease, would alienate volunteers who had worked hard to raise money for their disease).

A number of medical research charities in both countries disagreed with the idea of making scientists accountable during their research since many investigations do not bear fruit until the projects are completed. Furthermore, they argued that scientists place a premium on freedom and independence, and any charity that tampers with this restricts progress instead of aiding it. Nonetheless, the vast majority of British and Canadian charities agreed that accountability upon completion of a research project should be compulsory.

The argument whether charities should enforce stricter guidelines to make scientists more accountable has heightened debate over the practicality of charities administering their own research facilities. Chapter five section V. A, listed the advantages and disadvantages that the (B)MRC enjoy over its Canadian counterpart in administering its own research units located in university science departments. The remaining question is whether other charities should emulate the Imperial Cancer Research Fund (ICRF) which, like the (B)MRC, funds and operates its own research laboratories. By carefully co-ordinating entire research teams, the ICRF claims it can influence the direction of
scientific investigation. Multi-disciplinary cancer research is made possible through close scientific collaboration of its various research departments. The ICRF cites the difficulty in co-ordinating university-based research.

"Medical research charities cannot instruct university-based scientists to take a project down a certain road or to collaborate with a scientist from a different university. These investigators simply see themselves as individuals owing allegiance to their own university department as opposed to a donor charity."

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On the other side of the debate, virtually all Canadian and British respondents identified the enormous costs of building and maintaining research facilities as the principal reason for not following the ICRF's approach. The Cancer Research Campaign, the ICRF's major competitor, was critical of the ICRF's inability to quickly shift its research focus quickly. For example:

"a large number of the ICRF's scientific staff are immunologists which is fine if the current thinking accepts that cancer is linked to deficiencies in man's immune system. However, if at a later date biochemists appear to be on the cutting edge of cancer research, the ICRF will be strapped with personnel possessing the wrong skills."

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The Cancer Research Campaign further argued that the ICRF's

41British Interview; Imperial Cancer Research Fund, 19 February 1987.

42British Interview; Cancer Research Campaign, 11 March 1987.
research establishments only perform well as long as their directorships are not vacant. If these positions became available either because someone has quit, retired, or has died, the direction of a research unit is thrown into disarray. "Incoming directors have little mobility to tailor their own research thrusts since investigators are normally committed to the previous director’s vision of success".43

II. Charity-State Co-operation: Joint Supply of Medical Research

While this section is unrelated to the issue of duplication it is central to our discussion of medical research as a jointly-supplied public good by charity and the state. It illustrates that in the bio-medical research policy field, co-operation between public and private sectors can be measured by the degree of interaction between charity and the (B)MRC/(C)MRC. In both countries, there are remarkable examples of close collaboration between charity and government in the joint-funding and administration of medical research projects.

In Britain, the best examples of collaboration is the partnership between the (B)MRC and Cancer Research Campaign in funding the Institute of Cancer Research (ICR). According to the ICR's Annual Report, 1985, the collaborative venture costs each agency £3.5 million each year.44 The ICR has a peculiar

43Ibid.

constitution in that it is a limited company, with a board of
directors, known as ‘Members of the Institute’. The ICR is a
registered charity. Its main function is to carry out research
into cancer and in this capacity, it is closely linked with the
Royal Marsden Hospital, where its staff have access to patients.
In return, the Royal Marsden utilizes the Institute’s laboratories
for pathological tests and other work. The (B)MRC began to fund
the ICR in the early 1950’s because the latter was suddenly
deprieved of funds. The ICR had previously depended heavily upon
the Royal Marsden Hospital and was taken over with it, by the
Ministry of Health, in 1948. In 1951, the National Health Service
(N.H.S.) separated the hospital from the ICR and stopped
supporting the latter on the ground that it was engaged primarily
in research. The University Grants Committee (UGC) refused to
pick up the funding for the ICR because the Institute did little
教学. In the end, the (B)MRC approached the Cancer Research
Campaign in an attempt to work out the details of a joint funding
arrangement for the ICR. At first, it was intended that the
Institute be administered by the (B)MRC as one of its own research
establishments and that the staff should be brought into the
Council’s sphere of control. The senior members of the existing
staff, along with the Cancer Research Campaign objected to this
arrangement as it would threaten their independence and academic
status. At the time, the Institute was registered as a
postgraduate school of the University of London and, therefore,
some members of the staff were fearful of losing their titles. As
a result of this protestation, the ICR established its own Committee of Management, whose members were nominated by the (B)MRC and the Cancer Research Campaign. This meant that all management decisions and policy directives would be determined in close consultation between charity and government. 45

Premised on the high quality of research conducted by the ICR, this joint venture represents a remarkable example of charity-state co-operation in the area of medical research. It also exemplifies the government's dependence on voluntary contributions to maintain facilities and services now considered primarily to be a state responsibility. 46

In Canada, there are similar examples of close collaboration between charity and government. The National Cancer Institute of Canada (NCIC) and the (C)MRC joint-funding of the Breast Cancer Screening Programme is perhaps the best. This research venture, costing each agency $8.5 million (£4.2 million), is implemented through a 'policy advisory group' representing the NCIC, (C)MRC, and the Department of Health and Welfare (DHW). The NCIC has 50 per cent voting rights, as do the (C)MRC and DHW combined, thus allowing each to participate in policy decisions affecting the


46Chapter seven section I assesses whether charities have become the victims of their own success. Evidence is given on both sides of the debate to evaluate whether the increasing income of medical research charities has allowed the British government to reduce its overall commitment to bio-medical research.
programme’s direction. The NCIC’s Director of Research described the collaborative venture as, “one that allowed us and government to do something that neither could do alone”.47

In the non-cancer field, the Muscular Dystrophy Group of Great Britain (MDGGB) provides us with another example of collaboration between charity and government. The MDGGB funds a (B)MRC research fellow who is a leading expert on DNA at the John Radcliffe Hospital in Oxford. This researcher uses the ‘charitable money’ to hire additional staff to work in the (B)MRC unit and, in turn, they investigate the relationship between DNA and muscular dystrophy. That is, the (B)MRC maintains the research unit which in turn, ‘sells’ the charity the laboratory bench space. The charity is not actually paying for overheads or rent, but it does provide the funds for a researcher to work in a (B)MRC unit. As the MDGGB’s Executive Director explained:

“When there is a (B)MRC unit which is dealing with a specific scientific problem within which we can put our own very specific part of that problem, then we will try to do so. This is what we have done with the genetic study of muscular dystrophy. When we learned that the (B)MRC’s DNA Laboratory was working on the whole human gene we approached them, put in our own people and concentrated exclusively on muscular dystrophy.” 48

The British Heart Foundation, which also funds scientists working

47Canadian Interview; National Cancer Institute of Cancer, 28 November 1986.

48British Interview; Muscular Dystrophy Group of Great Britain, 19 February 1987.
in (B)MRC units, described these arrangements as "peculiar examples of charity directly subsidizing what is properly (the responsibility of) government". In Canada, where the (C)MRC does not maintain its own research institutes, or units within universities, this type of collaborative venture is not possible. Instead, jointly sponsored research projects like the Breast Cancer Screening Unit are conducted by scientists from one or more university science departments.

In various disease areas where there has not been direct collaboration between charity and government, it is more difficult to determine whether each views the other as a partner or a competitor. Several of the larger British and Canadian charities view themselves as 'senior partners' and look to government to fill in gaps left by the charities. They claim they rely on government only for the provision of a scientific infra-structure -developed in Britain through the dual support system and in Canada through the (C)MRC. This infra-structure involves the (C)MRC and (B)MRC providing training fellowships so that the charities will receive future grant applications from qualified scientists. In contrast, smaller charities like the Multiple Sclerosis Society of Canada view the (C)MRC as an equal partner. "We look upon the (C)MRC as our older sibling; they have a little more experience with funding bio-medical research and have people

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49 British Interview; British Heart Foundation, 3 March 1987.
on their staff whom we can call on when we need advice".50

III. Determination of Government Research Priorities

A slightly less obvious kind of collective good, and one that is often supplied by charities, is the work of a pressure group. If a pressure group works on behalf of a group of people with common interests, its activities are clearly a collective good to those people. Some pressure groups, however, represent people who share not so much interests as attitudes.51 For example, many of the supporters of the Cancer Research Campaign are not cancer patients and in the non-medical research field, most supporters of the Howard League for Penal Reform are presumably not likely to become clients of the prison service. Nevertheless, if collective goods are defined in reference to wants, the activities of this latter kind of pressure group would be collective goods to the groups of people who share the relevant attitudes. Many commentators have argued there are certain kinds of pressure group activities that are collective goods and best provided by charities.52 Since the purpose of a pressure group is to exert influence on government, this is hardly an activity that can safely be left to government. Although there have been examples

50Canadian Interview; Multiple Sclerosis Society of Canada, 3 December 1986.
of government-sponsored pressure groups (the Community Development Projects initiated in 1969 increasingly took on this role), a pluralist democracy has traditionally relied on independent organisations that are able to criticize the government without any clash of loyalties.53 It is shown below that pressure group activity is undoubtedly a significant part of the work undertaken by British and Canadian medical research charities.

Whether British and Canadian medical research charities have large incomes or small, collaborate closely with the (B)MRC/(C)MRC or view themselves as competitors, all would like to see government spend more on researching the disease they represent. Given that the fund raising success of other, non-medical-research, charities has been inversely related to the role played by government, the statement is a surprising one.54 Where government involvement has increased, public support of charity, through decreased voluntary donations has normally followed. For example, in Canada, with the federal government’s expansion of the Department of Environment to address issues like acid rain, charitable support for organisations with similar aims and objectives has declined.55 However, one argument is that medical research charities support increased governmental presence in

53It is worthwhile mentioning that the Community Development Projects were eventually closed down by the government.


55Canadian Interview; Secretary of State – Voluntary Action Programme, 27 January 1987.
their policy area since the (B)MRC/(C)MRC fund a different type of research which attracts little public attention.

As previously discussed in chapter four, British and Canadian medical research charities tend to fund disease-oriented research, often referred to as applied research. Since many small and medium-sized charities are administered by disease sufferers or are influenced by volunteers who are sufferers, expenditures on research tend to be for investigations promising to yield immediate, practical results. In both countries, larger charities like those funding cancer research, can afford to support both applied research and to a lesser extent non-disease-related basic (or pure) research, which is the type of investigation that the (B)MRC and (C)MRC concentrate on. Most charities do not fund basic science, as it is difficult to raise money for research that has no apparent relevance to disease sufferers. It is important to add, though, that all basic research has a connection to a specific disease(s). Sometimes this connection can be clearly identified before research is initiated; in other words it is only by chance that basic research leads to discovering the cause and cure of a disease. An example of the former is the previously discussed DNA research project supported by the (B)MRC which was thought to hold great potential for understanding the cause of Muscular Dystrophy. Similarly, basic research conducted by the (B)MRC/(C)MRC into muscle fibre has long been thought to assist charity-funded scientists in understanding the causes and cures for, physical handicaps.
Unlike charities, the (B)MRC/(C)MRC begin their research by examining the normal functions of a healthy body, for example: how muscle fibre works, how the brain functions, or how the body's immune system operates. These types of studies provide the opportunity for the abnormal to 'spring-out' of an understanding of the normal. Occasionally it is advantageous for basic researchers to understand the 'normal' by examining disease conditions which pervert normality.

Both the (B)MRC and (C)MRC argued that they are in a difficult position to fund basic research since it is less appealing to the public than the disease-related research supported by charities. In correcting this, both agencies have given priority to public education on the relevance of basic research in finding the causes of and cures for diseases. This is because it has become increasingly difficult to justify basic research to-taxpaying publics who see people dying of specific diseases. In other words, the (B)MRC and (C)MRC's marketing strategy has been to strengthen the connection in the public's mind between basic research and applied research. As the (B)MRC respondent noted:

"Our adoption of this approach has been influenced – perhaps instigated is the right choice of words – by the large number of questions that we are asked either in Parliament or by the media. It's part of our mandate to prove ourselves accountable to the public in a way that the lay person can understand."

56British Interview; Medical Research Council, 2 April 1987.
In the process of doing so, the (B)MRC has written a computer programme which classifies their grants as to their relevance to specific diseases. The problem with this is that there are endless variations in the (B)MRC’s formulation of their commitment to specific diseases, since basic research may overlap with ten different disease areas. For example, in response to a parliamentary question relating to the government’s research commitment to cystic fibrosis, the figure of £1 million was supplied by the (B)MRC. The Cystic Fibrosis Research Trust described this figure as "... ludicrous since of that amount only £30,000 has ever been specifically earmarked by the government for cystic fibrosis research, the remaining £970,000 was spent on related chest and respiratory investigations". While the (C)MRC does not have a comparable computer programme, it has recently appointed an ‘information officer’, who liaises with the media, as a means of publicizing the (C)MRC’s contributions to medical research progress. In both countries, these two approaches symbolize that governments are aware of its need to defend their research programmes.

Chapter four listed a number of reasons why charities representing less popular diseases like schizophrenia, bowel disease, and sexually transmitted diseases, encounter difficulty raising voluntary donations, despite the large number of people

57British Interview; Cystic Fibrosis Research Trust, 24 February 1987.
afflicted. One might argue that the state has a responsibility to fund disease areas that are under-funded by charity. If this is the case, then the question remains why successive governments have operated like their charitable counterparts by giving less support to unpopular and horrific diseases. Furthermore, why have the British and Canadian governments strongly endorsed cancer and, recently, AIDS research?

The combined government and charitable commitment to cancer research varies dramatically between Britain, Canada and the United States (U.S.). In the U.S. approximately $9.98 billion is spent on cancer research. With a population of 250 million, this represents almost $4 per capita. In Britain, with a population of 50 million, approximately $75 million is spent on cancer research; this translates into £1.50 per person. With Canada's 25 million population, £25 million is spent on cancer research, representing £1 per person. Although Britain spends 30 per cent more per capita on cancer research than Canada, data indicate that this is far more than is spent on less popular diseases in each country.58

The (B)MRC and (C)MRC have defended their records by arguing that they fund the best quality research applications which happen to come from scientists working in the cancer field. In the (C)MRC's own words:

"We would gladly support research into the less

58Data for cancer research expenditures in Britain, Canada and the United States obtained from the National Cancer Institute of Canada. Canadian Interview; National Cancer Institute of Canada, 28 November 1986.
popular areas on a larger scale but we can only do that if we receive grant applications from skilled scientists who have better proposals than researchers in the area of cancer."

Herein lies the fundamental problem facing charities representing less popular diseases. Since these organisations encounter difficulties raising voluntary donations, they cannot afford to develop a pool of talented young investigators in their disease area. In contrast, large charities like the National Cancer Institute of Canada and the Cancer Research Campaign have the resources to groom researchers from the beginning of their careers until they are fully able to compete for government funding. Furthermore, the larger and more prestigious research awards offered by the cancer organisations often attract the best researchers, thus leaving less capable scientists to devote their careers to researching 'orphan' diseases. When these scientists apply for (B)MRC/(C)MRC funding they are less able to compete with the 'top-flight' cancer researchers. Lastly, because of their large incomes, the cancer charities are able to support a mixture of 'applied' and 'basic' research. When their scientists apply for (B)MRC/(C)MRC funding they are able to tailor research applications to the government's requirement for an orientation to basic research. In contrast, charities representing less popular diseases are limited to funding applied research. As a result, when their scientists later apply to the (B)MRC/(C)MRC,

59Canadian Interview; Medical Research Council, 28 January 1987.

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highlighting their disease-related research careers, they are less successful than their cancer counterparts.60

Obtaining figures on the level of (B)MRC and (C)MRC funding for specific diseases is difficult since their statistics are not calculated on the basis of disease but rather disease areas. For example, instead of the (B)MRC and (C)MRC listing figures relating to their research commitment to heart research, they provide information on the amount spent on researching the circulatory system. Based on this, some charities have been able to compare their research commitment to that of government's. The figures given by the charities representing less popular diseases, illustrate that these organisations often assume the leading research role vis-a-vis the government. For example, in Britain, while the MDGGB spent £1.6 million on muscular dystrophy research, the (B)MRC spent only £150,000 on all types of neuromuscular diseases.61 Similarly, in 1986, the Multiple Sclerosis Society in Britain allocated £2 million for research compared to the (B)MRC's £460,000.62 As the Executive Director of the Cystic

60A further problem with medical research charities representing 'orphan' diseases is that charitable donations are often wasted on funding the wrong type of research. Because of the pressures exerted by volunteers to fund applied research, charities frequently try to find the cure for their disease before they know its cause(s). The (B)MRC/(C)MRC grant policy does little to correct this problem, since for the reasons identified above, they fund little basic research into these less-popular diseases.

61British Interview; Muscular Dystrophy Group of Great Britain, 19 February 1987.

62British Interview; Multiple Sclerosis Society, 25 February 1987.
Fibrosis Trust explained:

"I have only heard of one project which could be called cystic fibrosis research that has been funded by the (B)MRC, and that was several years ago. Even that research project was funded at a token level of £30,000. As far as I am aware the (B)MRC does not fund a single investigation which is specifically related to our disease." 63

In Canada, it is also difficult for charities to know how much the (C)MRC is spending on specific disease research. Only one respondent - The Canadian Cancer Society - was able to give a precise figure. Of the remaining 17 respondents, 16 viewed themselves as the leading research funding agency. Likewise, 22 of Britain's 26 charities interviewed saw government as funding less basic research in their specific disease area than applied research funded by themselves. Most respondents claimed that this knowledge was acquired by the scientists themselves who tend to know better than anyone, where research money emanates from.

Much of the existing Canadian and British science literature argues that the (B)MRC and (C)MRC are insulated from political influences over the allocation of research budgets amongst various disease areas.64 However, this can be challenged by focusing on how the (B)MRC/(C)MRC research policies are determined and the role played by charities and government in influencing this

63Ibid.

In Britain, one of the major influences on the (B)MRC, which is often overlooked, is the DHSS. This department has representatives on all the (B)MRC's Research Boards and senior officials attend all (B)MRC executive meetings. The DHSS is also involved in nominating members of the (B)MRC's four Research Boards giving them direct influence on research priorities. The DHSS' own priorities are, in turn, influenced by several forces including, strong lobbies organized by charities as well as pressures from elected officials. Not surprisingly, the strongest and most effective lobbies come from organized interests representing popular diseases like cancer. The cancer charities have the capital and human resources to sway the attitudes of elected officials which, in turn, are filtered down through the DHSS and eventually to the (B)MRC. As one executive director from a small British charity noted:

"In the medical research policy field politicians are reactionary - they respond only to strong pressure and unfortunately that has not been forthcoming from us, but it has come from the cancer research charities. It is not the civil servants that are controlling the government's research priorities, it is the politicians themselves who bend under political pressures. Until we develop a strong lobby, (disease name omitted) will always be disregarded by...

65 The four Research Boards are the Neurosciences and Mental Health Board, Cell Biology and Disorders Board, Physiological Systems and Disorders Board, and the Tropical Medicine Research Board.
Similarly, the lobbyist for the Canadian Cancer Society remarked that "our success in influencing government research priorities is clearly a result of continual pressure being placed on both elected and unelected officials." The Canadian Geriatrics Research Society explained that, while millions of Canadians suffer from the debilitating effects caused by the aging process, the federal government's response in funding research in this area has thus far been limited. This is likely to change in 15 years when an extra 20 per cent of Canada's population turns 65 (retirement age) and the financial burden of supporting an economically unproductive population becomes too great. In Britain, the Back Pain Association has provided government officials with statistical evidence demonstrating the economic costs of this affliction, including the number of lost working days and related NHS costs. Thus, in both countries, evidence suggests that governments are often responsive to public pressures which include economic arguments when determining research priorities. One can argue this is being done to the exclusion of any substantial consideration of incidence rates.

66British Interview; March 1987.
67Canadian Interview; Canadian Cancer Society, 30 January 1987.
68Canadian Interview; Canadian Geriatrics Research Society, 12 January 1987.
In Canada, departmental officials from Health and Welfare, as well as elected officials, frequently attend (C)MRC organisational meetings where research agendas are set. Furthermore, in the cancer and spinal cord disease areas it has recently been demonstrated that federal politicians have even bypassed the (C)MRC and become directly involved in acquiring research funds for popular, high profile, diseases. For example, in 1979, a young Canadian named Terry Fox, who had lost a leg from cancer, attempted to run across the country. His run evoked a tremendous charitable outpouring, eventually raising £26 million dollars (£13 million) for the National Cancer Institute of Canada (NCIC). The Liberal government of the day dramatically increased its commitment to cancer research by $8 million (£4 million) in the one year period 1980 - 1981. As a result, the NCIC collected more money for research than was possible to spend, given the shortage of qualified cancer scientists. Prior to the Terry Fox run, the Canadian cancer research community had established an equilibrium of researchers to match existing resources. With the sudden insurgence of charitable money and (C)MRC funds (the latter for sheer political reasons) the cancer field, for a short time had more money than talent.69 Similarly, in 1986, Rick Hansen - a Canadian suffering from a spinal cord disease, successfully travelled around the world in a wheelchair. When Hansen arrived in Ottawa during what was popularly referred to as his 'marathon

of hope’, the current Prime Minister, Brian Mulroney, staged an elaborate press conference where he pledged $1 million (£500,000) in taxpayers’ money for spinal cord research. In response, one Canadian respondent explained:

"Where was the government money for spinal cord research before Rick Hansen came along? Better still, where do you think the government will stand on spinal cord research when Rick Hansen has finished his trip. I think it is disgraceful that medical research priorities are determined by political whims."

A. Determination of government research priorities: the case study of AIDS

Among medical research charities, the AIDS issue has triggered strong disapproval of the British and Canadian government’s tendency towards funding popular diseases. In both countries, the government has approached the AIDS problem on two fronts, through education and research. On 26 February 1987, the British government announced that it would channel £14.5 million to the (B)MRC specifically earmarked for AIDS research.\(^1\) Prior to that, the government had funded a £20 million public education campaign that included the distribution of 23 million leaflets to every household bearing the slogan "AIDS Don’t Die of Ignorance". This was augmented with a television advertising campaign urging people to read the literature. In January 1987, the Canadian

\(^{70}\) Canadian Interview; Canadian Geriatrics Research Society, 12 January 1987.

\(^{71}\) The Times, 26 January 1987.
government responded in a similar way by committing $39 million (£19.5 million) to AIDS research and by funding a comprehensive AIDS awareness campaign through the media. As argued in chapter five section IV. A, the early response to AIDS in 1980 in both countries was slow when the disease was thought to affect only male homosexuals. When epidemiological studies revealed the potential danger to heterosexuals, government research and education funding was increased dramatically. Now the administrators of some charities have criticized the government for writing a blank cheque for AIDS researchers. Most respondents interviewed, felt the reversal in government policy towards the disease was influenced by public opinion to find a cure for a disease described daily in the media in such terms as, 'worse than the Black Death' and, 'a scourge of pandemic proportions'.

In 1984 the British government established a special Cabinet committee to consider the need for funding AIDS research, it was to collect evidence from many sources, including pharmaceutical companies, charities and the (B)MRC. In doing so, the government’s response to AIDS differed from its response to funding other diseases. Normally the Advisory Board for the Research Councils (ABRC) makes its case to DES each year for the money it needs for bio-medical research, based on information collected from the (B)MRC. The ABRC’s bid is then passed on to the Treasury where the funding level of the science budget is determined. However, in the case of AIDS, the Cabinet committee

liaised directly with Treasury officials to encourage the development of an effective AIDS research programme. The extra £14.5 million given to the (B)MRC was a result of public and political pressures combined with the (B)MRC’s own special pressure on government for increased funding.73

As in Britain, additional funds for Canadian AIDS research were attributed to political interventions. Jake Epp, the Minister of Health and Welfare, established the National Advisory Committee on AIDS (NACA) to advise him on any issue relating to the ‘research and prevention of this disease’. Similar to the special Cabinet committee in Britain, NACA was instrumental in negotiating the $39 million (£19.5 million) increase to the (C)MRC’s budget. The (C)MRC’s early response to funding AIDS research differed from the (B)MRC in that it bypassed existing peer review committees by running an ‘open grants competition’.74

In doing so, a respondent identified at least one problem that arises when medical research becomes politicized.

"Because there has been a lot of public pressure placed on the government to find a cure for AIDS, the politicians have dramatically increased the (C)MRC’s research budget. However, in doing so they have also tampered with their granting mechanisms. The (C)MRC’s open competition for AIDS research has called into question the (C)MRC’s independence and scientific reputation. Via the rumour mill, you hear that AIDS research projects are being funded despite their inferior quality. In other words, successful AIDS

73British Interview; Medical Research Council, 2 April 1987.
74Toronto Star. 17 January 1987.
This has angered Canadian medical research charities for two reasons. First, by offering special 'AIDS Funding', some charities have feared losing their best scientists who are naturally inclined to 'grab the carrot' being offered by government. Second, charities representing less popular diseases have argued that the money for AIDS research would be taken from other research programmes thereby displacing the already minimal investigations being conducted in their disease area by (C)MRC supported scientists.

The major criticism that British and Canadian charities expressed of their government's response to AIDS centred on the notion of incidence rates and their role in determining government research priorities. For example, in early 1987 the Cystic Fibrosis Research Trust argued that government spends £14.5 million on AIDS research when a mere 389 people have died from the disease, while only £30,000 has been spent on cystic fibrosis research where 400 new cases are diagnosed each year in Britain.76 Governments have justified their level of spending on AIDS research because the disease is not just debilitating but inevitably fatal. Yet, 95 per cent of all cystic fibrosis

75Canadian Interview; McMaster University Medical School, Department of Pathology, 19 January 1987.

76British Interview; Cystic Fibrosis Research Trust, 24 February 1987.
patients also die by the time they have reached their early thirties.77 Similarly, in Canada, The Alzheimer Society argued "that it is scandalous that government earmarks $39 million (£19.5 million) for AIDS research when 224 people have died from the disease compared to only $1 million (£50,000) for research to help the 30,000 existing Alzheimer's sufferers".78 The charity's executive director recognized that Alzheimer is not a contagious disease like AIDS but nonetheless argued that unlike Alzheimer's, AIDS could be prevented by individual action. This last point has galvanized that charity's (and others) disaffection with the government's response to AIDS. As one respondent remarked:

"I personally feel bitter about the government's handling of the AIDS issue. It is frustrating to watch government respond to a disease like AIDS just to score political points when we are working tirelessly to raise voluntary donations; it strikes me as absolutely uneven and disproportionate. It is insulting when government spends this amount on researching a disease that could be prevented by people simply exercising greater morality. In turn, government spends a mere pittance on researching our disease which cannot be prevented."

Both British and Canadian charities have had difficulties expressing public discontent with the government's handling of the AIDS issue. Medical research charities have not wanted to give

77Ibid.
78Canadian Interview; Alzheimer's Society of Canada, 10 February 1987.
79British Interview; Cystic Fibrosis Research Trust, 24 February 1987.
the donating public the impression that charities representing different disease areas are competing among themselves because inevitably this would dampen all fund-raising efforts. Again, the medical research charities have not wanted to condemn the state spending more on medical research, since overall this remains a fundamental objective of most organisations. Moreover, and this is an argument advanced by only a few charities, basic research of relevance to AIDS, which is funded through the (B)MRC/(C)MRC, might actually yield important results about the body's immune system that might be relevant to other virus-based diseases.

AIDS has highlighted the extent to which the (C)MRC and (B)MRC are susceptible to political influences in the determination of research priorities. One conclusion which departs from widespread belief is that medical research charities and the (B)MRC/(C)MRC are not 'fully' complementary, since charity and government fund the same popular diseases at unrealistically high levels in comparison to less popular diseases with high rates of incidence. Governments will continue to fund popular diseases in response to public pressure as a means of augmenting its support, while the level of voluntary support for charities will always be determined by the nature of the disease being represented (chapter five section IV. B). Unfortunately the forces at work on government and charity are the same, and the result is a dual bias in favour of particular diseases.

B. Charity and the disease lobby

Chapter three described the restrictions placed on charities...
with regard to their political activities. Despite the law
British and Canadian charities have nonetheless become drawn into
the political process to better achieve their aims and objectives.
Because of the British and Canadian governments' susceptibility to
public influences, and the resulting tendency towards funding
popular diseases like cancer and AIDS, it is not surprising that
charities representing less popular diseases have begun to lobby
government as a means of correcting this imbalance.

The Back Pain Association (BPA) is one British charity that
has successfully influenced government to increase its research
commitment towards their disease area. In 1973, the BPA presented
its own study to government using 'Whitehall statistics',
illustrating the economic costs that back pain was levying on the
National Health System. The study concluded that government and
the British taxpayers could actually save money if more was spent
on research and if a cure was found. The more interesting point
is the ways in which this charity convinced elected officials to
consider their report:

"Our report would never have seen the light of
day in Parliament if it were not for our chairman
- Stanley Grundy - who was at the same time the
Chairman of the Conservative Association of
Twickenham."

80

The Back Pain Association's chairman was able to induce his Member
of Parliament (Tobby Jessel) to ask questions of the then Minister
of Health, David Owen, concerning the charity's report. In the end, the government did what it normally does when it is confronted with a unique problem; it appointed its own committee of inquiry. In 1976, the committee was established and chaired by Professor Archy Cochrane who presented his report three years later. It concluded that "the economic costs of back pain equalling 33.3 million lost working days warrants the government to make this highly debilitating disease a research priority."81

In Canada, too, charities have used economic arguments in their plea to government to spend more towards researching their particular disease. Many of the arguments strike at the root of other government policies relating to Canada's health-care system. For example, the Canadian Psychiatric Research Foundation (CPRF) has provided statistical evidence to government indicating that it could save tax dollars if a small proportion of the budget spent on institutionalizing mental health patients was redirected towards research. In CPRF's own words:

"If government took this money and reallocated it to research, it would more than pay back itself over the long run. Our lobbying efforts strike at the fundamental government policy which is impregnated in the system. The institutional infrastructure already in place used for 'warehousing' mental health patients is proving difficult to dismantle."

81 Ibid. This report has remained unpublished.

82 Canadian Interview; Canadian Psychiatric Research Foundation, 8 January 1987.
The CPRF further explained that decision makers have been unwilling to act on its advice since government has been inundated by other interest associations like the Canadian Civil Liberties Association. The demands made by them have been to maintain the status quo, and actually to increase the number of patients committed to psychiatric hospitals especially those people with past criminal convictions.83

In both countries, charities have become adept in utilizing personal contacts in their attempts to influence government to increase spending on researching their disease. Britain's Multiple Sclerosis Society explained that, "in the Houses of Parliament there is what I regard as a Multiple Sclerosis Party which is a group of members in both Houses who are sympathetic to the aims and objectives of our charity".84 As with most charities, the Multiple Sclerosis Society has long-standing relations with elected officials from both sides of the House. These relationships are mutually beneficial since charities have spokesmen to represent their interests in debates on science or health-care issues. In return, members are supplied with information and ideas on what needs doing in these policy areas. As one British charity executive remarked:

"If we need assistance, I know that I can go to certain members in either House and obtain that assistance knowing full-well that I'll get a

83Ibid.
84British Interview; Multiple Sclerosis Society, 25 February 1987.
sympathetic hearing. We can exploit this relationship if we consistently keep our friends in Parliament informed of the progress that we are making and give them credit for the assistance they have given us in the past.”

85

In both countries, executives from charities of all sizes spoke of their networking with politicians as a means of influencing government to spend more money on research in their disease areas. Politicians often attend ‘gala’ fund raising events where personal contacts are established and maintained. One British respondent, who asked that his or her identity not be revealed explained that: “Tony Newton, the present Minister of Health, is a good friend of this organisation. He was our keynote speaker at our last annual meeting and is closely attuned to what this charity is doing and what we want government to do”.86

Likewise, in Canada, the Diabetes Association spoke openly of the way in which they have used a senior aide to the Prime Minister as a means of increasing the government’s commitment to Diabetes research.

“We feel that our contact in the Prime Minister’s Office, who is himself a diabetic and a long time school friend of Mulroney, has his ear. We are optimistic that he will be able to get the CMRC to ‘beef-up’ its research commitment to

85British Interview; Cystic Fibrosis Research Trust, 24 February 1987.

86British Interview; February 1987.
Several British and Canadian charities were quite willing to provide the details of their contacts with elected and non-elected officials. However, the vast majority of respondents noted that they did not see lobbying or interaction with government over research-related issues as part of their formal mandate. One charity official explained that they had encountered a 'backlash' from the donating public when they began to lobby government over its research commitment. "If lobbying is executed with little discretion, it can often be viewed by the public as an intangible product and as a misapplication of charitable funds."88 In contrast, expenditures on medical research have always been seen as a 'hard product', something whose value can be easily measured and evaluated. This frustrated the Executive Director of the Kidney Foundation who argued that a small investment of $50,000 (£25,000) to pay for a full-time lobbyist in Ottawa might possibly yield $2-3 million (£1-1.5 million) more for kidney research over a five year period. This forecast is based on similar results obtained by the Canadian Cancer Society (CCS) after they hired their own lobbyist for this specific purpose.89 The arrangement

87 Canadian Interview; Canadian Diabetes Association, 4 December 1986.

88 Canadian Interview; Canadian Foundation for the study of Infant Deaths, 8 January 1987.

89 Canadian Interview; Kidney Foundation of Canada, 3 December 1986.
has worked well for the CCS partly because it has involved the charity's volunteers. Their Ottawa lobbyist must report to the charity's 'public issues committee' which consists of 25 volunteers from across Canada and which meets four times a year. The committee sets policies on various issues relating to cancer research and gives directives to its lobbyist. Ken Kyle - the CCS' lobbyist - described his responsibilities in the following way:

"My role is to advocate, which means I am a small '1' lobbyist. I spend a lot of time with the media drafting news releases and I attend news conferences speaking on behalf of the Canadian Cancer Society. I also prepare briefs made to the government as well as write letters to ministers and government officials on various issues of concern to this charity. Aside from the 'research issue' my time is taken up with lobbying government on approximately twenty other issues."

Most medical research charities have not followed the example set by the CCS since they have encountered difficulties receiving the authorization from their Board of Directors to hire a lobbyist. In these cases it was explained that the people sitting on these boards are of two types. First, there are disease sufferers who have viewed patient services and medical research as a priority and lobbying as a mere 'luxury'. Second, there are high-profile business executives and lawyers who do not seem to apply entrepreneurial criteria when making administrative decisions.

90 Canadian Interview; Canadian Cancer Society, 28 November 1986.

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decisions on behalf of their charity. These people lose their eagerness to take risks, (such as hiring lobbyists) because of their responsibility to the public who have given voluntarily of their time and money. In making this point, the Canadian Alzheimer's Society gave an example:

"We presently have approximately $100,000 (£50,000) of investment income but our Board is adamant about putting this money in three-month term deposits at a mere six per cent interest. Their thinking is that we might need to withdraw the money in the event of an emergency. In the ten years that I have been here we have never had such a need. Alternatively, we could have had this money in one year term deposits accruing ten per cent interest. In other words, according to my calculations this equals $30,000 (£15,000) in lost revenue. This may not seem like very much but it is enough to fund a major research programme for three years."

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Of course, a charity's refusal to hire a full-time lobbyist does not preclude them from presenting their views to government in many other ways. Most officials from British and Canadian medical research charities remarked that they 'could actually affect more substantial changes in government policy through more subtle means that did not involve professional lobbyists'. It is difficult to determine whether this is the case or whether medical research charities are simply reluctant to hire full-time lobbyists because of legal restrictions on their political activities. Of the 44 British and Canadian charities interviewed,

91Canadian Interview; Alzheimer's Society of Canada, 10 February 1987.

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all claimed they were not either intimidated by or confused about the requirements of this law, and they refused to identify it as a reason for not hiring lobbyists. This response seems to contradict the views of the Charity Commission. In an interview with an official from the Commission it was revealed that recently they had given legal advice to several medical research charities on this very matter. The charities were informed that:

"any expenditure of charitable funds on objects outside of the organisation's remit or on activities deemed 'partisan' would be classified as unlawful political activities. Expenditures on non-partisan issues considered to be part of the charity's objects or ancillary to thereof would be acceptable activity according to the Charity Commission's interpretation of existing common law."

92

Since lobbying government for a greater research commitment would be difficult to turn into a 'partisan issue', and would be ancillary to a charity's object, an alternative explanation for the absence of paid lobbyists must exist. The most likely reason, as suggested above, is that medical research charities (indeed all types of British and Canadian charities) fear that lobbying public will take an 'edge-off' efforts to raise voluntary contributions. Many British charities stated unequivocally that they have never lobbied government on any issue and would never consider this as a 'proper' activity for a charity to engage in. One British respondent boldly remarked:

92British Interview; The Charity Commission, 31 March 1987.

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"Charity and politics mix like oil and water. We are conscious that the public and our volunteers see charity as the antithesis of government. We are not part of the public policy process but rather free and independent of its forces."

This might seem convincing, indeed logical, given the existing literature describing the freedom and independence from government that British charities have historically enjoyed. Perhaps the best examples are those scholarly works describing the history of the Charity Organisation Society. However, in interviewing a retired senior DHSS official, a rather different scenario was described:

"When I sat in at meetings with Ministers when they received executives from medical research charities, their plea was typically that they wanted government to spend more on research in their disease area."

A list of the charities supplied by the respondent who made representations to elected officials in this fashion included three British charities that denied having any contact with government. The DHSS official went on to describe two instances where charity executives attempted to 'down-play', underscore or

93British Interview; February 1987.


95British Interview; February 1987.
to cover-up their interaction with government:

"When I retired I had two of these charity executives approach me and urge me not to make public that they met with Ministers to make a special plea."

Presumably, these charity executives did so as their meeting with Cabinet ministers somehow clashed with the 'spirit of volunteerism' which is grounded in this notion of independence.

In both countries, the relationship between medical research charities and government has traditionally been defined by a mutual acceptance of each other's autonomy. Historically, many smaller British and Canadian charities have viewed the (B)MRC and (C)MRC, respectively, as being the senior partner in the medical research 'firm'. These charities viewed their role vis-a-vis the government as simply adding money to a particular disease area also funded by the state. For many years, charities did not see themselves as being in competition with the (B)MRC/(C)MRC, since the two could co-exist independently yet be complementary to each other. Because of this, the charities did not appreciate the (B)MRC/(C)MRC telling them what kind of research they wanted funded and a similar attitude was adopted by the research councils. This did not pose serious problems since the financial contributions of charities towards research was modest in proportion to the research funded from the public purse. However, beginning in the early 1960's, and continuing throughout the

96Ibid.
1970's, many new research charities were established which quickly amassed large incomes through successful appeals to the public for voluntary contributions. In both countries, the financial success of these charities afforded them the opportunity to examine and question for the first time, the manner in which their respective governments financed medical research. The types of lobbying that has been undertaken subsequently by charities, in both countries, appears to be symptomatic of their disaffection with the governments' apparent bias towards funding popular diseases at the expense of less popular, yet highly prevalent diseases.

(B)MRC and (C)MRC officials were asked to comment on whether the formal representations made by charities had any affect on the way in which they divided their research budget among the various disease areas. The (B)MRC explained:

"I suppose we may not even know which charities are trying to influence us in that sort of way. It is difficult to determine whether DHSS is telling us about every instance where charities have lobbied them. However, the Minister has followed through on several occasions and asked us why we have not funded a certain area."

(B)MRC officials were quick to add that a DHSS directive to spend more on researching a disease should not necessarily be credited to a successful lobbying effort by charity but rather to the DHSS's own appreciation of what is being funded by charity and government in a specific research field. In comparison to

97British Interview; Medical Research Council, 2 April 1987.

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Britain, (C)MRC officials flatly rejected the assumption that the Canadian Department of Health and Welfare would ever acquiesce to the demands made by particular charities to have more spent on researching their disease. Dr. Belec, the (C)MRC's information officer added:

"We are aware of the increasing contributions of medical charities in this country and we see their growing politicization as a natural outgrowth of that. It is no surprise to us that the Canadian Cancer Society has hired a full-time lobbyist in Ottawa. To my way of thinking, this is an early signal that Canadian charities are moving in the direction of their U.S. counterparts who have employed 'hard-ball' lobby tactics for many years. The U.S. cancer lobby during the early 1970's, which succeeded in influencing Nixon to declare his 'war on cancer', is a prime example of what charities can achieve."

Lastly, it is interesting to note how the AMRC has responded to the British government's bias towards funding popular diseases like cancer and AIDS. For obvious reasons, the Association is unable to criticize government for spending too much on cancer research, since this would alienate the cancer charities which carry much of the financial burden of administering the AMRC. Instead, the Association is in the process of implementing a new educational programme that seeks to inform the public about diseases that are relatively neglected and under-funded by both government and charity. The approach is designed and implemented with two goals in mind. It is aimed at helping smaller charities

98Canadian Interview; Medical Research Council, 28 January 1987.
raise more money for less popular diseases. Furthermore, it seeks to mobilize the public in pressuring government to allocate more research dollars for less popular diseases without decreasing the existing amount expended on cancer and AIDS research. As an adjunct to this, the AMRC has lobbied the government to increase the (B)MRC’s budget for all types of research, with the view that a more equitable distribution among disease areas can be achieved with additional funds from the (B)MRC.
Chapter Seven
Charities’ Lobby Against Privatizing Medical Research

This chapter examines both the state’s declining responsibilities for financing medical research in Britain and Canada and also the response by charities to this development. In Britain, the (B)MRC’s budget has been cutback so that it is no longer capable of supporting the ‘alpha’-rated research applications it receives from scientists. These applications are now being sent to the charities for funding. In Canada, the (C)MRC’s budget has been frozen and all future increases are to be calculated on the basis of extra money generated by the private sector – in particular money raised by charities. This suggests that, in both countries, the state has shifted a portion of its responsibility for the support of a bio-medical research infrastructure to the charities. British medical research charities have used their association – the AMRC – to lobby against these cutbacks and in doing so, have succeeded in altering public policy decisions that affect the progress of ‘disease related research’. In Canada, where no comparable association exists for medical research charities, similar attempts to influence public policy have been less successful.

We argue that medical research charities are not a ‘perfect’ alternative funding source to government. For example, charities
are unable to support the 'basic' long-term research which has been the traditional target of the research councils in each country. In essence, this chapter exposes the interdependencies between charity and government in the medical research policy field. This supports the assumptions that the two are not necessarily competitors but rather mutually-dependent actors in the bio-medical research community. In illustrating this, the chapter divides into two sections. The first section describes the British government's declining commitment to bio-medical research since 1980 and discusses how British medical research charities have successfully managed to increase their incomes during the same period. Furthermore, arguments are outlined as to why charities are ill-suited to assuming a greater responsibility for funding medical research in the wake of declining government commitment to this policy field. Section II examines the federal government's newly introduced formulae for funding Canadian bio-medical research. It is argued that with this new arrangement the Canadian government (like the British government) has shifted a portion of its responsibility for funding this policy field to charities.

I. Government Sponsored Research in Britain: A Period of Decline

Since 1980, the most important issue affecting relations between medical research charities and the state has been the state's declining contribution to the funding of research and development. In Britain, central authorities account for
approximately half of the nation’s total spending on research. However, as Figure 7.1 illustrates, a substantial proportion of this expenditure (approximately 50 per cent) is allocated to defence-oriented research. This pattern of resource distribution differs markedly from that of Britain’s major competitors, including Canada, with the notable exception of the U.S. (see Figure 7.2). The priority that the British government has attached to defence research since 1980, results in a higher proportion of GDP being channelled into this area than in any of the other major OECD nations shown in figure 7.3, with the exception of the United States. Furthermore, it is precisely this bias that has made government cutbacks to non-defence research areas seem unfair to medical researchers and their supporting organisations including the (B)MRC, AMRC and the individual charities.

British Government expenditures on ‘non-defence’ related research originates from many different sources. The data contained in Table 7.1 indicate that in 1983/84 government departments together accounted for 47 per cent of spending on this activity although there are marked variations in the contribution to this total from individual departments. However, it is the direct funding by government of research undertaken in universities and by the five research councils that is the specific concern of this section. As the Secretary of State for Education and Science stated in 1985:

"The Research Council's and Government..."
Figure 7.1

British Government Research and Development Expenditure by Broad Sector, 1983/84

Total spending = 3.923 Billion

Figure 7.2

Government Funded Research and Development: Proportion of Total Allocated to Defence Research in Selected OECD Countries in 1984

Figure 7.3

Proportion of Gross Domestic Product Allocated by Government to Defence Research in Selected OECD Countries in 1983

### Table 7.1

**Government Expenditure on Research and Development by Department in 1983/84.**

<table>
<thead>
<tr>
<th>Department</th>
<th>Millions</th>
</tr>
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<tbody>
<tr>
<td><strong>Civil Departments</strong></td>
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<tr>
<td>MAFF</td>
<td>118.6</td>
</tr>
<tr>
<td>DES</td>
<td>11.4</td>
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<tr>
<td>DEn</td>
<td>34.0</td>
</tr>
<tr>
<td>UKAEA</td>
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</tr>
<tr>
<td>DoE</td>
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<tr>
<td>ODA</td>
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</tr>
<tr>
<td>DHSS</td>
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<td>HSC</td>
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<tr>
<td>Home Office</td>
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</tr>
<tr>
<td>DTI</td>
<td>313.1</td>
</tr>
<tr>
<td>DTP</td>
<td>27.8</td>
</tr>
<tr>
<td>NI Departments</td>
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<td>Other Departments</td>
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<td><strong>Total Civil Departments</strong></td>
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<table>
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<tr>
<td>ESRC</td>
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<tr>
<td>MRC</td>
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<td>NERC</td>
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<td>SERC</td>
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<td><strong>Total Research Councils</strong></td>
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<td><strong>Total Civil</strong></td>
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<table>
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<th><strong>Ministry of Defence</strong></th>
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<tbody>
<tr>
<td>MOD (Research)</td>
<td>357.2</td>
</tr>
<tr>
<td>MOD (Development)</td>
<td>1555.8</td>
</tr>
<tr>
<td>MOD (Staff &amp; Superannuation)</td>
<td>71.0</td>
</tr>
<tr>
<td><strong>Total Defence</strong></td>
<td>1984.0</td>
</tr>
<tr>
<td><strong>Net Total</strong></td>
<td>3923.0</td>
</tr>
</tbody>
</table>

departments constitute the nation's science base which provides for our national research capability and trains the highly qualified manpower essential for our increasingly science-based society."

In 1983/84, universities and the research councils received a total of £1,031 million from the central government. This amount represented 26 per cent of all government spending on research and development during that financial year. However, since 1980, both arms of the dual support system have experienced severe financial pressures that have in turn raised concerns about the level and quality of medical research conducted in Britain. The Thatcher government has premised its economic policies on the idea that an economy grows in direct proportion to its efficiency. According to this theory people and institutions become more prosperous to the extent that they use their resources with decreasing wastefulness. This has been relatively uncontroversial in commercial enterprises but since 1980, the British government has applied the same theory to the management of essentially non-commercial enterprises - including the NHS and bodies engaged in medical research. Budgets have been steadily reduced, since they represent a 'drain' on public expenditure; and reducing the Public

1H.C. Debs. (U.K.), Vol 80, Col 1125.

2This figure is calculated by adding the total research expenditure of the five research councils with comparable figures for the UGC. (see Table 7.1) These statistics are derived from the Cabinet Office, Annual Review of Government Funded R and D, 1985. London: HMSO, 1986.
Sector Borrowing Requirement is the *sine-qua-non* of policy.3

As discussed in Chapter five section V. A and B, one of the major sources of financial support for research within the university system is the UGC.4 This body distributes resources to the universities in the form of block grants to cover teaching and research. The precise allocation of UGC funds between these two activities is unknown5 but research is now estimated to account for approximately £600 million of the total each year.6 In scientific fields, the UGC’s input into research is designed to provide the basic necessities for research to be conducted in university departments. This is believed to be essential if speculative ideas are to be generated and developed to the stage where they may attract support from external sponsors.7 These

3*The Lancet*. 1 December 1985. The article went on to explain that when these expenditure cuts are discussed by ministers, there is nobody in the Cabinet who speaks up determinedly for medical and scientific research.

4Funds also come from research councils, government commissions, industrial sponsorship and charitable bodies.

5Estimates of the volume of UGC resources channelled into research are based on a long-standing formula which allocates about one third of university workers’ time to this activity. This division originates from an exercise undertaken in the 1960’s in which university staff maintained a record of their activities for a period of one week *New Scientist*. 5 September 1985. However, apportionment in this way may be less relevant today and a study is currently in progress which it is hoped will provide better information on the volume and distribution of university research.


outside supporters would include bodies like the (B)MRC, medical research charities, and pharmaceutical companies. However, the UGC has experienced cuts in its budget since the start of this decade. Overall, University funding has declined by almost eight per cent since 1981/82 and according to AMRC publications there is evidence to suggest that budgetary cuts have fallen disproportionately on research. Furthermore, it is estimated that the universities' budget is continuing to shrink at a rate of one and a half to two per cent per annum, allowing for increased costs and for the problems of setting salary increases within the government's national allowance.

Reductions in available resources on this scale have inevitably had a severe impact on the provision of basic laboratory equipment, technician assistance and other elements of the scientific infra-structure required by medical researchers. In turn, this development has resulted in some (B)MRC funds intended for use as research grants being diverted to supply basic support facilities within university science departments. Furthermore, it has meant that able medical research groups have frequently been ill-equipped with research support, even in competitive fields where being at the forefront of new scientific


9 'Where has all the stuffing gone?', Nature. 6 September 1985.
discoveries is of paramount importance.  

With regard to the (B)MRC, available data indicate that government pledges to protect the total combined income of this agency appear to have been fulfilled. Table 7.2 shows that over the period 1981/82 to 1984/85 the growth in the science budget exceeded increases in price inflation by four percentage points. However, this apparent ‘surplus’ should not be interpreted as real growth in the capacity to support medical research for several important reasons. Resources available to the (B)MRC have increasingly been deflected from ‘investigative’ uses to meet other non-scientific costs. In addition to the demands arising from the cut back in UGC funds noted above, a growing proportion of funds have been absorbed by superannuation and restructuring expenses. Unlike government departments, the (B)MRC has been required to meet both of these costs. Expenditure on superannuation is a major financial commitment – for example, these costs absorbed 8.5 per cent of the (B)MRC’s 1984/85

10For example, the March 1981 Public Expenditure plans stated that: “The Government wish to give protection to the support of basic science, an activity that underpins further development and is a particular strength of the United Kingdom. Within the declining level of the total programme for education and science, the plans allow for provision of science to be held broadly at the current level throughout that period. It should thus be possible for the research councils, along with other activities, to maintain their selective support for research in universities and polytechnics at broadly the current level at a time when provision for higher education is planned to decrease.” See, HMSO, Public Expenditure Accounts, 1985/86. London: HMSO, 1986, p. 62.

11This view was re-affirmed by (B)MRC officials when interviewed. British Interview; Medical Research Council, 2 April 1987.
### Table 7.2

**Science Budget in 1981/82 to 1988/89**

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<th>YEAR</th>
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<tr>
<td>1986/87 projected</td>
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</tr>
<tr>
<td>1987/88 projected</td>
<td>613.5</td>
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</tr>
<tr>
<td>1988/89 projected</td>
<td>620.7</td>
<td>139</td>
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parliamentary grant-in-aid.12 According to the MRC's Victoria Harrison, "restructuring costs have been generated by programmes of early retirement, redundancy and institute rationalization. But these measures are themselves a response to real reductions in income."13

Specifically, in the 1984/1985 financial year, the MRC had to cope with an effective cut of £2 million out of the £135 million total that it was able to spend.14 Of this, £600,000 went to shore up payments from the MRC's pension fund. Another £400,000 went to meet wage settlements for researchers employed on short-term contracts to carry-out work on MRC funded projects.15 The MRC has had no control over these pay scales, which are negotiated between the Association of University Teachers, the universities and the Department of Education and Science. Furthermore, 'rounding down' somewhere in the Department of Education and Science slashed another, £500,000 off the MRC's 1984 budget, and a further £200,000 went to pay increases in the MRC's subscription to the European Molecular Biology Organization caused by the weakness of the British pound.16

13British Interview; Medical Research Council, 2 April 1987.
15Ibid. p. 27.
16The cost of subscriptions for participation in international collaborative endeavours accounts for about ten percent of the research council's total income. The largest
damage at the Dunn Nutrition Unit accounted for an additional £200,000. Furthermore, the (B)MRC had to pay £100,000 more than it expected towards the running costs of the Synchrotron radiation source at the Science and Engineering Research Council’s Daresbury laboratory.17 Moreover, in 1984 the ABRC decided to ‘tax’ the (B)MRC and the SERC in order to finance restructuring in two of its other departments, the AFRC and the NERC (in past years, in fact, a reverse flow operated). This taxation of the (B)MRC has continued up to the present, resulting in a lost income of £0.9 million in 1984/85 and £1.8 million in 1985/86.18

The central government refuses to acknowledge that the difficulties facing the (B)MRC are a result of cutbacks, but see them rather as symptoms of mismanagement during a period of ‘level-funding’.19 However, one might expect that ‘level-funding’ means that researchers could buy the same this year as they did last year. Yet the (B)MRC has not viewed it this way. The major reason for this is that the ‘cash-limit’ within which all government departments have to budget is calculated on the basis of what the (B)MRC views as unrealistic estimates of inflation in both wages and the price of equipment.20 The costs of modern proportion of this sum involved stems from the Science and Engineering Research Council’s membership of the European Centre for Nuclear Research.

17British Interview; Medical Research Council, 2 April 1987.
19British Interview; Medical Research Council, 2 April 1987.
medical research have been increasing at a considerably faster pace than the costs of those items comprising the Retail Price Index (RPI) - which is the index used in calculating inflationary increases to the (B)MRC’s budget. The electron microscope, for example, is of central importance to research in many different fields including bio-medical research as well as in metallurgy and solid state physics. Yet, the costs of the best machines have risen from £12,000 in 1968 to between £250,000 and £1.5 million today.21 The (B)MRC estimates that for the year 1984/85, actual inflation was approximately two per cent more than the ‘cash limits’ allowed for. An added annoyance has been the rigid accounting rules that prevent the (B)MRC from carrying funds over from one year to the next.22

Given the cutbacks to the (B)MRC’s grant-in-aid, the agency in turn has had to impose spending limits on the researchers it supports. For example, in 1984 the (B)MRC ordered its researchers to make do with an average cut of 16 per cent in spending on laboratory consumables which amounted to a saving of £1.4 million. Labour M.P. Tam Dalyell, along with other politicians from both sides of the House, have used Parliament as a forum for criticizing the government’s science policy. The general tenor of these criticism is evident from the following account.

"Take for example the (B)MRC Brain Metabolism Unit in the University on Edinburgh. It has a

21H.C. Debs. (U.K.), Vol. 80, Col 1136.
22'Medical Science on Crutches', pp. 26-27.
complement of some 40 staff working on both clinical and basic scientific problems. The areas of research span such illnesses as schizophrenia, depression, Parkinson's disease, Down's syndrome, Alzheimer's dementia. All are crippling diseases suffered by a significant percentage of my, and every other M.P.'s constituents. For example, 5 per cent of people over 65, and 20 per cent of people over 80, become demented and half of them suffer from Alzheimer's dementia. I am appalled to learn from constituents who work in the unit that for the six months April to September 1984, they were given only £87,000 - a reduction of 45 per cent in their expenditure for the same period last year - and nothing for capital equipment. It is quite simply the opinion of the staff that research cannot be continued under such financial constraints."

The real impact of the government's 'level-funding' policy can be measured by the number of 'alpha-rated' research applications submitted to the (B)MRC that were unable to be funded. The (B)MRC received more first-class research grant applications in 1983/84 than in any single previous year. Yet, in 1983/84 the (B)MRC was unable to fund 199 approved applications for project grants - usually of three year duration - and 22 approved applications for longer-term support for research programmes. Largely as a result of this the total number of


24The Lancet, 5 January 1985, p. 26. The recent cuts in public spending, which have led to a reduction in the (B)MRC's grant-in-aid from government is especially galling to medical scientists when their U.S. counterparts have had their medical research budgets substantially increased. For a statistical analysis of American research funding see J.K. Inglehart, 'The NIH Appropriation', New England Journal of Medicine, 31 (1984), pp. 1132-36.
research grants submitted to the (B)MRC the following year decreased significantly from 672 in 1983/84 to 527 in 1984/85. At the same time, the (B)MRC’s Secretary, Sir James Gowens, informed University Vice-Chancellors that the Council had to reduce provision for new ‘out-of-house’ programme grants by 25 per cent (in terms of the number of grants), for new project grants by about 7.5 per cent and for studentships in research and advanced courses by 30 per cent. Also, the (B)MRC reduced by ten per cent the number of intercalculated awards to medical students.25 This was seen as a serious blow to medical schools whose raison d’être has been to develop the future generations of medical scientists. Table 7.3 lists data comparing the four research councils’ funded grants with unfunded ‘alpha-rated’ grant applications from 1980 to 1985.

In addition to the (B)MRC cutbacks which resulted in the abandonment or delay of many potentially valuable research projects, the scarcity of finance is also seen to have had an undesirable impact on the distribution of those funds that are available.26 Dr. P.O. Williams, the Executive Director of the Wellcome Trust, has suggested that:

"Under present circumstances, well-established research teams may be more likely to attract financial support than less well-known groups pursuing perhaps more innovative endeavours."


26British Interview; The Wellcome Trust, 14 March 1987.
<table>
<thead>
<tr>
<th>Year</th>
<th>SERC</th>
<th>EPSRC</th>
<th>MRC</th>
<th>SERC</th>
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<th>MRC</th>
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<td>122</td>
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</tbody>
</table>


Table 7.2

Grant Funding by Four British Research Councils 1980/81 to 1984/85
Uncertainty surrounding future supplies of funds may in addition be fostering a situation in which ‘short-term’ projects with easily attainable results are favoured and long-term more fundamental research is neglected."

Debate has also focused on what is seen by some science commentators as an increasing preference for economically relevant applied projects at the expense of basic pure research. In particular, concern has been expressed that the British government now spends a smaller fraction of its research and development budget in basic research, ‘the seedcorn of tomorrow’s technologies’, than any of its major competitors. It is argued that further reductions could be highly damaging because progress in ‘applied’ fields depends on new insights in the related basic sciences. Consequently, adequate resources would need to be available to the latter in order to foster technological advance. Such support is also thought to be required to facilitate understanding of the developments emanating from research centres in other countries and to train the scientists and technologists who are responsible for transferring new knowledge from the laboratory to industry.


29 Applied research embraces investigations ‘with clear potential for wide-ranging uses in industry, medicine and so on, but where it is too early in the development of the work for specific applications and products to have been clearly determined’. See H.C. Debs. (U.K.), Vol 80, Cols 1187-1189.
The developments described above have been associated with a number of other costs. In particular, morale within the research community is said to have been damaged and, as a consequence, able young people are rejecting careers in research while others, trained at great expense to British taxpayers, are seeking opportunities abroad. For example, it has been reported from the Department of Virology at Glasgow University that only three of the 15 British Ph.D’s to graduate since 1981 are working in medical research within the United Kingdom – 10 of the group have gone to the United States.30

A. Financial success of British medical research charities

At the same time as medical research funding by the (B)MRC and UGC becomes increasingly constrained, financial support for this activity provided by the medical research charities has grown considerably. As illustrated by Figure 7.4 the volume of research money supplied by the medical research charities has increased from £37 million in 1979 to £115 million in 1984. The AMRC’s 1984/85 Annual Report records that the combined income of its 35 members amounted to £137 million in 1984 and that £115 million of this total was committed entirely to research.31 Furthermore, the latter sum understates the overall charitable commitment to research funding because it excludes the contributions of many

Figure 7.4

Association of Medical Research Charities (AMRC)
Income and Research Expenditure, 1979-1984

£ million

160
140
120
100
80
60
40
20


AMRC-1 = Total income of AMRC member charities
AMRC-2 = Total expenditure on research by AMRC member charities
(B)MRC = Total expenditure on research by the British Medical Research Council

other charities who do not belong to the Association. By comparison, the (B)MRC spent £116 million on research in 1983/84.\textsuperscript{32} The charities' contribution to medical research in 1979 amounted to just more than 50 per cent of that of the (B)MRC, while in 1984 the two sources were virtually equal. Even when price inflation is taken into account, this growth still represents a doubling of funds available from this source. It is clear that future income trends will reflect developments in the charities sector as a whole - changes in both overall voluntary-giving and distribution of growth among competing medical research charities. Focusing on the latter, individual charities are increasingly employing new and more sophisticated techniques in order to gain a greater portion of this highly competitive 'donations market'. This includes the hiring of professional fund raisers, the implementation of computerized mailing lists and the distribution of glossy fund raising literature. The extent to which medical research charities can adopt innovative approaches to marketing will therefore influence how successfully they can improve upon their present fund raising capabilities. In relation to other areas of charitable activity, it is evident from the available data that medical research charities have hitherto been successful in raising voluntary contributions. For example, in 1984/85, 18 of the 35 AMRC members were included in the Charities Aid Foundation's list of the 'top 200 grant-seeking charities' and taken together attracted 16 per cent of the 200 club's voluntary

\textsuperscript{32} Ibid., p. 5.
income of £526 million. However, more recent data suggests that the income of British cancer research charities declined slightly in real terms in 1986.

It is interesting to contrast the recent fund raising success of medical research charities with other types of charities. It may be estimated that the total 1984/85 income of these bodies amounted to £6.4 billion. In unadjusted cash terms this amount was 16 per cent greater than the previous year, 36 per cent up on the 1982/83 figures and growth may be expected to continue. One of the reasons for this optimistic outlook is that the recent famine crises in Africa may have led to a permanent increase in the numbers of people who wish to support charitable causes. The Executive Director of the British Heart Foundation explained:

"We feel optimistic that the Ethiopian Famine sparked a philanthropic nerve in people in this country that will benefit many charities operating in areas outside of Third World relief for many years to come. I personally feel the Live Aid fund raising drive educated people about being 'charitable' - it made giving fun, pleasurable and most of all a socially trendy thing to do."


35 This estimate is calculated on the basis that the income of the 'top 200 grant-seeking charities' - £956.7 million in 1984/85 - accounts for between 10 and 20 per cent of the total charitable income. See, Charities Aid Foundation, Charity Statistics, 1984/85. Tonbridge: CAF, 1985, pp. 184-199.

36 British Interview; British Heart Foundation, 3 March 1987.
However, within the group of British medical research charities interviewed some argued that a substitution effect would take place over the 'long-run' which would see Third World relief charities prosper at the expense of charities operating in other unrelated fields. As the Executive Director of the Muscular Dystrophy Group of Great Britain explained:

"We are fearful the Ethiopian crisis will have serious implications on our ability to raise voluntary donations for many years to come. Our own studies tell us that while many of the Live Aid supporters will be 'one-off' types, some people may make that cause a personal favourite. However, it is too early to forecast whether we have lost supporters to this last group."

Furthermore, and as discussed in Chapter four section I. B, some potential also exists for growth in voluntary contributions made available by industry. The Charities Aid Foundation has calculated that the leading 200 corporate donors gave £43 million to charities in 1984/85. After adjustments for inflation and an especially large once only donation, this sum was ten per cent greater than in 1983/84. On average, each of the 200 corporations donated an amount equivalent to 0.2 per cent of their pre-tax

37 British Interview; Muscular Dystrophy Group of Great Britain, 19 February 1987. According to a study conducted by the Charities Aid Foundation, charities adversely affected by the Live Aid appeal but which recovered the following year included many medical research charities (excluding those in the chest and heart field) youth organisations, arts related charities and benevolent funds. See Charities Aid Foundation, Charity Trends, 1986/87, p. 101.
In interviewing the government's Chief Scientist (1978-81), the respondent remarked that government officials view corporate giving as an area in which British charities should make a greater effort to increase their incomes. The government has supported this line of argument by illustrating that if British companies had matched the level of contributions estimated for the United States, the sum available from these sources would have exceeded £300 million in 1983/84. A number of British charities have rebuked the government's estimates arguing that drawing comparisons between the level of American and British corporate giving ignores cultural and economic differences.

At the time of writing, it is impossible to assess the impact of the 1986 budget, which contained proposals to revise tax laws on charity fund raising. These amendments have enabled individuals and companies who contribute to charities to offset donations against tax. Some predictions indicate that the changes could lead to an increase in the annual income of the charities by 30 per cent. However, in the absence of more detailed information all that can be said is that charities obtain their income in different ways from a variety of sources so that the impact of any possible alteration in the tax laws is likely to


40 The Times, 19 February 1986.
vary from one organisation to another.

While long term trends may have to remain largely speculative, there is a greater degree of certainty about the short-run prospects for charities' funding of medical research. Early in 1986, the Wellcome Trust sold one-fifth of its share in the Wellcome Foundation, the pharmaceutical company it wholly owned up to that point. The sale raised approximately £200 million which in turn has been re-invested to generate an annual income of around £15 million. Dr. P.O. Williams - The Wellcome Trust's Executive Director - explained in an interview that "all of this new capital would be employed to support medical research." 41

Consequently, if it is assumed that the other members of the AMRC maintain their current level of spending (in cash terms) then in 1989 charitable funding should amount to £133 million, thereby making them a larger financial contributor to medical research than the government via its grants-in-aid to the (B)MRC. 42 Already, British medical research charities are performing an increasingly vital role in sustaining the level and quality of

41 British Interview; The Wellcome Trust, 14 March 1987.

42 This calculation is based on assumptions that might turn out to be erroneous. For example, the projected growth in the funds made available for research by the charities may be inaccurate as, indeed, might the value of the new investment income anticipated by the Wellcome Trust. In addition, the precision of the exercise carried out above is marred by differences in the financial 'year-ends' to which different charities operate. Nevertheless, on the basis of current evidence, it seems likely that in the near future charitable bodies will be making a larger financial contribution to medical research than the government via its grant-in-aid to the (B)MRC.
British science. These charities are, for example, now able to offer financial backing for initiatives that the (B)MRC have approved but has not been in a position to support. As Dr. Harrison of the (B)MRC explained:

"Because of these cut-backs we have passed on 'alpha-rated' applications to charities whose remit embraces these proposed research projects. Additionally, we have found that the number of applications made to the MRC has decreased since the scientific community are well aware of our declining resources. Consequently, the charities have not only received more applications but higher quality ones."

The (B)MRC has expressed some concern with this development on the grounds that research grant applications submitted to the charities may not be subject to proper peer-review. This is not an entirely unfounded fear given that some charities have gained a reputation for supporting research projects based on emotion rather than on scientific merit (see Chapter five section IV. B).

B. Implications of privatizing British medical research

The AMRC has argued that it is erroneous for government to cite the recent financial success of medical research charities as a means of justifying further restrictions in the growth of resources allocated to the (B)MRC. The reasons behind this claim are easily understood. Dr. David Evered, the Ciba Foundation's Executive Director, aptly describes the paradox now facing British medical research charities:

43British Interview; Medical Research Council, 2 April 1987.
"We (British medical research charities) are the victims of our own success. It is plausible to assume that government is looking at our success in raising voluntary donations and saying to themselves ... 'here is privatization taking place without government having to legislate it' - so therefore lets cutback on the (B)MRC's budget even further."

44

In interviewing 26 of the AMRC's 35 member organisations, all agreed that the major challenge facing charities was to prevent the state from doing less in a situation where charities are steadily contributing more. The only apparent solution to this problem has been for the charities to rely on the AMRC to highlight the differences between medical research charities and the (B)MRC in terms of the type of research each supports. In doing so, the AMRC has argued that the implications of shifting from funding basic research to more applied research is that scientific investigations would become stultified and rendered impotent since basic research provides disease researchers with the building blocks of knowledge. As one Canadian scientist remarked:

"To do applied (disease oriented) research without relying on basic science would be like trying to understand how a light can be switched on without knowing what electricity is."

45

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44 British Interview; Ciba Foundation, 27 February 1987.

45 Canadian Interview; McMaster University Medical School, 19 January 1987.
The irony of the (B)MRC cutbacks has been highlighted by the government’s commitment to AIDS research and their own admission that the disease will likely be conquered by utilizing (B)MRC laboratories and basic immunology research. In essence, what further reductions in (B)MRC spending might do is eliminate the government’s ability to respond quickly to new public health problems — especially those that medical research charities have been unsuccessful in addressing. This may pose serious problems for the (B)MRC if in the future another infectious disease gains public support in a way similar to AIDS. Cutbacks might also erode the broad base of research, into many disease areas, which has been a policy of the (B)MRC since its establishment. The fundamental basis of this policy has been to insulate government from public criticism, if the need arises, when public health problems escalate in seriousness. In such circumstances, governments have traditionally been able to respond to their critics by arguing that ‘research into disease X has been financially supported in the past but that a greater research effort is currently required’.

Another major difference between the type of research funded by charities and by government relates to the research priorities adopted by the two funding sources. For example, a substantial proportion of the charities’ total expenditure is directed at just two diseases — cancer and heart disease. As previously examined in Chapter five section IV. A and B, this pattern of distribution does not necessarily reflect the seriousness of such diseases as
represented by their incidence rates. However, it has meant that other major illnesses such as senile dementia and sexually transmitted diseases are not significantly funded by charity. While it was shown that (B)MRC funding is also skewed in favour of popular diseases like cancer and AIDS, further cutbacks in (B)MRC funding would significantly impede any attempts to correct this bias.

Furthermore, the approaches to research funding adopted by the (B)MRC and the medical research charities are substantially different. The former has historically had a major commitment to long-term research; in fact the (B)MRC presently supports 60 major research establishments on a long-term basis, and these account for 60 per cent of its funds.46 On the other hand, the charities apply most of their funds—approximately two-thirds—to clearly defined projects of limited duration. 47 Most unendowed charities have largely been unable to support long-term research programmes because of fluctuating annual incomes. For example, even a large charity like the Cancer Research Campaign which has an annual income of £35 million disperses two-thirds of that in the form of


47 Ibid. p. 5. The charities that are members of the AMRC presently provide grants for more than 2700 research programmes and projects by comparison with 1800 supported by the (B)MRC. While many of the grants from the charities are for periods of one or two years the standard for the (B)MRC is a three-year project grant. The short-term grants serve two purposes—they provide funds for clearly-defined projects of limited duration, and also they provide seed money to test the feasibility of new ideas and new techniques.
short-term grants - normally having a duration of one to two years. Charitable foundations, despite the fact that they are able to conduct long-term financial planning, have also contributed to the pattern of funding shorter term research projects. One reason for this relates to the spiralling costs associated with medical research. In other words, while a charitable foundation may be able to predict its income with some degree of certainty, it is more difficult for it to assess the costs of supporting long-term research. There are of course anomalies, like the ICRF, whose projects are normally funded for five to eight years; but this is practical in its case since the charity maintains its own research laboratories. However, this example provides no proof that charities generally represent a viable alternative to government as a funding source for medical research.

The charities also argue that they have also adopted this funding approach since government, via the (B)MRC, has always provided the long-term money for research. As one charity executive stated:

"If there is to be research facilities like the laboratory for molecular biology in Cambridge where they have won nine Nobel prizes, it takes a lot of money. It must be given regular support and employ a very large full-time staff. There simply is no charity in Britain which is large enough to do that."

48

48British Interview; British Diabetic Association, 2 March 1987.
The (B)MRC cutbacks have also had an impact on jointly funded charity-government research projects. Prior to 1980, medical research charities tried to use their money to ‘pump-prime’ research projects in their disease areas knowing that if they were successful that the (B)MRC would not let them fail. The charities have always justified their partial or complete withdrawal from successful projects partly on the grounds that they did not have guaranteed annual incomes. But they also believed, that if a programme was successful and had the potential to improve public health standards, it was a state responsibility. As one respondent remarked, this proved to be a successful strategy prior to the cutbacks but now the reverse is true:

"Now we are beginning to find that government is doing the pump-priming because it doesn’t have the money for ‘continuation funding’, they are looking at the charities to pick up the tab for long-term projects. We simply cannot operate this way."

Lastly, charities have argued that (B)MRC cutbacks have signalled government’s failure to provide an adequate physical and human infra-structure for scientific investigation to flourish. Historically, the dual support system in Britain provided this bio-medical research infra-structure in the universities and hospitals. Increasingly, since 1980, charities have been placed under pressure to provide for a portion of the physical over-heads

49British Interview; Mental Health Foundation, 20 February 1987.
such as equipment and consumables. Resistance to this has been marshalled by the AMRC which has argued that charities should not be funding items that are properly government's responsibility. While this is perhaps true, there are other reasons why charities have not been prepared to take on-board such expenses. As Anne Luther, the AMRC's Secretary explained;

"It is very difficult for medical research charities to go to their volunteers and donating public and ask for financial contributions if the public knows that their donations are being used to employ a cleaner or pay for new lightbulbs. From this point of view, these cutbacks have the potential to detract from our members' fund raising capabilities and from our overall contribution to medical research in Britain."

Unfortunately for the medical research charities the decision not to pay for these overhead costs poses a dilemma. In many instances, if the charities refuse to make financial allowances for the purchase of new equipment or for laboratory maintenance, a unit may be forced to shut-down. This then becomes problematic for charity executives who must explain to volunteers why promising research projects financed with voluntary donations have been terminated when charities' annual incomes have been increasing.

The loss of personnel is another cost associated with the (B)MRC cutbacks since many 'top-flight' scientists are either leaving the country, or leaving the research field to take up

50British Interview; Association of Medical Research Charities, 4 March 1987.
private practice (if they have medical qualifications). Furthermore, young graduate students contemplating a future in research have begun to opt for other careers since the number of 'career investigatorships' offered by the (B)MRC have been reduced by 30 per cent.51 In the past, universities have had tenured lectureships but these have dwindled in numbers since positions vacated by retiring professors have not been renewed. This same scenario has been apparent in the (B)MRC's own research facilities that are operated independently from the universities. This development is one that medical research charities have been unable to compensate for because of their limited funds. The problem is compounded by the fact that the cost of maintaining a tenured post until retirement for a researcher who is now 35 years old is £1/2 million.52 Not only is this expensive but it requires an expenditure which is premised on income stability - something that is virtually impossible for any charity. Alternatively, charities have lobbied government via the AMRC to make provision for the training of future researchers, as well as to develop a sound career structure that includes salaries competitive with those available in foreign countries. Their argument is that the career structure for scientists is ill-defined, in that the majority of young scientists are now employed under two or three year contracts and are continuously searching either for new

51'Medical Science on Crutches', New Scientist, p. 27.

52British Interview; British Heart Foundation, 3 March 1987.
positions or for new grants. As the AMRC’s Secretary argued:

"Unless the issue of career structures can be corrected, medical research in Britain will remain an uncertain business and people will continue to be attracted to the United States where salaries are higher and job security more attainable."

Not only have budgeting restraints on the (B)MRC affected British medical research charities but so too have other cutbacks in the NHS. In 1984, the DHSS announced that there would be manpower controls placed on investigators involved in clinical research. Before medically-qualified researchers can become consultants they must attain the status of senior registrar. However, the government argued that there were too many senior registrars to fill the more limited number of consultancy posts. Rather than create more consultant posts, as the AMRC demanded, the government decided to make redundant a certain proportion of senior registrars to match the existing number of consultants. Yet in the process of doing this, the DHSS did not take account of the number of senior registrars funded by the charities.

Many young investigators secure short-term contracts after completing their doctorates. Senior researchers will then spend a lot of time training them in advanced research techniques. The problem is that after they have received one or two contracts and are beginning to make substantial contributions many realize how limited the opportunities for advancement are and the best of them often look for employment elsewhere. To make matters worse the (B)MRC has refused to fund investigators after they have reached a certain age or after a certain number of years of contract work. This is largely because old researchers command higher salaries.

British Interview; Association of Medical Research Charities, 4 March 1987.
Consequently, it was feared that the medical research professional career structure would be geared towards producing a proportion of researchers at levels based exclusively on the (B)MRC's staffing requirements. If this had happened the AMRC argued "that the medical research charities would be unable to find enough researchers to support disease related investigations." Additionally, they were concerned that senior registrars funded by the charities who were to be stripped of their status would be ineligible to continue with projects in progress - some of which were near completion. If this were to happen, the volunteers and donating public would again question why projects had been allowed to remain uncompleted when consistently more money has been raised voluntarily each year.

The AMRC's initial response to this proposed staffing policy was so outspoken that the DHSS agreed to establish a Consultative Board whereby the charities were permitted to comment formally on the draft recommendations. The AMRC in turn, appointed Dr. P.O. Williams of the Wellcome Trust, and Professor Arthur Buller (Research Director for the Muscular Dystrophy Group of Great Britain), to put the charities case to government officials. In an interview Dr. Williams described his submissions to the Consultative Board in the following way:

"I pointed out to the government officials that given that charities support so many senior registrars the government should take account of

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55British Interview; Association of Medical Research Charities, 4 March 1987.
this and in turn give the AMRC a quota of senior registrars which reflects the financial contribution made by the charities to medical research. The quota allocated to us, as compared to the (B)MRC should reflect the fact that charities collectively spend as much as the (B)MRC on research."

By the fall of 1986 the DHSS announced that it had reconsidered its initial quota of senior registrars by building into its new estimates the staffing requirements of the charities. In the end, the AMRC was able to secure a quota of 100 senior registrar positions specifically earmarked as non-governmental or externally supported investigators. Not only was this heralded as a success for the scientific community it also augmented support for the AMRC's bid to act as an effective lobbying vehicle for its member charities on issues of collective concern.

Given all of the concerns raised by charities in response to the (B)MRC cutbacks it is not surprising that their association has lobbied government over this issue. The main thrust of the AMRC's representation's to government has been that medical research charities are major participants in funding research in their own right and therefore should be involved in all decision-making processes that impact on the way they operate. The implications of charities not having participated in public policy debates on issues of direct concern have posed problems in the past. For example, the Executive Director of the Muscular Dystrophy Group of Great Britain offered the following anecdote;

56British Interview; The Wellcome Trust, 14 March, 1987.
"One of our funded researchers, Professor Alan Emery who was the head of the Genetics Department at Edinburgh University, decided to retire about four years ago (1983). The government, without consulting us, simply decided to close the department, which effectively meant that our entire research efforts were terminated. We, and not the government, managed to help two of Professor Emery’s research assistants acquire jobs elsewhere so that they could continue doing muscular dystrophy research."

Historically, it was never necessary for the medical research charities to become involved in politics since they merely provided a small financial supplement to the (B)MRC. Stated differently, the combined research budgets of all the medical research charities has always been modest in proportion to what was being given for research by the public purse. However, now that this position is becoming reversed, charities have begun to rely on the AMRC to lobby government on research-related issues ranging from the use of animals in experimentations to scientific staffing requirements. Indeed, one of these issues has centred on the (B)MRC’s aspirations to compete directly with medical research charities in raising voluntary donations from the public. While as yet the (B)MRC has not launched a public fund raising appeal, it has published a booklet that is freely available to the public explaining how money can be bequeathed to the (B)MRC. There are two points to be made in connection with this. First, the

57British Interview; Muscular Dystrophy Group of Great Britain, 19 February 1987.
budgetary cutbacks imposed on the (B)MRC have obviously forced it to search elsewhere for funding. Second, competing directly with the charities for funds, rather than seeking their financial assistance, is indicative of the (B)MRC's unwillingness to accept that its own 'senior position' in the research funding complex is being threatened by the charities. Several member charities who were interviewed wanted the AMRC to make representations to government urging them to impose regulations on the amount of fund raising the (B)MRC is able to engage in. However, since the (B)MRC has charitable status there is nothing illegal in its efforts to acquire non-government funds in the form of voluntary donations. These same charities argued that a more sensible yet temporary solution to the (B)MRC's fiscal problems would be for the charities to subsidize various (B)MRC projects that are in need of 'rescue money'. However, as one respondent argued, there is little possibility of this occurring.

"There is an enormous pride at the (B)MRC - as well there should be given its remarkable past achievements. It is unlikely that Sir James Gowen (President of the (B)MRC) would ask the charities for money, since the chaps he would have to talk to are the Executive Directors who are fund raisers. He simply will not ask for subsidies from a group of 35 generals, for want of a better phraseology - they are distinguished generals but they know nothing about science."

Quite separate from the fact that private donations help to lessen the financial crisis facing the (B)MRC is the realization

58British Interview; February 1987.

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that such funds give the (B)MRC flexibility to do certain things otherwise not immediately permitted with government funds. For example, in the past the (B)MRC has used private funds (which have always comprised less than 5 per cent of its total income) to move scientists from one research centre to another without having to wait for their salary increases to be approved by DES officials. When departmental approval is given for such plans, and the money is forthcoming, the private (voluntary donations) budget is then reimbursed. As the (B)MRC respondent clarified;

"I do not want to give the impression that private funds are used for purposes which the Treasury would not approve of, rather these monies allows us to by-pass long and detailed administrative and bureaucratic procedures when something urgent needs to be done."

II. Government Sponsored Research in Canada: Changing the Rules

The most important issue affecting Canadian medical research charity-state relations revolves around the federal government’s implementation of a matching-grants scheme which in the future will affect the way in which the government calculates its level of support to the (C)MRC. At the time of writing the matching-grants scheme had only been in effect six months. Thus, the following discussion represents the views of government and charity officials regarding the anticipated impact of the scheme.

59British Interview; Medical Research Council, 2 April 1987.

60Ibid.
on the future funding of medical research in Canada.

Since 1981, the (C)MRC has operated under five year plans which have doubled its government grant-in-aid from $80 million (£40 million) (1981) to over $160 million (£80 million) in 1986. However, like the (B)MRC’s budget, these apparently large funding increases have been eroded by high inflation associated with the costs of conducting medical investigations. In 1986, the (C)MRC was given initially an increase of $6.2 million (£3.1 million) but this was subsequently affected by a two per cent cut in overall government spending which produced a budget of $161.2 million (£80.6 million). This represented only a two per cent increase over its 1985/86 budget. In February 1986, the federal government announced a series of new measures for funding the research councils that sought to replace the five year plan. In the remaining four years of the (C)MRC’s five year plan (1987-1991) its budget is to be frozen at $161.4 million (£80.5 million). However, the (C)MRC will be able to supplement this through contributions to university research development from the private sector, and the federal government will match these contributions, dollar for dollar, up to a maximum of six per cent over the (C)MRC’s previous year’s budget. For the purposes of the ‘matching-grants policy’, the term ‘private sector’, has been used to embrace profit-seeking businesses, individuals, designated

The main objectives of the matching-grant policy are twofold. First, it is aimed at increasing the overall level of university-based bio-medical research and research training through a partnership with the private sector. This growth will of course only take place if non-governmental organisations like charities are successful at increasing their annual incomes. Second, it is anticipated that the matching-grants scheme will increase the level of private-sector/university collaboration and increase the speed at which research results are transferred to the private sector for application. These objectives are examined in more detail beginning with the first.

Many Canadian medical research charities are doubtful that the matching-grants scheme will increase the (C)MRC's income in real terms. As illustrated in Table 7.4 the anticipated private sector contribution during the first year of the matching grant scheme (1987/88) would be $10.0 million (£5 million). Most respondents believed that this is an attainable target income and that they would welcome the corresponding $10.1 million (£5.05 million) that would then be matched by the federal government. However, for the (C)MRC's budget to continue to experience a real growth of six per cent it would be required to prove to government that private sources had contributed an extra $20.9 million (£10.4 million).

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62Ibid., p. 8.

Table 7.4
The Canadian Federal Government's Five-Year Financial Plan
For University Research ($Millions)

<table>
<thead>
<tr>
<th>Medical Research Council</th>
<th>1985/86</th>
<th>86/87</th>
<th>87/88</th>
<th>88/89</th>
<th>89/90</th>
<th>90/91</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>(A) Previously Approved Budgets</td>
<td>161.4</td>
<td>130.8</td>
<td>130.7</td>
<td>130.7</td>
<td>130.7</td>
<td>130.7</td>
<td>653.6</td>
</tr>
<tr>
<td>(B) Budget Increases</td>
<td>-</td>
<td>37.7</td>
<td>30.7</td>
<td>30.7</td>
<td>30.7</td>
<td>30.7</td>
<td>159.9</td>
</tr>
<tr>
<td>(C) Federal Matching of Private Sector Contributions (Maximum)</td>
<td>-</td>
<td>-</td>
<td>10.1</td>
<td>20.9</td>
<td>33.2</td>
<td>46.8</td>
<td>110.0</td>
</tr>
<tr>
<td>(D) Anticipated Private Contributions</td>
<td>-</td>
<td>-</td>
<td>10.1</td>
<td>20.9</td>
<td>33.2</td>
<td>46.8</td>
<td>111.0</td>
</tr>
<tr>
<td>(E) Total</td>
<td>161.4</td>
<td>167.4</td>
<td>181.6</td>
<td>203.2</td>
<td>227.8</td>
<td>255.0</td>
<td>1035.5</td>
</tr>
</tbody>
</table>

PAGINATION ERROR
million) in 1988/89, $33.2 million (£16.1 million) in 1989/90 and
$46.8 million (£23.4 million) in 1990/91. According to the same
respondents, these targeted incomes would be virtually impossible
to attain since charities have a 'limited market' from which to
raise voluntary contributions. Some argued that if the federal
government amended the Income Tax Legislation to encourage
personal and corporate giving by offering tax credits, then these
targets could, possibly be met.

The main criticism of the scheme is that the (C)MRC's budget,
and ultimately the country's medical research infrastructure,
would be susceptible to the whims of the donating public. For
example, if the aggregate income of the medical research charities
decreased from the previous year by 10 per cent because of a 'one-
off' public out-pouring towards another charitable cause, then the
availability of total research funds for Canadian investigators
would decrease by 20 per cent since the (C)MRC matching-grants
from government would decrease correspondingly by 10 per cent. In
essence, the policy underlying the matching-grants scheme implies
that charities would 'drive' the research growth in Canada. As
one respondent explained, this would erode the complementary
relationship that has characterized relations between medical
research charities and state since the 1960's.

"As the senior partner in the research funding
complex the (C)MRC has always been highly revered
by Canadian charities. Because of their vast
income in comparison to individual charities and
the breadth of their research effort, the (C)MRC
has always set the standards for the charities to
adhere to. Now that the matching-grant programme
has been introduced this relationship will be weakened - for it says that the (C)MRC’s future ability to succeed will be determined by the success of the charities to raise more and more money each year. To think that the country’s research infra-structure will depend on emotional appeals, garage sales and bingo games is, to say the least, a travesty.”

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The charities’ fear of being unable to raise the voluntary donations required to meet the targeted income levels each year has raised speculation that the universities will likely begin launching their own fund raising appeals. The universities would aim to raise more voluntary donations in order to increase the matching-funds given to the (C)MRC which in turn would be dispersed to university-based researchers. However, if this transpires the medical research charities would then be forced to compete with the universities for the ‘limited’ number of voluntarily donated dollars. From the charities perspective, the implications are far reaching, especially since the alumni networks would be a lucrative means for the universities to capture a portion of the voluntary donation market.

An added concern of both universities and charities located in areas outside of Ontario and Quebec is that larger schools (for example, the University of Toronto and McGill University) will be able to raise more research money than smaller schools like Mount Allison University in New Brunswick. As a result, this would create an even greater disparity in the level and quality of the

64 Canadian Interview; January 1987.

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research conducted in universities located in the 'have' and 'have-not' provinces. The (C)MRC would be unable to counterbalance this as it has in the past, since the largest proportion of matching-grants given by the government to the (C)MRC would in turn be given to those universities that have raised the most so-called 'private sector' money.

Furthermore, one respondent remarked that as part of the universities' efforts to raise their own research money, "scientists would themselves be relied upon to establish contacts with pharmaceutical companies as a means of securing corporate donations." The problem is that having senior scientists preoccupied with fund raising might lead to the neglect of teaching and development-training of young university researchers. As a result when the present research personnel retire, there may not exist an adequate number of scientifically qualified people to replace them.

65The terms 'have' and 'have-not' provinces are used to designate regions that require federal transfers payments in order to ensure that the range and quality of public services meets national standards. The actual computation of provincial 'equalization payments' is complex. The initial calculations are based on a population-weighted average of provincial tax rates. Then these average rates are applied to each province's own revenue base, which yields a calculation of the potential per capita revenue to the province. Again, if a province's estimated per capita yield, from all the tax source, is below the national average per capita yield, the federal government makes up the deficiency. Based on 1984 figures, the 'have' provinces were Ontario, Alberta and British Columbia and the 'have-not' provinces were Newfoundland, Prince Edward Island, Nova Scotia, New Brunswick, Quebec, Manitoba and Saskatchewan.

66Canadian Interview; Muscular Dystrophy Association of Canada, 5 December 1986.
While Canadian medical research charities are generally ambivalent about the matching-grants scheme, they did respond favourably to its proposal during the consultation process with government. In 1985, the medical research charities received a copy of the draft proposal of the scheme and were asked for their comments. Most organisations supported the scheme under the false assumption that donations raised for a specific disease would be matched by government and given to the (C)MRC to be earmarked for research into that same disease area. Instead the charities later learned that all matching-grants given to the (C)MRC would be diverted into its general fund to be spent on the disease areas the (C)MRC so desired (typically cancer and heart). Consequently, the greatest challenge to the matching-grants scheme has come from the smaller charities representing less-popular disease who have argued that they will be subsidizing research into popular disease like cancer and heart. Indeed, this will indeed be the case, since the more money raised voluntarily, the more money the (C)MRC will receive from government to support its traditional research biases. As the Executive Director of the Canadian Diabetes Association commented;

"The way the programme is designed, I do not think it has a chance of succeeding. I met with the Minister of Health - Jake Epp - and simply put the following question to him. What incentive do the smaller charities representing low-profile disease have to go out and raise more money if there are no guarantees that one additional penny
of government money will be spent our way?" 67

The matching-grants scheme has highlighted the difficulties facing Canadian medical research charities in participating in the public policy process. The Executive Director of the Muscular Dystrophy Association of Canada admitted, "we wrote letters and made telephone calls to the minister's office but we had no illusions that our one voice would make a difference in the final decision of whether or not to go ahead with the proposed scheme." 68 While British charities did successfully lobby the central government through their association to acquire a quota of senior registrars, Canadian charities have failed to achieve similar success on the matching-funds issue, partly because of their disorganized dealings with the federal government. Consequently, the establishment of an association comparable to the AMRC has been strongly endorsed by several Canadian medical research charities. As one respondent noted; "the impetus behind the formation of such an agency will likely come as the financial burden for the support of bio-medical research shifts from the public to private sector." 69

It was mentioned that the second objective of the matching-grants scheme is to increase the level of private-sector/

67Canadian Interview; Canadian Diabetes Association, 4 December 1986.

68Canadian Interview; Muscular Dystrophy Association of Canada, 5 December 1986.

69Canadian Interview; Arthritis Society, 19 January 1987.

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university research collaboration and to accelerate the transfer of these research results to the private sector for commercial application purposes. The charities have criticized this on the grounds that the type of scientific investigations conducted in the universities will shift from basic research to more applied research. Their thinking is that university researchers in search of non-governmental funds will enter into contractual-type research arrangement with pharmaceutical companies. If this happens, then basic research would be supplanted by more applied clinical investigations that reflect the research agendas of the large multi-national pharmaceutical companies. This would have the dual effect of limiting the number of researchers submitting basic research grant applications to the (C)MRC, as well as limiting the number of researchers submitting 'disease-focused' research grant applications to the charities. One respondent explained:

"I am convinced that government knows that basic research will be sacrificed by the matching-grants scheme but this merely confirms my suspicions that government does not see the (C)MRC as performing a particularly useful function. Very few politicians are scientists and therefore very few understand that you need basic research to build a stock of knowledge prior to making a practical research discovery."

In the non-medical research field a good example of basic research leading to a commercial application involves experiments...
on the nutritional requirements of grass and other plant forms. In 1954, biologists received money from the federal government to conduct basic studies of plant growth and in doing so coincidentally discovered the formula for 'weed killer'. That discovery alone spawned the growth of a $20 million (£10 million) fertilizer industry that has created 859 new jobs for Canadians.71 The same opportunities exist for commercial products to spring from basic research in the medical sciences. However, if the matching-grants scheme reduces the level of government-sponsored basic research there will be no other source of funds for that kind of scientific investigation. This will be the case if charities continue to acquiesce to the demands placed on them by their volunteers to support 'disease-focused' research and if the pharmaceuticals continue to fund commercially oriented 'drug research'.

The matching-grant scheme cannot be compared directly to the (B)MRC cutbacks but the underlying government policy in both countries regarding bio-medical research funding is the same. The Conservative governments of each country have sought different ways of shifting the burden of responsibility for medical research funding to the private sector - to charities in particular. In both countries, this is symptomatic of the British and Canadian governments' attempt to reduce their deficits by limiting their public sector borrowing requirements. The steadily increasing incomes of both British and Canadian charities have made this

71Ibid.
government policy relatively easy to implement since the level of research conducted in both countries has remained constant. While the level of research is a concern of British and Canadian charities, so too is the shift away from basic research. This is not a problem that charities themselves in either country can correct by raising more voluntary contributions. Consequently, they will always see the provision of basic research as a governmental responsibility, disease focused research as their own responsibility, and commercial oriented research as the responsibility of the pharmaceutical industry. In the past, this division of responsibility between each sector has been clearly defined. However, as one respondent noted:

"As the lines dividing the three sectors becomes blurred the question remains as to how the quality of our medical research will be affected. It will remain to be seen whether Canada and Britain have the medical research infrastructure ten, twenty or thirty years from now to deal with public health problems comparable to AIDS."

This chapter has addressed an important theoretical question that has been raised often by economists when considering the role of charities in providing welfare services. This question can be simply stated: What advantages do charitable organisations have over statutory ones in delivering similar services? One argument which appeals to those who believe that the public sector is necessarily wasteful is that charities can operate with lower

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72 Canadian Interview; McMaster University Medical School, Department of Immunology, 14 January 1987.
cost. However, this chapter and previous ones have presented no
evidence to suggest that charities are particularly cost-effective
in 'supplying' medical research, except in the crude financial
sense that volunteers do not have to be paid. Economic theory
suggests that it is competition not private control, that is the
best guarantee of cost effectiveness. As Judge has argued, this
provides a strong case for purchase-of-service contracting once
the state has accepted responsibility for financing and planning a
service.73 However, in the context of medical research we have
seen that the British and Canadian governments have not opted to
'contract-out' to charities but rather to simply cut back their
financial commitment to their own research infra-structure—the
(B)MRC and (C)MRC. Assuming that British and Canadian medical
research charities did supply their services on a contractual
basis for government one might expect competition for contracts
between agencies (whether from other charities, profit-seeking
businesses or other statutory agencies) to reduce costs. In this
context, however, the charity would essentially be acting as a
firm, just as a building society does when it competes with
private banks and Giro. This is very different from the claim
that charities provide services more cost-effectively in resource
terms than statutory agencies.74

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73K. Judge, 'The public purchase of social care: British
Confirmation of the American experience', *Policy and Politics*
10(1982), pp. 397-416.

74R. Sugden, 'Voluntary Organisations and the Welfare State'
Another common argument about the advantages charities have over statutory agencies is that the former are 'pioneers of the welfare state' and are inherently more innovative. However, Kramer has criticized this theory as an outdated myth by arguing that statutory agencies are just as capable of innovation as voluntary organisations are.75 The traditional pioneering theory is that, at any time, there will be some welfare services that are not accepted as proper activities for the state; but if far-sighted individuals combine to provide these services voluntarily, the general public will come to recognize their value and eventually the state will be able to take over. As Johnson explains, pioneers can make mistakes, and so new ventures must be regarded as experiments. Charities are often seen as organisational structures in which experiments can be made. Creative ideas that work successfully can then be adopted by the state and those that fail can be abandoned at relatively little cost.76 The Wolfenden Report best documents how 19th century charities pioneered most of the main activities of the 20th-century welfare state.77 Indeed, there are numerous examples of more recent pioneering work by British and Canadian charities—including citizens' advice bureauxs, the Samaritans and hostels


for battered women. However, the application of the pioneer argument to either explain or justify state reliance on medical research charities to finance bio-medical research is not convincing. This is true since medical research charities are themselves (as is the state) constrained from developing innovative ideas by the nature of their charitable activity. As one Executive director of a Canadian charity explained:

"Medical research is different from providing relief to the poor since there is little room for developing creative solutions for problems. In addition, the creativity for solving health problems lies in the hands of qualified scientific investigators not in the hands of a group of charity administrators. Moreover, what little creative aspirations medical research charities have are further constrained by our volunteers who discourage us from funding the same kind of basic research that is supported by government."

In conclusion, it is worth emphasizing the point that medical research charities (in comparison to other types of charities) cannot be innovative in the area of research funded by government. This is true since medical research charities are under pressure from 'donors' not to fund basic research despite whether their investigation are innovative or not. In addition, many British and Canadian charities are too small to fund basic research and even the large charities suffer from significant variations in annual income to make it difficult for them to take on long-term

78 Canadian Interview; January 1987.
research commitments demanded of this type of scientific inquiry.
Chapter Eight

Medical Research Charities: Lobbying on Non-Research Issues

While the previous three chapters have focused on medical research, this chapter examines patient service and public education issues. In doing so, it is demonstrated that volunteers and the donating public - themselves often disease sufferers - exert considerable pressure on a charity's executive to lobby on their behalf.

The chapter divides into three sections. The first deals with a number of patient-service-issues directly related to the pharmaceutical industry. It is shown that British and Canadian medical research charities have supported a number of lobbies organized by this industry. Explanations are given as to why this has happened and its impact on the charities fund raising capabilities. Section II examines patient-service-oriented issues unrelated to the pharmaceutical industry that have prompted medical research charities to lobby on behalf of disease suffering volunteers and financial contributors. It is shown that British and Canadian medical research charities have lobbied government on a host of issues, ranging from discrimination against disease sufferers in the workplace, to their members' restricted access to health-related statutory benefits. Section III differs from the
previous two sections, in that it focuses not on lobbies organized around patient services, but rather lobbies organized around public education or preventive medicine. Specifically, it examines the role of medical research charities in the anti-smoking lobby. Here, the skill and sophistication of these organisations in pressuring government for legislative reform is revealed.

I. Medical-Research Charities and the Pharmaceutical Lobby

The economic success of the pharmaceutical industry has depended on its record of innovation. Worldwide, it is recognized that private enterprise and competitive multinational pharmaceutical companies are responsible for the discovery and development of new medicines. However, innovative-based success has been costly; one study illustrates that £50 million is now required to develop a successful new pharmaceutical drug1 (see figure 8.1). For a corporation to expect limited success, at best, in pharmaceutical innovation it must invest significant sums of this order within short periods of time - a figure of £20 million has been suggested.2 With investment of this magnitude at


2Ibid., p. 18. In Britain, the pharmaceutical industry was spending over £350 million per year (1982 figure) on pharmaceutical research and development. In real terms, this is about a six-fold increase over 1963 and three times the research budget of the Medical Research Council. Nevertheless by international standards British company spending is fairly modest.

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Figure 8.1


£ millions

risk, neither government research establishments [(B)MRC and (C)MRC], academic institutions nor medical research charities have been inclined or realistically capable of investing the funds necessary to discover new medicines. Nevertheless, the pharmaceutical industry's innovation record has largely depended on basic pharmacological and pathological knowledge developed in academic institutions and government research centres.3

While the economic success of British and Canadian drug companies has depended on their record of innovation their interest associations have argued that this has been threatened by increasing research and development costs brought on by various forms of government regulation. As a consequence, it is further argued that fewer companies are now financially capable of participating in the search for new medicines. For those manufacturers for whom this still represents a feasible strategy, cost escalation has placed a limit on the number of new 'chemical entities' (potential drugs) that have been submitted to the development process. As a result, the number of new drugs reaching the British and Canadian markets has also declined.

It is estimated that by 1979 Hoffman - La Roche of Switzerland alone was spending about £150 million a year on research and development. Worldwide, the pharmaceutical industry is estimated to have spent about £4,000 million on research and development in 1981. Thus Britain spends about eight per cent of the worldwide pharmaceutical research budget, although its home market accounts for only four per cent of total world sales. Figures taken from M. Burstall, Multinational Enterprises, Governments and Technology: Pharmaceutical Industry. Paris: OECD, 1981, pp. 33-34.

significantly since the early-to-mid 1960's (see figure 8.2).

Given the regulatory climate in Britain and Canada, it is not surprising that pharmaceutical companies from both countries have lobbied their respective governments to relax industry controls that hitherto have limited profitability. In their efforts to do so, pharmaceutical companies have encouraged medical research charities to collaborate with them in various lobbying campaigns. British and Canadian organisations responding favourably to this request have done so for an obvious reason: to seek the continuation of financial support from the pharmaceutical industry. While the data listed in Figure 8.3 do not indicate the amount of pharmaceutical donations given specifically to British medical research charities it does reveal the total amount of the industry's corporate donations in comparison to other industrial and commercial sectors. In interviewing a spokesman for the Association of British Pharmaceutical Industries, it was explained that, although precise data was not available, a 'large proportion' of the industry's corporate contributions go to medical research charities. In most instances, this has been a relatively easy policy decision for charity executives to justify to volunteers and the donating public, since a relaxation of regulatory controls would increase industry profits and in turn, increase the amount of pharmaceutical research. This is a priority of disease sufferers whose hope for the future lie in the

4 British Interview; Association of British Pharmaceutical Industries, 9 April 1987.
Figure 8.3


Corporate Donations £000

A. Banks, Insurance, and Building Societies
B. Manufactures of Motor Vehicles and Electronic Components
C. Retailing
D. Pharmaceutical and Chemical
E. Food Processing, Tobacco and alcohol
F. Fuel and Energy
G. Hotels, Catering and Television
H. Others
I. Printing and publishing
J. Transport
K. Rubber and Textile Manufacturing
L. Construction

Number of Organizations

development of new drugs. However, as is discussed in section I. C, charities that have lobbied on behalf of the industry have risked internal division between those interested in patient services and those interested in medical research. This is true since a relaxation of some industry regulations has resulted in higher drug prices.

A general theme developed in this section is that medical research charities formulate their policies in consideration of their fund raising bases. Many of these policies relating to the pharmaceutical industry have included decisions to lobby government for both legislative and regulatory reform. In doing so, further proof is given that medical research charities are not free and independent of the policy formation process but rather a participant whose function has yet to be fully understood.

Section I of this chapter examines four types of government regulation that industry spokesmen claim have limited their profitability. Although each of these four issues are interrelated, each is best described individually. These issues include 1) regulatory pressures on prescribing 2) regulatory erosion of patent protection 3) regulation of drug development and 4) government restrictions on promotion.

A. Regulatory pressure on prescribing

British and Canadian pharmaceutical companies claim that industry regulations have reduced the number of drugs that are covered under government drug plans. Consequently, they argue that many patients have been unable to pay the total cost of
certain medicines required for treating their afflictions. As a result, fewer products are being sold and less profits are being generated by the industry.

In most countries, there are some arrangements for pharmaceutical companies to be reimbursed under social security schemes covering at least part of the population. Britain lies at one extreme with a centrally tax-funded health service, fully controlled by the central government. In countries like West Germany, France, Italy, Switzerland and Canada, both private and government health insurance schemes exist covering virtually the entire population. These are financed by a variety of insurance funds and treatment is provided by government, charitable and private health care organisations. The United States lies at the other extreme in that the nation's two publicly funded health care schemes - Medicare and Medicaid - cover just 22 per cent of total medical expenditures. Only 50 million out of the total population of 250 million are covered by these two programmes. The remainder of the expenditure, by the vast majority of the population, is covered either by private insurance or involves direct patient payments for treatment received. Thus the United States alone has a substantial private market for medical care, whereas in all other countries the bulk of health care expenses are prepaid through collective health care schemes.5

Focusing specifically on pharmaceutical reimbursement, the

British and Canadian governments—unlike the United States—cover part of the cost of pharmaceuticals supplied to patients on doctors’ prescriptions. However, in each case, patients must pay a portion of the cost of all, or part, of the medicine which they receive. In Britain, patients pay a fixed charge of £2.60 per item prescribed, but 78 per cent of prescriptions are exempt from this charge, either because of the age or indigence of the patient, or because a person is suffering from one of a number of specific diseases. Overall, 94 per cent of the cost of all prescribed medicine is reimbursed in Britain.6

In recent years, two principal methods of attempting to control pharmaceutical costs have been introduced in Britain, Canada and a host of other countries. This has included the creation of ‘positive’ and ‘negative’ lists for medicines which may be reimbursed under social security schemes. The first sets out a limited list of medicines which are reimbursed while the second sets out a list of medicines which are not. In the absence of either a positive or negative list, all medicines prescribed by doctors would be reimbursed under the government’s social security scheme.7 Table 8.1 summarizes the government policy in seven countries regarding the implementation of these lists. It is clear that Japan is an anomaly since doctors are given complete freedom to prescribe the medicines of their choice and all drugs

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6Ibid., p. 19.

### Table 8.1
The Existence of 'Positive' and 'Negative' Lists to Restrict Prescribing in Seven Countries.

<table>
<thead>
<tr>
<th>Country</th>
<th>'Positive Lists'</th>
<th>'Negative Lists'</th>
</tr>
</thead>
<tbody>
<tr>
<td>United Kingdom</td>
<td>-</td>
<td>Yes</td>
</tr>
<tr>
<td>Canada</td>
<td>-</td>
<td>Yes</td>
</tr>
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<td>West Germany</td>
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<tr>
<td>France</td>
<td>Yes</td>
<td>-</td>
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<tr>
<td>Japan</td>
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<tr>
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<td>-</td>
</tr>
<tr>
<td>United States</td>
<td>-</td>
<td>Yes</td>
</tr>
</tbody>
</table>

are paid for by the state.

In countries where 'positive lists' have been implemented problems have arisen when government's have reduced the number of drugs eligible for reimbursement. This has especially been a problem in Britain when the government decided in 1984 to withdraw tranquillizers and a number of other drugs from the National Health Service's medicine exemption list. Mental health patients and other disease sufferers affected by this decision were forced to bear the total cost of their prescribed medicines. The British pharmaceutical industry whose profits were threatened, and medical research charities whose members 'out-of-pocket' drug expenses increased, began to lobby government to change their prescriptions, policy. The way in which this lobby was organized is particularly interesting. For example, Sir John Cox, the Executive Director of the Spastics Society explained:

"In 1984, our Medical Advisory Committee noticed that when the drugs on the NHS exemption list were being reduced, three drugs used by cerebral palsy sufferers were among them. A number of pharmaceutical companies approached us and asked us to endorse a much longer list of drugs which they were lobbying on behalf of. Our response was only to support those drugs which affected cerebral palsy patients."

The respondent also explained that had the Spastics Society received larger corporate donations from the pharmaceutical industry, the charity would have had to acquiesce to all their

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8British Interview; Spastics Society, 23 February 1987.
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demands. Instead, because the organisations had derived only a small proportion of their income from the pharmaceutical industry the charity's directors chose to lobby DHSS officials on their own.

Several British medical research charities explained that they were offered money by pharmaceutical companies - which they accepted - for the specific purpose of influencing government to put a number of their products on the NHS exemptions list. One of these charities, the Mental Health Foundation, explained that it had not received a charitable donation from a pharmaceutical company during the course of its 15 years of service prior to the government cutbacks to the NHS prescription list. However, when these cutbacks were announced in 1984 this changed:

"I was offered money by a pharmaceutical company if I succeeded in getting the Secretary of our Grants Review Board - who is one of the most eminent scientists in Britain - to get certain drugs included on the exemption list. It was an offer we could not refuse since the money allowed us to fund several projects that our volunteers have wanted for many years."

Medical research charities have not always accepted large donations from pharmaceutical companies as they have not wanted to create the impression to volunteers that one company's products are being endorsed. Several charities explained that had they close financial ties to the Distillers Company Limited in 1962,

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9British Interview; Mental Health Foundation, 20 February 1987.
when the 'crippling' drug Thalidomide was sold to the public, its credibility and fund raising capabilities would have been undermined permanently. Other charities, like the Canadian Foundation for the Study of Infant Deaths, argued that it was 'financial suicide' for any charity to rely on just one large corporate sponsor like a pharmaceutical company that might, for any number of reasons, withhold future support. For example, in the event of this taking place, charity's with funded research projects for periods longer than twelve months would have difficulties meeting their commitments.10 As a result, most medical research charities that have opted to accept voluntary donations from pharmaceutical companies have done so from more than one source. As one respondent remarked; “by accepting large corporate support from many different drug companies, charities are not fearful of leaving themselves vulnerable to outside tampering and agenda setting by their financial contributors.”11 Most respondents denied encountering similar problems to those facing charities in the non-medical research field that derive most of their income from government. One Canadian medical research charity executive explained:

“We are not like the Canadian Wildlife Foundation which receives approximately 78 per cent of its income from the federal government and has Officials from the Department of Environment sitting on the charities Board of Directors. The

10Canadian Interview; Canadian Foundation for the Study of Infant Deaths, 8 January 1987.

11Canadian Interview; December 1986.
problem with that arrangement is that government officials try to tailor the charity's programmes around existing or proposed government environmental policy."

British charities that have involved themselves in the NHS exemption list issue have done so not only to secure corporate contributions, but also to represent the interests of their Volunteers who are concerned with lowering drug prices. Since the volunteers and donating public are often disease sufferers, from a fund raising perspective the issue of drug prices has become an important matter for each organisation. Most executive directors of British charities remarked that political involvement in the NHS issue has been time consuming and expensive but vital to maintaining their fund raising infra-structure. In some cases, the pressure from volunteers has been so great that charities have not only attempted to get various drugs reinstated on the NHS exemption list but also to obtain new ones on the list. For example, medication for alleviating symptoms of cystic fibrosis have never been reimbursed by the British government. The reason for this is that individuals below the age of 16 are not required to pay prescription charges for any of the medicines they receive. When the NHS exemption list was first drawn up in 1948, there were very few cystic fibrosis patients who lived past the age of 16—pneumonia often claimed their lives. However, since pneumonia has been controlled effectively cystic fibrosis patients are now living into their twenties and are having to pay enormous sums of

12Ibid.
money for their medicines. Since the period of suffering has increased and more 'layers' of people surrounding these victims have been affected, pressure on the Cystic Fibrosis Research Trust to influence government policy has increased. As the Executive Director of this charity remarked:

"The CFRT has made this issue one of its priorities and it's something we are beginning to lobby quite fervently on. For example, we have gained support in Parliament, particularly from Mr. Pollock and Mr. Ivan Thomas who act as spokesmen for the CFRT in the House. They have managed on occasion to get an adjournment debate in order to get the Cystic Fibrosis medications put on the NHS exemption list. Furthermore, both the CFRT and our two parliamentary supporters are constantly making representations to government, particularly the DHSS, for this kind of reform."

The same respondent was asked how these two Members of Parliament came to support the CFRT. In both cases the M.P.'s were fathers of cystic fibrosis children.

In terms of their lobbying methods, most medical research charities have tended to utilize their own in-house scientific staff to negotiate with similarly qualified people at the DHSS. Since many scientists working for medical research charities hold cross-appointments with the (B)MRC (see chapter six, section I.C.) contacts within the governments' scientific network have usually been well established. As one respondent remarked:

"We are well aware that given the present

13British Interview; Cystic Fibrosis Research Trust, 24 February 1987.
government's commitment to reducing public spending. The reform that we are interested in will only come about with the strong support of senior officials from within DHSS. To think that we could affect change by walking up and down Whitehall with placards shouting and chanting is completely ridiculous."

In conclusion, the regulatory controls on prescribing illustrate that both charities and the pharmaceutical industry have an interest in seeing that more drugs are eligible for reimbursement under the government's social security scheme. If this happens, pharmaceutical companies would sell more of their products and generate larger profits. For charities, a greater number of drugs on the NHS prescription list would mean that disease sufferers would pay less for their medicines. The pharmaceutical industry's efforts to entice medical research charities to join their lobbying campaigns have been largely effective. However, charities have not only supported the industry's lobby but have also participated in the debate in order to satisfy the demands placed on them by volunteers. Charities failing to do so have feared jeopardizing their fund raising infrastructure.

B. Regulatory erosion of patent protection

Both Canadian and British pharmaceutical companies have argued that profits have been eroded by generic drug companies who are allowed to make inexpensive copies of existing drugs without

14 British Interview; February 1987.
spending large sums of money on research and development. In the past, this has been deterred by manufacturing patents which restrict generic competition for a specified period of time (this period varies from country to country). Pharmaceutical companies have lobbied government to extend the period of patent protection so that larger profits can be generated. The longer companies hold a monopoly in a product area, the larger their profits become - profits which the industry claims, are necessary to finance the escalating costs of discovering and developing new medicines.

In most countries, pharmaceutical products are covered by patents. In general, two types of patent protection are available. One covers the actual medicine itself - a 'product patent' - the other covers only the method of manufacture - a 'process patent'. The latter provides only weak protection for the innovator, as it is often possible to produce a person's novel medicinal chemical by a different production process (referred to as a generic drug), thus circumventing the intended patent protection. In addition, it is extremely difficult to prove that an imitator is actually using the patented production process, particularly if the onus of proof lies with the original patent holder. Until the 1950's, most countries relied on process patents for pharmaceutical products. However, since then, all countries, with the exception of Canada and several other non-European nations have had the stronger 'product patents' for at least 20 years. Canada has continued to rely only on 'process patents', thus enabling pharmaceutical imitators (generic drug
companies) to operate freely in their country. In EEC countries 'product patents' now run for 20 years from the date of application. In the United States they last for 17 years and in Japan for 15.15

Canada's postwar government inherited the original British provision in the patent laws which allowed generic drug companies to apply for compulsory licences for pharmaceuticals, and which required the Controller of Patents to grant such licences unless he could see good reason for refusing to do so. In Britain, this provision of the Patent law was repealed in 1977. However, instead of repealing this provision, the Canadian government chose to extend its application to permit importation of generic products as well as their local manufacture. Thus while Britain strengthened its patent protection, the Canadian government in the 1970's substantially weakened the protection afforded to new pharmaceutical discoveries. Furthermore, under its provincial health insurance plans, Canada has allowed substitution of generic medicines in place of the original brands prescribed by the doctor.

The effect of these substitution laws were strengthened by the introduction of 'Maximum Allowable Cost' provisions into the Social Security Schemes. Thus pharmacists have been reimbursed only at the price of the cheap generic copy product - they could not afford to dispense the original brand which had been

15Chew, Pharmaceuticals in Seven Nations, p. 37.

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prescribed. 16

According to the Pharmaceutical Manufacturers Association of Canada, the effects of these provisions on the Canadian pharmaceutical industry have been disastrous. Canada now carries out little significant pharmaceutical research and much of its pharmaceutical requirements are met by imports. 17 Figure 8.4 illustrates the decline of Canada's negative balance of pharmaceutical trade during the late 1970's, while Britain's positive trade balance at the same time improved.

Conversely, there are those advocating strongly the presence of generic drug manufacturing in Canada since it provides both lower drug costs and employment as well. Take for example, a typical 60 year old man whose doctor has recently diagnosed him as having an ulcer and has prescribed medication to control the problem. If this man is part of the 15 per cent of Canadians who are not covered by provincial drug programmes or private insurance plans, he must bear the entire cost of his medications. A one month supply of Tagamet, made by the multinational pharmaceutical company, Smith Kline and French would cost him $36.88 (£18.44) but the same number of pills of Cimetidine, the generic equivalent of Tagamet, would cost only $11.60 (£5.80). The quality of medicine is the same. Even if that same man was covered under a provincial health plan or private health insurance scheme, his monthly costs

16 Ibid., p. 56.

Figure 8.4

Comparison of British and Canadian Pharmaceutical Trade Balances, 1975-1979

£ million

450
400
350
300
250
0
-100
-122
-200
-300

Britain
Canada

premiums would also increase substantially. 18

In the future Canadians may not be able to get lower-priced generic copies of new drugs. At the time of writing, the Canadian Parliament is debating legislation (Bill C-22) that would take away an individual's right to choose between generic and non-generic medications. If the Bill is passed, new drugs would not face lower-priced generic competitors for ten years. 19 Canada would enforce product patents on newly discovered medicines similar to those found in Britain, the United States and Europe. Prior to 1969, Canadians would not have had that choice. Multinational companies introducing a drug into Canada would hold a monopoly on that drug until the patent on it expired - which at the time was up to 17 years. Without any competition, drug prices stayed high; in fact, three major federal reports during the 1960's found that Canadians were paying among the highest prices in the world for their medicines. Finally, in 1969, the federal government passed a bill allowing for compulsory licensing. Since then even if a drug is patented, a generic drug company can go to the Commissioners of Patents in Ottawa and get a licence to import and sell the drug in Canada. In return, the company receiving the licence pays the patent holder a royalty.

The multinational drug companies which lost their monopolies were naturally unhappy about the proposal to allow generic drug


19Toronto Star. 18 April 1987.
companies to take-over a portion of their Canadian market. Their interest group, the Pharmaceutical Manufacturers Association of Canada, spent more than $75,000 (£125,000) lobbying against the 1969 legislation. A number of scare tactics were utilized in an attempt to generate opposition to the proposal. Canadians were warned that in the event of an epidemic, the necessary drugs might not be available. As such, people would die due to the poor quality of drugs the generic companies would supply.20

After 1969, the multinationals kept up their lobbying efforts, and by 1984, the pressure started to have a political impact. The federal government appointed University of Toronto economist, Harry Eastman, to conduct an inquiry into all aspects of the pharmaceutical industry. Eastman held public hearings during the fall of 1984, and issued his report in May 1985. His findings indicated that contrary to the companies' claims, the multinationals had profited well under generic competition; in fact profit levels in Canada were higher than in almost all other western industrialized countries. Growth in the pharmaceutical industry from 1969 to 1984 was even better in Canada than in the United States where generic drug competition is not permitted. Furthermore, he concluded that the multinationals had lost only a small 3.1 per cent of the Canadian market to generic drug companies.21


It is true that the multinationals were not doing much research in Canada, but it has been argued they never had, even before 1969. The reason for the lack of research in Canada, according to one Canadian pharmaceutical spokesman is easily understood: "virtually all companies do most of their research in their home country". Since there are no multinationals headquartered in Canada there is little pharmaceutical research conducted in the country. Finally, and most importantly, Eastman found that in 1983 compulsory licencing had stimulated competition and as a result saved Canadians at least $52.5 million (£26.25 million) in drug costs. On a national drug bill of about $1.4 billion (£700 million) annually, compulsory licensing was shaving 16 per cent off the cost of prescriptions.

By the time the Eastman Report was published, a federal election had been held that brought to office the Progressive Conservative Party led by Prime Minister Brian Mulroney. During the election campaign Mulroney supported the position of the multinational drug companies. Once in office the Government initiated discussions with the United States regarding a comprehensive free-trade agreement, giving American-based multinational drug companies another means to exert pressure. Not only could U.S. based pharmaceutical companies directly lobby the federal government but they could also use their considerable

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22Canadian Interview; Connaught Laboratories, 11 February 1987.
23Department of Finance, Royal Commission on Canada's Pharmaceutical Industry, pp. 26-27.
influence in Washington to press their case. This so-called 'Washington connection' proved very powerful. Both U.S. President Ronald Reagan and Vice-President George Bush raised the subject during bi-lateral negotiations with their Canadian counterparts. In addition, the chief U.S. trade representative, Clayton Yeutter, publicly rebuked Canada for taking too long to respond to the U.S. pharmaceutical industry’s demands.24

Finally, in November 1986, Consumer and Corporate Affairs Minister Harvie Andre tabled Bill C-22 in Parliament. If enacted by the House of Commons, the Bill will give drug companies a ten year monopoly on any new drug they introduce, that is, pharmaceutical companies would restrict competition from cheaper generics for a period of ten years. The price of drugs already available would not change. There would be some provision for the creation of a Drug Price Review Board to ensure that prices for new drugs do not increase dramatically. However, the person likely to be appointed to head the board, Harry Eastman, has argued that without competition for ten years, new drugs would be more expensive than if there was competition.25 The Consumers Association of Canada has estimated that Bill C-22 would add an extra $300 million (£150 million) to drug costs by 1995.26 In return, for their ten year monopoly, the multinationals have


offered to invest $1.4 billion (£700 million) in research and development in Canada over the next ten years and create 3,000 new ‘high-technology’ jobs. An information paper from the Department of Consumer and Corporate Affairs speaks of creating ‘a world-class industry’ in Canada, a goal the Eastman Report warned was ‘virtually impossible’.27

In the context of relations between medical research charities and the state Bill C-22 is significant in that drug companies have attempted to encourage charities to join their lobby in support of the legislation. As in the case of the British pharmaceutical industry’s handling of the NHS exemption list Canadian drug companies have pressured charities to either support the Bill or have their corporate funding reduced. As a result, serious problems have been raised for Canadian medical research charities; support for the legislation would mean alienating patient service advocates. This group includes drug-dependent volunteer fund raisers and the donating public who are disease sufferers. Their demands have consistently been for their charities to lobby on their behalf for lower priced medicines – in other words, for generic competition. As a result, the typical response of most organisations that have research and patient service programmes has been to remain neutral on this issue. The Canadian Cancer Society (CCS) explained that when the issue first emerged its Executive Director sent a telegram to the Prime Minister of Canada, advising him of the dangers of Bill C-22.

27Department of Finance, Royal Commission on Canada’s Pharmaceutical Industry, p. 29.
Minister opposing the proposed amendments to the patents Act. His opposition was grounded in the belief that tens of thousands of cancer patients would be adversely affected by increased drug prices. However, when the Director of the CCS's Research Committee became aware of this, an emergency Board meeting was convened whereupon it was decided to withdraw the telegram and launch a study into the issue. As Ken Kyle, the CCS's Ottawa lobbyist explained:

"When the facts and complexity of the debate over Bill C-22 started to emerge, it became clear that we had shot ourselves in the foot by sending the telegram. People within our research wing were threatening to resign as well as to go public. As a result, the decision was made to withdraw our criticism of the Bill and remain neutral until we had a better grasp of the facts. To help us do this we commissioned two Carleton University researchers to study the proposed Bill and make recommendations to us, bearing in mind the two very different camps within our charity."

Of the 18 Canadian charities interviewed, eight stated that their charity had no official policy regarding the proposed legislation. Two charities were in full support of the pharmaceutical industry's bid to extend the patent protection and three were firmly opposed. Surprisingly, five respondents refused to make comments regarding their position on the grounds that it was a sensitive issue for their fund raisers. Of this last group, two executive directors later agreed to make comments 'off the

28 Canadian Interview; Canadian Cancer Society, 30 January 1987.
record' if anonymity was guaranteed.

Full support for the pharmaceutical industry and the proposed patent legislation has been demonstrated by charities like the Canadian Geriatrics Research Society (CGRS) which devotes all its funds to research. As the charity’s Executive Director explained:

"Our Board of Directors like Bill C-22 since it will facilitate the pharmaceuticals to make larger profits and in turn, do more research in Canada; perhaps more research into Gerontology."

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The same respondent was asked whether the CGRS had been contacted by pharmaceutical companies or their association to lobby in support of the proposed legislation. It was revealed that such contact had been continuous, since two of the charities' board members were senior pharmaceutical executives:

"Dr. Bill Cochran - Vice President of Connaught Laboratories - and Mr. Jim Dougherty - Vice President of Life Sciences at Connaught Laboratories - both sit on our Board of Directors. They have provided detailed studies showing us how our charity will benefit from the Bill as a result of the increase in Canadian pharmaceutical research."

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Since this same charity also derives approximately 21 per cent of its income from pharmaceutical companies, it is not surprising that it has supported unconditionally the industry’s lobby for

29Canadian Interview; Canadian Geriatrics Research Society, 12 January 1987.

30Ibid.
greater patent protection. Its support was described in the following way:

"We have written the Minister of Health Jake Epp and Consumer and Corporate Affairs Minister Harview Andre on several occasions expressing our support for Bill C-22. We have used our monthly newsletter to urge people to write their M.P.'s and the opposition party leaders demanding that the Bill be passed by the House as quickly as possible. Finally, we have also allowed the Pharmaceutical Manufacturers Association of Canada to add our name to its list of organisations supporting the legislation. It's a small effort, but if there is enough like-minded people in charitable and non-charitable organisations that lobby in this sort of controlled and responsible way then the legislation will most certainly succeed."

The charities that have suffered the most as a result of Bill C-22 are organisations that have relatively strong patient service programmes as well as medical research programmes, and which are heavily dependent on donations from the pharmaceutical industry. For example, the Parkinson Foundation of Canada receives money from four drug companies, Sandos, Markshop, Dall and DuPont. At the time of interviewing the largest sponsor - Sandos - had already threatened to withhold future funding for scientific conferences organized by the foundation if the charity did not alter its 'neutral' policy. However, due to the influence of Parkinson's sufferers on the charity's Board of Directors these corporate donations have been foregone as the price for containing drug prices. At present, Canadian Parkinson sufferers have two

31Ibid.
generic drugs available to them which means their present prescription charges are approximately half what they would be if ten year patents were in effect. Given that Parkinson sufferers require large amounts of medication and can live many years with their affliction, fighting higher drug prices has become a priority for both themselves and for their charity.32

Several smaller Canadian medical research charities representing less popular diseases have also lobbied against Bill C-22. For example, the Canadian Foundation for the Study of Infant Deaths has argued there is nothing in the proposed legislation that will actually force the multinationals to commit their newly generated profits towards research in Canada. The charities claim that the Bill says there will be a review of the legislation after four years and again after ten years. On the one hand, it is only presumed, that if the companies have not kept their promise to do more research, their ten year patent protection may be revoked. On the other hand, it might not actually be revoked, depending on the whim of whichever party is in power in Ottawa at the time. Thus, several medical research charities have written letters to various ministers seeking the inclusion of a ‘sun-set’ provision in the legislation. As one respondent explained:

"The ‘sun-set’ provision would re-evaluate the research commitment of all the drug companies in Canada every two years. If they were not meeting

32Canadian Interview; Parkinson Foundation of Canada, 20 January 1987.
pre-determined research levels or quotas then the bill would be scrapped and we would revert back to the present day system. The re-evaluation provision that is now being proposed does not set-out a detailed formula for calculating how much of the 'new profits' should be ploughed back into Canadian research. Instead, the pharmaceutical industry is merely proposing a "dummy" sun-set provision. As such, there will be nothing for us to do but watch newly generated profits flow south of the border."  

Smaller Canadian charities representing low profile diseases have also refuted drug company claims that greater patent protection and resulting increased profits would allow for the discovery of important new drugs. These charities argue that "pharmaceutical companies operate on the profit motive - if there was no money to be made in producing new medicines, the companies would be in some other line of business." Furthermore, the charities claim that, to minimize the risks involved in investing large sums of money for the development of new medicines, there has been a tendency on the part of manufacturers to concentrate their efforts on disease areas where both knowledge already exists and market potential is promising. In other words, British and Canadian pharmaceutical companies, like their governmental and charitable counterparts, have skewed their research efforts towards 'popular diseases' like cancer and heart. Interviews with pharmaceutical company executives in both countries revealed that

33Canadian Interview; Canadian Foundation for the Study of Infant Deaths, 8 January 1987.

34Canadian Interview; January 1987.
much drug-related research is conducted in these two popular disease areas because of the considerable amount of basic and applied research knowledge supplied by cancer and heart research charities and government. This has left those afflicted with multiple sclerosis, muscular dystrophy and cystic fibrosis with little promise for new medicines as their comparatively small numbers have not constituted profitable markets. Furthermore, several of the smaller British and Canadian charities argued that most of the pharmaceutical companies' research and marketing efforts are directed towards merely improving existing drugs that have the greatest sales and profit potential - not necessarily the greatest health need. Both British and Canadian respondents noted that as a result, 'research clustering' occurs in disease areas where medicines are already available. For example, in 1983 eleven new drugs for the treatment of ischaemic heart disease were added to the list of 33 products already available for this affliction.35 A further example of this type of practice is non-steroidal drugs for which 14 are presently available on the Canadian market for treating arthritis - a figure that is anticipated to increase to 20 by 1990.36 As the Executive Director of the Arthritis Society explained:

"If you read the medical literature you will find that by and large not one of these drugs is superior to any of the others. So why do they

35British Interview; Chest, Heart and Stroke Association, 20 February 1987.

36Canadian Interview; Arthritis Society, 20 January 1987

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keep appearing? The answer is simply that the Canadian market for arthritis drugs for one year is a lucrative $100 million (£50 million).”

Furthermore, one Canadian scientist explained that approximately 24 new drugs are introduced into Canada each year, but that only about ten per cent of these represent major therapeutic gains over already existing products. In addition, 60 per cent of these new drugs offer little or no therapeutic advantage; instead they are brought out because the companies believe there is money to be made in selling them.38

In conclusion, the conflict over Bill C-22 reveals that most Canadian medical research charities tend to formulate their policy decisions in consideration of those who supply their funding. Again, in Britain, medical research charities heavily dependent on pharmaceutical donations have lobbied the government to include various drugs on the NHS exemption list. In each case, the decision to actually lobby was partly determined by those who controlled the organisation’s fund raising efforts namely, their corporate sponsors. Pressure was also exerted by volunteers and the donating public who are sympathetic to the welfare of disease sufferers though in the Canadian patent case this tended to work against the interest of the drug companies. Both organisations have had to respond in some way to these various demands in order

37Ibid.

38Canadian Interview; McMaster University Medical School, Department of Pathology, 19 January 1987.
to avoid undermining their fund raising infrastructure. As one fund raiser noted:

"It is not good for business if a charity creates the impression that high drug prices is not worth lobbying government for reform. This is especially true if the organisation’s volunteers are heavily dependent on drugs."

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C. Regulation of drug development

Before new medicines are sold to the public, pharmaceutical companies must test their products for any potential adverse effects. In Britain and Canada the time required to do so is approximately ten years. In both countries, the pharmaceutical industry, and more recently medical research charities, have lobbied for the time period of ‘regulatory testing’ to be shortened. The industry’s main argument has been that excessive government regulation in this respect has dramatically increased the costs of developing new medicines, thus fewer products are reaching the market.

The history of regulation in the pharmaceutical industry goes back more than a century and a half. In the United States the Vaccine Act of 1813 was enacted to regulate the production and sale of medicine for smallpox. However, the first major regulation to control the testing and marketing of new medicines were introduced in the U.S. by the Food and Drug Administration (FDA) in 1938 in response to a disaster with the elixir of

39Canadian Interview; January 1987.

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Sulphanilamide. This occurred because the manufacturers used a toxic solvent to produce the elixir which killed 107 people before the mistake was realized. It was the Thalidomide tragedy in 1962 which precipitated the much stricter pharmaceutical regulations in force today, embodied in the 1962 Amendments to the Food and Drug Regulations in the United States, in the 1968 Medicine Act in Britain and in the 1970 Hazardous Product Act in Canada. The 1968 British legislation gave statutory backing to voluntary drug safety arrangements which had been introduced in 1964 under the Dunlop Committee.


41. Thalidomide was the name given to a drug developed in Germany in the 1950's that was taken primarily as a sedative and sleeping pill by pregnant women. Through a licencing agreement the drug was marketed in Britain by the Distillers Company Limited during the late 1950's and early 1960's. After reports from abroad that pregnant women taking the drug were producing physically deformed children, the drug was withdrawn from the British market. This incident brought to the government's attention the need to increase its regulation of the pharmaceutical industry's product development programmes. Moreover, the incident for the first time raised the need for government to provide long-term compensation (on a large scale) to those adversely affected by defective medicine. While this important theme is outside the main focus of this thesis, the point must be made that the British government (through the DHSS) provided a considerable sum of money (originally £3 million) to the Rowntree Memorial Trust Family Fund to disburse to Thalidomide sufferers and their families. By organizing a 'compensation package' through a non-state agency (a charity) the argument has been made that the state deflected the antagonism about the under-supply of such 'compensation' away from itself. See Jonathan Bradshaw, 'The DHSS-Rowntree Memorial Trust Family Fund: an innovation in quasi-government', in Anthony Barker, Quangos in Britain: Government and the Networks of Public Policy-Making. London: MacMillan, 1982, p. 109.
In an interview a British pharmaceutical spokesman argued that:

"The Thalidomide disaster must be taken in perspective - between 1940 and 1980, 250,000 childhood deaths were avoided by medical developments. In contrast, the number of British children tragically damaged by Thalidomide was fewer than 500. That is over 500 lives saved for each damaged child. I am not arguing that such a ratio makes the Thalidomide disaster 'acceptable' in any sense. But it does indicate that benefits and risks from medicines must be seen as a question of balance."

However, critics of the pharmaceutical industry have provided contemporary examples to show why government should not succumb to industry pressure to shorten the development time for new medicines. Their best arguments have centred on the drug 'Opren' - an anti-arthritis drug, made by Eli Lilly in the United States, introduced to Britain in 1980 and given to 500,000 patients. It is now alleged the range of side effects from Opren includes internal bleeding, kidney and liver diseases, skin rashes, blood disorders, distorted nails and abnormal hair growth. There have been, it is alleged, nearly 100 Opren related deaths and the number of injured plaintiffs seeking compensation is over 1,000 in the United Kingdom alone.

Industry critics have also been concerned about over-zealous pharmaceutical researchers who falsify, invent or otherwise

42British Interview; Astro Pharmaceuticals, 6 March 1987.

present misleading scientific data on new products to expedite product 'approval' by government regulatory officials. In a recent case, an eminent British scientist working in an Australian University faked important research which gave a new 'birth-control' pill an 'all-clear' report on its side-effects. According to an inquiry, Professor Michael Briggs, former head of Deakin University's science department and a world authority on the 'pill', failed to do any of the research in Australia that he claimed to. Not only did Briggs not have a personal laboratory to perform his alleged research, he was never seen conducting experiments. He nevertheless published influential scientific papers on the pill's side-effects which he claimed to have produced at Deakin between 1976 and 1984. The low-dose 'triphosic' pill gained the most from Brigg's unethical efforts, with them being presented as the least likely to produce risks of heart disease and other serious illnesses. Had this impropriety not been detected and the drug not 'called-back', two million British women who were using the drug may have been adversely affected.

The British and Canadian pharmaceutical industries have not opposed all forms of government regulation of drug development. Since the Thalidomide tragedy, the industry has recognized a need for government to provide additional safeguards to reduce the risk of adverse reactions from medicines. Indeed, the industry has welcomed a system of licensing of medicines prior to marketing in

order to keep out irresponsible manufacturers who might otherwise be tempted to 'cut-corners' and bring the industry into disrepute.45 Nevertheless, the industry has complained that the inevitable element of bureaucracy involved in a government scheme of regulatory controls has associated costs. The Association of British Pharmaceutical Industries notes that these costs include "the manpower needed in both government and industry to deal with the regulatory affairs in each country."46 More importantly, from the industry's point of view, the 'costs' include delays in marketing new medicines. A recent British study estimated that, apart from other factors, the 1968 Medicine Act and its subsequent regulations, had by themselves resulted in annual costs of between £30 and £85 million (at 1978 prices), absorbed the time of over 1,000 staff, and added two years on to the time required to develop a new medicine. This is in addition to the increased costs and longer delays caused by the greater sophistication of pharmaceutical development as a whole which the industry has identified.47

Hartley and Maynard concluded that "in the circumstances of mounting criticism and genuine doubts about the value of the 1968 Medicine Act we would argue that now is the time for a serious re-

45British Interview; Association of British Pharmaceutical Industries, 9 April 1987.

46Ibid.

appraisal of the U.K.'s regulatory arrangements. In fact, since the Hartley and Maynard study was conducted, there has been an important move to reduce the effects of regulation by the introduction of a Clinical Trial Certificate Exemption Scheme. This has cut out much of the purely bureaucratic delay which had occurred in Britain before a new medicine could be tested on patients, but the pharmaceutical industry argues that it has not substantially altered the overall problem of excessive drug development regulations. Similarly, in Canada, there have been moves to relax regulatory measures required before new medicines can be introduced. Nevertheless, the average delay between the first discovery of a new pharmaceutical chemical entity and its marketing in both countries is still approximately ten years.

Those British and Canadian medical research charities with strong patient service programmes have supported the pharmaceutical industry's lobby to reduce the development time for new medicines. Both groups have stated to their governments that a society as a whole would benefit if delay could be reduced and if new medicines could be made available sooner without reducing their margin of safety. As the Executive Director of the Cystic Fibrosis Research Trust explained:

"We have had two recent cases of medication which have been unnecessarily delayed in being approved by government regulatory officials. One drug involved the preparation of enzymes for digestion which two commercial firms had developed. These preparations were tested and were found to be

48Ibid., p. 122.
extremely effective since they could reach the digestive tract before being dissipated to other areas of the body. The government took quite a long time to approve these drugs for public consumption which has meant longer periods of suffering for our members."

Charities in this position have had to respond carefully. On the one hand, they have had to appear to be representing the interests of their fund raisers and donating public (many of whom are disease sufferers). On the other hand they have had to lobby discretely and separately from the drug manufacturers. As the Executive Director of the Arthritis Society explained:

"Several Canadian pharmaceutical companies have asked us to join the lobby organized by the Pharmaceutical Manufacturers Association of Canada to reduce drug development regulations. They clearly did so since they know we are pressured by our members to get new drugs for arthritics on the market as quick as possible. Our response has been to make our own little noise in Ottawa but to distance ourselves from the industry's much larger and aggressive lobbying campaign."

Apart from safety measures before a new medicine is approved, there is a particular concern about the effectiveness of what is described as 'post-marketing surveillance' after a new medicine has actually been sold to the public. This has arisen largely from the experience with the anti-rheumatic drug Benoxaprofen

49British Interview; Cystic Fibrosis Research Trust, 24 February 1987.

50Canadian Interview; Arthritis Society, 20 January 1987.
which was withdrawn from sale in 1982 after 61 deaths had been reported in Britain. The Committee on Safety of Medicines, headquarterd in London, which recommended the suspension of the preparation’s licence for sale after reports of the deaths had been received, was accused of acting too slowly.51 As a result, in many countries, there have been discussions between government regulatory officials, pharmaceutical corporations, and several medical research charities to examine ways of improving the detection of potentially ‘toxic’ drugs that are already on the market. Medical research charities have examined the feasibility of providing government officials with lists of patients in emergency situations such as when a drug is first suspected of being defective. In doing so, pharmaceutical companies and government experts could design clinical trials to confirm or deny suspicion of ‘product failure’. The charities would be an obvious source of this information as most organisations keep lists of disease sufferers, since many are volunteer fund raisers or financial contributors to their organisations.52

In conclusion, the issue of ‘drug development’ is complicated since pharmaceutical companies and medical research charities want new drugs available on the market as quickly as possible yet for them to be completely free of adverse side-effects. As with other pharmaceutical-related issues, British and Canadian medical


52 British Interview; The Wellcome Trust, 19 March 1987.
research charities have lobbied in support of the pharmaceutical industry for regulatory reform. On the one hand, if the period of drug development is shortened pharmaceutical companies would be able to sell their products to the public sooner, and in doing so to reduce their drug development costs. On the other hand, charities would be able to claim victory for representing the interests of their volunteers and donating public who would have quicker access to new medications. The respondents in this study that had participated in these lobbies freely acknowledged that they had done so in order to preserve their fund raising infrastructure. In most cases, organisations were fearful of losing corporate support as well as support from disease suffering volunteers. This issue differed from the issue of 'patent protection' in that charities which have lobbied for regulatory reform have not alienated those members and others interested in medical research. Consequently, internal debate between patient service advocates and medical research advocates on this issue was not evident in any of the charities studied.

D. **Government restrictions on promotion of pharmaceutical products**

In Britain and Canada there exist both voluntary and statutory restraint on the pharmaceutical industry's sales promotion activities. In Britain, since 1958, the industry has had its own Code of Practice to ensure that advertising is accurate and responsible. This is policed by a committee under the chairmanship of an independent barrister. In addition, the
1968 Medicines Act imposed further restrictions; for example, every advertisement must be approved by both a doctor and a pharmacist before it is published. Each medicine must have a 'Data Sheet' which sets out the limits of the claims which can be made for the medicines, and its adverse effects and contraindications. Furthermore, the volume of 'permitted' sales promotion in both Britain and Canada is limited to ten per cent of sales; any spending above this limit is added back to profits in price negotiations under the Price Regulation Scheme in each country.53

These voluntary and statutory controls on the industry's sales promotion have generally been effective in preventing misleading claims and in ensuring a reasonably balanced and honest presentation of a medicine's advantages. There are, however, very real difficulties in trying to cutback on promotion expenditure once a drug is being sold on the market. Thus, in both countries there is apparent extravagance in spending by certain companies. The industry's relatively strict Code of Practice which specifically prohibits excessive entertainment of doctors has been particularly hard to administer. Doctors are naturally flattered by generous 'entertainments' provided to attract their attention to certain products. In addition, competition between companies has resulted in each trying to out-do the others in their efforts

to get doctors to prescribe their product brand. 54

In response to public pressure and consumer interest groups, the British and Canadian governments have contemplated increasing their regulation of pharmaceutical promotions. However, the Office of Health Economics (OHE), has claimed that further restrictions on both the content and volume of information provided to doctors will ‘crystallize existing drug consumption patterns’. This, they argue, would delay the introduction of genuine advances in treatment that hold new promise for a large number of disease sufferers. For example, it has been estimated by the OHE that if the introduction of all new medicines of the 1940’s, 1950’s and 1960’s had been delayed by a year almost 10,000 additional children would have died because they would have been denied the benefits of the medicinal innovations of those years. 55

As Mrs. Francis Charlesworth from the Association of British Pharmaceutical Industries explained:

"If the introduction of treatment for today’s fatal diseases, such as cancer and heart disease, are delayed, unnecessary mortality in adults would occur. There is already evidence that doctors have become slower to adopt the use of new medicines since the Thalidomide tragedy in the 1960’s."

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54 Ibid., p. 20.


56 British Interview; Association of British Pharmaceutical Industries, 9 April 1987.
Despite these arguments stricter government regulation of product promotion is being contemplated in both Britain and Canada. Pharmaceutical companies have begun to rely on medical research charities to promote their products. For example, as part of their 'public education programme' the Arthritis Society has recently produced a video about their organisation which is financed entirely by three pharmaceutical companies. For their part, the three companies received a credit at the end of the film and on all printed material promoting the charity and its cause. As the Executive Director of this charity explained:

"The pharmaceutical companies sponsor these kinds of activities in order to get our 'good-name' associated with their products. We must be careful to avoid promoting the products of just one company since we know that our members are vulnerable to the advice we provide them."

The same charity also explained that one pharmaceutical company recently provided a donation of $10,000 (£5,000) to organize a symposium in Toronto to be attended by leading medical experts on arthritis disease. Again, while the charity was given the credit for staging this event the donating company was present at the symposia in order to promote its products. Another very important marketing tool for the British and Canadian pharmaceutical industry has been the information magazine published by medical research charities for their disease.

57Canadian Interview; Arthritis Society, 20 January 1987.
58Ibid.
suffers. As the spokesman for the Canadian Diabetes Association explained:

"They (the pharmaceutical companies) finance the entire production of our monthly newsletter to a tune of $200,000 (£100,000). They do this principally through advertising space for their products. However, we are extremely careful not to give exclusive advertising rights to any one company and we refuse to endorse products."

A (C)MRC official explained that government regulatory agencies have only recently come to appreciate the extent to which the pharmaceutical companies are promoting their products through charities. Their main contention is that drug companies are able to spend more than ten per cent of their profits on product advertising since the monies given to charities are not included in the calculation of that figure. This is the case since money earmarked for product promotion is normally treated as a charitable contribution. Furthermore, in Canada, not only does this allow the corporations to spend more on advertising, but it allows them also to do so at a reduced cost since voluntary contributions to registered charities are tax deductible to the donor. As the Executive Director of the Asthma Research Council noted:

"The pharmaceutical companies are getting a great

59 Canadian Interview; Canadian Diabetes Association, 4 December 1986.
60 Canadian Interview; Medical Research Council, 28 January 1987.
deal when they use our news-magazine to advertise their product since their message is going directly to the consumer. We both know that doctors are the ones prescribing the medicine. However, we both recognize that people are more knowledgeable and less trusting of the medical profession and are beginning to state their preference for various treatments when consulting with a physician."

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Respondents from the pharmaceutical industry defended their financial support for medical research charities on the grounds that corporate contributions normally flow into an organisation’s core budget whence expenditure is then determined by the charity. In other words, the industry has suggested that contributions are not given to medical research charities for the purpose of promoting their products. However, as one Canadian respondent argued:

"It is true that they (pharmaceutical companies) direct their money into our general revenue fund since they are then able to claim their donation as a charitable contribution from Revenue Canada. Nevertheless, they do specify on what projects or programmes they would like their money spent."

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Of the ten British and Canadian medical research charities interviewed that had neither public education or patient service programmes not one had received financial support from the pharmaceutical industry. British and Canadian charities that exclusively fund medical research offer no valuable service to the

61British Interview; Asthma Research Council, 10 March 1987.
62Canadian Interview; January 1987.
pharmaceutical companies. For example, drug companies have not made donations to these charities for the purpose of ‘contracting out’ part of their own research. As explained by the Charity Commissioners, there is an important legal reason for this.

"Since medical research charities are registered under the education category, all funded research results must be of an educational nature and must be published. Scientific results must be published so that other interested parties—whether they be other researchers or pharmaceutical companies—can build on that knowledge for the benefit of the community."

Since the success of pharmaceutical companies in developing new products is contingent upon keeping scientific results secret from their competitors, charities have not been good vehicles for conducting contractual research. With this in mind, the corporate contributions that have been made to medical research charities must be seen to be for other non-research related purposes, such as for projects like product promotion. This being the case, contributions from the pharmaceutical industry should not be viewed as purely philanthropic gestures but rather as quid pro quo transactions in return for commercial services.

In conclusion, the four areas of government regulation, namely regulatory pressures on prescribing, regulatory erosion of patent protection, regulation of drug development and regulations of pharmaceutical promotions, have all affected the pharmaceutical industry’s ability to generate larger profits. Since evidence has

63British Interview; The Charity Commission, 31 March 1987.

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been given showing that medical research charities have participated alongside the pharmaceutical industry in support of their various lobbies, the question remains as to how much credit should flow to these organisations if public policy is affected. To do this quantitatively or qualitatively is virtually impossible. However, what can be concluded is that voluntary donations are being used by charities to seek regulatory reforms so that non-charitable organisations can generate larger commercial profits. One would not want to overstate the degree to which charitable funds are being used to support purely non-charitable purposes but an argument can be made that this potential does exist and can be exploited further.

II. Medical Research Charities and the Patient Service Lobby

This section of the chapter examines issues unrelated to the pharmaceutical industry that have prompted medical research charities to lobby on behalf of their constituents. As with their lobbying for the drug companies, charities have responded to these demands to largely maintain their fund raising infra-structures. British and Canadian medical research charities have lobbied on behalf of disease sufferers on a host of issues ranging from discrimination in the workplace to restricted access to health-related statutory benefits. Since health care is not a federal responsibility, Canadian charities have lobbied provincial governments on issues concerning patient services. As such, most representation to governments are executed either through a
charity’s provincial office or its local branches. Nevertheless, the national wing of most Canadian medical research charities are actively involved in developing patient service policies and in getting these services delivered at comparable levels of quality in each region of the country. British medical research charities have largely focused their patient service lobbies on the central government, particularly the DHSS. However, occasionally representation will be made on behalf of disease sufferers to local social service offices. Very seldom do local branches or regional offices participate in these lobbying activities instead, most policy and personal advocacy is executed through a medical research charity’s national office.

A. Personal advocacy

In Britain, the Cystic Fibrosis Research Trust has been actively involved in personal advocacy on behalf of their patients. The DHSS now provides an ‘attendance allowance’ for individuals whose medical conditions have meant they require a large amount of ‘home care’ and attention beyond what is normally required. Medical experts have recently found that children suffering from cystic fibrosis require extra physiotherapy, extra dietary care and constant monitoring with regard to personal hygiene. However, these additional benefits have normally been denied to cystic fibrosis patients when they first apply for the attendance allowance. According to the trusts’ Executive Director:
"Most cystic fibrosis patients seem to have to go through a negotiative process with local DHSS officials before they qualify for assistance under this programme - this is when we are called in. Usually we will advocate on a child's behalf to government officials and present them with the 'grim realities' of this disease. Having done that we have been successful 95 per cent of the time in getting our members this money."

Likewise, the Kidney Foundation of Canada, has met with Ministry of Health officials on behalf of patients who have failed to receive the statutory services they are entitled to. Don Lamont, the Foundation's Executive Director remarked:

"Our most celebrated case involved a woman living in Sudbury who tried for five years on her own to get a home-nurse. Through one of our fund raising appeals she heard of our organisation and contacted us. Over the span of just one week we managed to convince Ministry officials that her kidney disorder required daily medical attention. Needless to say both her and her family have subsequently become very committed financial contributors to this charity."

Other areas of personal advocacy in which charities have involved themselves, centre on issues of discrimination. For example, in the area of employment the Canadian Cancer Society (CCS) has represented several cancer patients who have been refused jobs or released from their positions after being diagnosed with the disease. Similarly, the Canadian Diabetic

64British Interview; Cystic Fibrosis Research Trust, 24 February 1987.

65Canadian Interview; Kidney Foundation of Canada, 3 December 1986.
Association CDA recently advocated on behalf of a person in Winnipeg whose employer - the Canadian National Railway - demoted him to a clerical position strictly because he was a diabetic. For seven years that person was forced to work at a lower paid job because he was deemed physically unfit to handle the responsibilities of his previous position. However, after making representations to the Canadian Human Rights Commission the CDA succeeded in influencing a decision which upheld the charge of discrimination.66 The CCS has also involved itself in issues of discrimination in the area of immigration. For example, according to the charity’s Ottawa lobbyist:

"We recently had a case where a married couple had gained an entry visa to live in Canada and therefore sold all their property in the United States. However, when they arrived at the border they were refused entry because one member had had a problem with cancer five years earlier. Our volunteers have pushed us hard to lobby government to put an end to this kind of discriminatory harassment and it’s something we have had to respond to immediately." 67

B. Statutory and regulatory reform

In Britain and Canada, those volunteering their time and money have urged their organisations to affect permanent legislative and regulatory reforms to improve the welfare of disease sufferers. The Canadian Foundation for Ileitus and

66Canadian Interview; Canadian Diabetes Association, 4 December 1986.

67Canadian Interview; Canadian Cancer Society, 30 January 1987.
Colitus has lobbied the Ontario provincial government and the insurance industry to reimburse bowel disease sufferers for the cost of 'parenteral-nutrition' treatment while convalescing at home. Presently the government's Ontario Health Insurance Plan (OHIP) will cover these same costs when a patient is in the hospital. The problem is that the government now classifies 'out-of-hospital' parenteral nutrition as 'food' not as 'drugs'. Consequently, many people suffering from bowel disease remain in hospital for much longer periods of time than is necessary, as they are unable to afford 'home treatment'. The Executive Director of this charity explained:

"Our volunteers have repeatedly asked us to raise the issue with government decision makers. In response, we have prepared a very lengthy and detailed document that explains the economic reasons why this treatment should be covered under government health schemes and private insurance. In doing so, we have made direct comparisons to diabetics who get their insulin free of charge regardless of whether they are in hospital or at home. Furthermore, we have shown that home-treatment costs only $60 (£30) a day whereas hospital treatment costs $380 (£190). We have given statistics relating to 'lost-time' at work and explained how this translates into higher health care expenses and inevitably higher taxes."

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Similarly, the Parkinson Foundation of Canada has lobbied government officials to cover the cost of home nurses for their disease sufferers. The charity has explained to Ministry of Health officials that Parkinson sufferers are in chronic care

68Canadian Interview; Canadian Foundation for Ileitus and Colitis, 12 January 1987.
facilities costing taxpayers $400 (£200) a day. Since many parkinson sufferers are diagnosed in their 40's and 50's and normally do not die of the disease, the cost of hospitalization for 20 or 30 years is enormous. The charity has argued that these patients would be better off living at home either with their family or with a 'home-nurse' and paid for with tax credits.69

An interesting dimension to the patient service lobby in both Britain and Canada is that charities facing similar problems—such as shortages of home nurses—have established coalition groups to articulate their concerns to government. As an example, the Canadian Neurological Coalition (CNC) was formed in 1980 as an umbrella organisation representing among others alzheimer's disease, huntington's disease, epilepsy, and multiple sclerosis. The main purpose of the Coalition which is itself a registered charity, is to negotiate with provincial governments for more comprehensive statutory programmes to help disease sufferers and their families cope more effectively with their afflictions. In doing so, CNC has presented government with innovative suggestions to help their constituents and at the same time reduce public health care expenditures. One proposal has been for government to establish 'day-care centres' so that people forced into employment can 'drop-off' their ailing husband or wife during the day while they go to work. The CNC have presented the economic arguments to government that this programme would be less expensive than

69Canadian Interview; Parkinson Foundation of Canada, 20 January 1987.
permanently institutionalizing people in hospitals or nursing homes. Likewise, in Britain the Spastics Society was active in the late 1970's in establishing the Community Care Campaigners (CCC) whose membership now also includes Dr. Barnardo's, MIND, and MENCAP. Like their CNC counterpart in Canada they are principally concerned with affecting legislative changes with a view to increasing the welfare of their constituents. In an interview with Sir John Cox, the CCC's principal spokesman, the coalition's contact with government was described in the following way:

"The coalition is active in lobbying each of the political parties to include certain items in their manifestos. In addition to that and to extensive letter writing, I meet face to face with elected officials. I will be meeting the Minister of Employment tomorrow, I talked to the Health Minister Tony Newton two weeks ago, I talked to John Major the Minister for Social Service last week and to George Younger, who is the Housing Minister, a few weeks before that. Furthermore, I personally have given evidence on behalf of the CCC to the All Party Disablement Group in both Houses."

The same respondent was asked whether or not the coalition and its individual members feared being deregistered for breaking the political bar rule. The response was that this has never been a concern as their issues have not been 'party political'. Furthermore, the coalition claims to have made equal representations to each of the political parties thereby avoiding

70Canadian Interview; Multiple Sclerosis Society of Canada, 3 December 1987.

71British Interview; Spastics Society, 23 February 1987.
being partisan in any overt way. As an example, it was explained that John Major from the Conservative Party wanted to have in-depth discussions regarding a number of proposals put forward by the coalition and therefore organized a one-to-one meeting that lasted an entire day. Again, Michael Meacher, the Labour Party’s Social Service spokesman arranged for the CCC to give a presentation to the entire front bench of the Labour Party. Furthermore, Cox argued that, if either party endorsed the CCC’s initiatives, the Charity Commission would not interpret that as party political but rather as a charity representing the views and interests of the physically disabled.72

The Muscular Dystrophy Association of Canada (MDAC), which has not utilized coalitions in their lobby of government, have raised several other important patient service issues. First, the charity has presented a number of reports to the Ontario Housing Commission, advocating the introduction of ‘barrier-free designs’ to the province’s Building Code. For many years muscular dystrophy patients confined to wheelchairs, have demanded that new buildings be constructed with access ramps and elevators. The charity is unable to claim victory in affecting permanent changes to the Building Code, but nonetheless argues that architects and construction companies have been educated about the needs of the disabled. Second, MDAC has also lobbied government to restore funding to programmes that supply ‘aids’ required for daily living to muscular dystrophy patients. In Ontario, Quebec, Alberta and

72Ibid.
British Columbia, provincial governments have reduced financial subsidies covering the cost of wheelchairs and specially modified home products ranging from toilets to home-computers. The MDAC's provincial offices in these regions have mobilized their volunteers to write letters to Members of the Provincial Legislature. At the time of writing, only the Alberta government had discontinued its policy, and it has actually increased its coverage for home-care services for muscular dystrophy patients under its provincial health care system.73

The Multiple Sclerosis Society of Canada has made one of its patient service priorities to lobby the federal government to allow its constituents to deduct home air-conditioning units from their personal income tax. The charity has presented strong medical proof to Revenue Canada officials that cool temperatures are effective in reducing several of the uncomfortable side-effects associated with multiple sclerosis.

"We recently had a lawyer write an article in our newsletter who encouraged multiple sclerosis sufferers to claim the purchase of air-conditioning units as tax exemptions. It has turned out that in some cases Revenue Canada has given the exemption and in other cases they have refused it. As a result we are trying to raise money to finance a test case that will force the courts to make a final ruling on this issue."74

73Canadian Interview; Muscular Dystrophy Association of Canada, 5 December 1986.

74Canadian Interview; Multiple Sclerosis Society of Canada, 3 December 1987.

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The Muscular Dystrophy Group of Great Britain has also attempted to lessen the impact of government cutbacks to statutory services available to muscular dystrophy patients. As its Executive Director explained:

"In 1985 we set up a special trust which is a subsidiary of this charity called the Joseph Patrick Memorial Trust with the specific aim of financing the 'adoption of cars, wheelchairs and other products' which under the Chronically Sick and Disabled Persons Act, 1970 should be covered by the state. Unfortunately, there are numerous areas where government has simply neglected to fulfil its statutory obligations."

The MDGGB has argued that greater success in influencing DHSS to spend more on 'aids for daily living' has been limited. Part of the reason is that the charity has been involved actively in other areas of patient service that have consumed much time, money and manpower. Since the early part of the 1980's the MDGGB began to receive numerous complaints from volunteers that recently diagnosed patients were being treated badly by doctors. Specifically, it was charged that children diagnosed with muscular dystrophy were being told very little about the disease and the types of social and medical problems they should anticipate. In response, in 1982 the MDGGB financed the creation of 'Family Care Officers' (FCO's) who are either trained nurses, occupational therapists, physiotherapists and social workers. These people are employed by a hospital and are 'attached' to a consultant-
normally a pediatrician or geneticist. Because the FCO's are health service employees the MDGGB pays their salaries to the hospitals which, in turn, distribute the money accordingly. If the charity paid these salaries directly to the FCO's they would effectively be 'brought out' of the health service which would threaten their benefits and pensions. The FCO's main purpose has been to contact the family of recently diagnosed muscular dystrophy patients in order to provide much more detailed information about the disease. During the initial stages, an FCO will visit the home frequently to allow those involved with the affliction to vent their fears and frustrations.76

As the Executive Director of the MDGGB explained:

"There are three traumatic moments for muscular dystrophy patients and their families. The first is the diagnosis, the second is the wretched experience of being placed in a wheelchair at the age of ten or eleven. Finally, there is inevitable death in their late teens or early twenties." 77

The FCO's are more than emotional counsellors, since they are also actively involved in informing families about the statutory benefits they are entitled to including: 'Attendance Allowances', 'Aids for Daily Living' and 'Mobility Allowances'. The MDGGB views the FCO programme as an important charitable contribution but it nevertheless would prefer to see this service being

76 Ibid.
77 Ibid.
provided by the state. The programme's unique feature is that volunteers initially called on the charity to deliver the service to fill a gap left by the state. However, given the success and increasing demand for FCO's, these same volunteers are now encouraging their organisation to lobby government to assume a greater financial responsibility for the programme. The MDGGB's Executive Director explained:

"We recognize that much more could be accomplished in the area of patient counselling at home if statutory funding was provided. As such we have discussed the issue with DHSS officials and in some very heated debate we have threatened to withdraw our support for the FCO programme. However, DHSS officials are a lot of things, but they are not all daft ... they know we were bluffing since our volunteers and donating public would never allow us to withdraw completely and allow the programme to disappear."

Another good example of medical research charities involving themselves in the policy process, relates to the British and Canadian Diabetes Associations' demands to increase government regulation of the food industry in their respective countries. The medical research charities have insisted that government force food producers to include the 'sugar-content' on the outside packaging of all their products. The charities have argued that this would save the lives of hundreds of diabetics who die each year as a result of accidental sugar overdoses. However, the Executive Director of the Canadian Diabetes Association explains

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78Ibid.
that while this is an important issue, there is some concern that their lobby might violate the ban on political activity.

"At one level Revenue Canada might interpret our lobby of the food industry as partisan since, the Conservative Party has tended in the past to reject any regulatory interference which threatens to raise the cost of doing business in Canada. As such, our lobby might help some patients but if we are deregistered we might be doing a much larger dis-service to diabetics."

In Britain, where sugar and caloric labelling has been gradually introduced on a voluntary basis, diabetics have frequently criticized the accuracy of the information provided by food producers. The most frequent problem is that food producers, who have changed the size or contents of their products for marketing purposes, have not made the necessary adjustments to their packaging information. As the Executive Director of the British Diabetic Association (BDA) remarked:

"I know it's a serious accusation to make but we suspect that diabetics have either died or become blind simply because food producers have been too cheap to change the printing on their packages. We have raised this concern to government officials and are awaiting a response. In the meantime we have had to spend a lot of our resources on monitoring changes to the volume and the content of food available to diabetics."

79 Canadian Interview; Canadian Diabetes Association, 4 December 1986.

80 British Interview; British Diabetic Association, 2 March 1987.
Lastly, the BDA has worked hard to influence DHSS officials to permit general practitioners to prescribe plastic syringes to diabetics at no cost to the patients, as is presently the case with the insulin they receive. Until now, the government has denied this request since permitting diabetics to use the syringes once - as prescribed - would be too expensive. However, the charity has submitted scientific evidence to government officials showing that diabetics have been capable of using the plastic syringes ten times before the needles become too blunt. Given this, the BDA has illustrated to government that by removing the 'single use warning' from the syringe package, and by allowing diabetics to receive them free from their doctors, the cost to the NHS would be reduced greatly.81

III. Medical Research Charities and the Anti-Smoking Lobby

Medical research charities participating in the anti-smoking lobby are unique since the issue is neither directly related to patient services nor to medical research. Instead, the issue could be organized under the category of either 'public education' or 'preventive medicine'. Charities representing diseases where the cause is known are able to educate the public as to their prevention through radio, television, newspaper and postal advertising. These charities have also pressured government to enact legislation that would regulate 'controlled factors' known to contribute to the increasing incidence of various diseases.

81Ibid.
Unfortunately, there are many diseases where the causes are still undetermined and where public education campaigns are unable to be organized; this would include diseases like multiple sclerosis, cystic fibrosis, leprosy, Parkinson and Alzheimer's to list a few. Conversely, there are the minority of diseases like some cancers, certain heart disorders and AIDS for which causes are known, and where governments have been pressured to invoke measures aimed at reducing incidence rates. For example, the governments of Britain, Canada and the United States have funded media campaigns urging individuals to use condoms during sexual intercourse as a means of limiting the spread of AIDS. In addition, intravenous drug users have been cautioned about the hazards of sharing needles especially with other AIDS-contaminated drug addicts. However, there are other disorders, including lung cancer, with which charities have been largely unsuccessful in influencing a government response. Nonetheless, the extent of medical research charities involvement in the anti-smoking issue, especially in Canada, is revealed in the increasingly sophisticated tactics employed by these organisations in pressuring government for legislative reform. British medical research charities involved in cancer research have not directly participated in the anti-smoking lobby since this movement is spearheaded by other non-charitable, non-medical organisations such as Action on Smoking and Health (ASH). British cancer research charities, through their membership with the United Kingdom Cancer Co-ordinating Committee (UKCCC), have limited their role in the anti-smoking
issue to one of providing scientific data on the tar and nicotine contents of new products entering the consumer market. This is done with a view to reaffirming the correlation between tobacco consumption and various types of cancer.82 In contrast, the Canadian Cancer Society (CCS) has involved itself in a wide range of issues related to smoking, including the banning of smoking on domestic airline flights of two hours or less, raising taxes on all tobacco products, increased regulation of tobacco advertising, and providing public funds for crop or income substitution for tobacco farmers.

The CCS has lobbied not only by itself on the anti-smoking issue but also as a member of an umbrella group known as the Canadian Council on Smoking and Health (CCSH). However, CCS officials noted that their individual lobbying efforts have been far more successful than those organized by the CCSH for a number of reasons. First, they explained that the coalition has shied away from 'hard-nose' lobbying tactics and has instead opted to involve itself in non-political programmes like ‘National Non-Smoking Week’ and ‘Weedless Wednesday’. Furthermore, the CCS argued that the coalition has made it easy for the individual member charities like the Canadian Heart Foundation and the Canadian Lung Association to opt out of their responsibilities to lobby individually against the tobacco industry. Since the CCSH has accomplished little in the way of legislative reform, partly as a result of being underfunded and understaffed, the CCS has

82British Interview; Medical Research Council, 2 April 1987.
developed into the most active and vocal organisation in this campaign. As the CCC’s Ottawa lobbyist explained:

“We suspect that the reason why the Canadian Heart Foundation has not done much lobbying is because their Executive Director is a heavy smoker. I’ve also heard that the Association does not want to see a strong Canadian Council on Smoking and Health because they are worried that the Council will get into programmes similar to their own which would hurt their fund raising efforts. The end result is a pretty weak Coalition that has done relatively little to affect legislative changes.”

There are two additional reasons why the CCS has been the only charity to lobby the federal government directly on the anti-smoking issue. First, respondents from the Heart and Stroke Foundation of Ontario (HSFO) and the Canadian Heart Foundation (CHF) explained that a more vocal and active involvement in the anti-smoking lobby would undermine their fund raising efforts in the tobacco growing belts in southern Ontario. As Susan Lawson from the HSFO explained:

“We know that the friends and families of those who stand to lose their farms and manufacturing jobs as a result of stricter tobacco laws will not support this charity if we are instrumental in that process. We are primarily a research-based charity and we are not willing to risk jeopardizing our fund raising base over this one issue.”

83Canadian Interview; Canadian Cancer Society, 30 January 1987.

84Canadian Interview; Heart and Stroke Foundation of Ontario, 22 December 1986.
According to the CCS, the Canadian Lung Association has been reticent to lobby the federal government individually since it is fearful of losing the 'Sustaining-Grant' it receives from the Department of Health and Welfare. As Ken Kyle the CCC's lobbyist explained; this has not been a problem for his charity.

"I have a copy of a letter which was recently sent by the President of the National office of the Canadian Lung Association to the Minister of Health and Welfare. It disassociates themselves from comments made by the President of the Canadian Council on Smoking and Health at a news conference which were extremely critical of that Minister for not moving fast enough in this area (the area of increased taxes on tobacco products). Because the Canadian Cancer Society is totally independent from government financing we have the added flexibility and autonomy to lobby in any way we see fit."

Since the CCS has been the most active charity in the anti-smoking lobby, it is worthwhile reviewing its methods and accomplishments. The CCS has made formal representations to the federal government regarding this issue since 1979. However, over this nine year period, successive Ministers of Health and Welfare have been reluctant to act on various recommendations put forward by the charity's National Executive. Consequently, in 1986 the CCS supported a Private Members Bill, Bill C-204, and known as the Non Smokers Health Act, which was sponsored by an opposition M.P. from the New Democratic Party. The Bill set forth a number of

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85 Canadian Interview; Canadian Cancer Society, 30 January 1987.
recommendations, ranging from a complete ban on smoking in public establishments (including restaurants, stores and sports facilities), to a complete ban on all tobacco advertising and promotions. The CCS's strategy has been to mobilize its 130,000 volunteers to support the bill through a series of public demonstrations and letter writing campaigns. As a result of these representations the CCS claims to have succeeded in getting Bill C-204 selected by an 'all-party committee' to be debated in the House of Commons. Their strategy has been to support the proposed legislation in order to force the Minister of Health and Welfare, Jake Epp, to formulate his own legislation that would be at least as comprehensive as Bill C-204. As Dr. Schofield of the CCS explained: "our strategy is contingent on the governing Conservative Party not wanting to be seen by Canadians as allowing the NDP to be running the country."86 However, as a result of a busy legislative agenda (due to free trade talks with the United States and several other long and complicated pieces of legislation), Bill C-204 was unable to be debated before the 1987 summer recess. Consequently, the CCS has continued to lobby the federal government as it did prior to the introduction of the Bill. The CCS has taken a number of individual issues and lobbied federal departments as a means of educating M.P.'s about the human costs of lung cancer and the financial burden it places on the country's health care system.87

86Canadian Interview; Canadian Cancer Society, 28 November 1986.
87Ibid.
As mentioned above, one of the charity's main goals was to push for smoke-free domestic airline flights lasting two hours or less. After meeting with John Crosbie, the Minister of Transportation in March 1986, the government agreed to implement a pilot project. Soon after, it was reported that the major Canadian tobacco companies had asked all their employees to boycott Air Canada's experimental smoke-free flights between Ottawa and Montreal. In response, the CCS immediately countered by urging its 130,000 volunteers to patronize these flights and to ask for a similar service from other Airlines. This was immediately followed with meetings between the CCS, the Deputy Minister of Transport and officials from the Air Transportation Association of Canada. These discussions generated further support for the smoke-free flight concept on the basis that greater in-flight safety and reduced cleaning costs would result.88 The CCS described its most recent lobbying efforts in the following way:

"We met with Don Mazenkowski - the former Minister of Transport and presented several briefs to him. We then followed this up with meetings with the Transportation and Health critics from the Liberal and New Democratic Parties. In the final analysis it is clear that this was a worthwhile exercise since the government has already decided to extend the pilot project for another year until permanent legislation can be enacted." 89

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88Canadian Interview; Canadian Cancer Society, 30 January 1987.

89Ibid.
Another smoking related issue that the CCS has involved itself concerns the tax on tobacco products. Before the February 1987 federal budget, CCS officials met with Michael Wilson the Minister of Finance and asked him not only to increase the taxes on cigarettes, but also to put a ‘quantum tax increase’ on fine-cut, ‘roll your own’ cigarettes. These products give individuals twice the lethal dose of tar and nicotine at half the cost of the manufactured variety. However, unlike the smoke-free flight issue the CCS has had far less success in lobbying on this issue. Canadian tobacco manufacturers have given $100,000 (£50,000) to establish a new group called the Smokers Freedom Society (SFS) whose aim has been to protect smokers’ rights, including the protection against unfair product prices. The SFS has also denounced studies showing a scientific correlation between second-hand smoke and lung cancer arguing that such studies are ‘inconclusive and contradictory’.90

The CCS has been actively involved though, in blocking the industry’s bid for the creation of a National Tobacco Marketing Board. In 1985, the Ontario Flue-Cured Tobacco Growers Marketing Board and its counterpart in Prince Edward Island asked the federal government to approve this proposal on the grounds that import and export prices could be controlled, thereby increasing industry profitability. To fight the proposal, CCS joined with charities like the Canadian Lung Association and other non-

90 Ibid.
charitable non-profit associations to form the Committee for Responsible Public Policy on Tobacco (CRPPT). In doing so, the CCS hired a lawyer and an economist to represent the CPPRT at hearings before a panel of the National Farm Products Marketing Council. As a result of this intervention, the proposal for a Marketing Board was dropped in November 1986.

While the CCS have succeeded on a number of small issues related to smoking, it has not realized its major goal namely, a comprehensive ban on the sale of tobacco for personal consumption. The CCS explained that this is a reflection of the strength and sophistication of the tobacco industry’s lobby.

"I believe that the Minister of Health is in favour of our proposal but I understand that he has met some opposition from individual cabinet ministers who are opposed for philosophical reasons and for other political reasons. For example, the tobacco industry is very powerful in Canada; (since 1979 they have given $1 million (£500,000) in political contributions to the Liberal and Conservative Parties since 1982). Furthermore, the federal Minister of Agriculture comes from a tobacco growing riding and has done absolutely nothing to help reduce the number of cancer related deaths. And lastly, the chief Fund raiser for the federal Conservative Party is a Senator from Ontario and the President of the largest Canadian tobacco company."

IV Conclusion

This chapter has revealed that British and Canadian medical research charities are engaged in many non-research related lobbying campaigns. This is because disease sufferers who either

91Ibid.
collect or contribute money towards charity look to their organisation for some form of political representation. This representation has in most instances been forthcoming from the charities to preserve their fund raising infra-structure.

The lobbying now being conducted by these charities is sophisticated and well organized to the extent that a number of regulatory and legislative reforms have been achieved. Furthermore, the legal rule restricting charities from engaging in political activities seems not to have been an irritant to organisations interested in lobbying on behalf of their patients. Instead, most British and Canadian charity executives have viewed this activity as an essential role for their organisation in representing the views and interests of disease sufferers that otherwise would not be articulated to government decision makers.
Chapter Nine

Conclusion

In this thesis the major theme concerning relations between charities and the state in Britain and Canada has centred on the former's political activities. It was argued in chapter three that all charities are restricted from engaging in many forms of political action. However, in our case study of British and Canadian medical research charities numerous examples of political involvement by organisations in a wide variety of issues have been presented. In the light of this, it is possible to summarize why the law might be seen to be at variance with 'present circumstances' which see medical research charities being drawn into the political process. This involvement should not be seen as an expressed invitation from the state to do so, but instead as a response by charities to government's own involvement in this policy area. When the first medical research charities were established in Britain and Canada the government of each country made no contribution of their own towards research into the prevention and cure of disease. Later, during the 1940's when political pressures came to bear on scientists to address war-related health problems a system of dual provision of funds for research - from charity and state - became firmly entrenched. The degree and complexity of interaction between charity and state has
steadily increased since that time due in part to the increasing number of medical research charities established in both countries since then and the public's increasing desire to see all diseases conquered. In response to this pressure (as discussed in chapter six, section I) charities and the state were forced to address mutual problems such as co-ordinating research in an effort to reduce wasteful duplication. However, had the state not encroached into charities' domain as the sole provider of 'research funding' the need would not exist, for example, for British charities to interact with DHSS and (B)MRC officials to avoid duplicating research.

British and Canadian medical research charities have been drawn into the political process in other ways in recent years. As explained in chapter seven, the large financial resources of the state, as compared to those of medical research charities, have meant the latter has now come to depend on the former for medically qualified personnel, technical advice, basic research and physical overheads - in short, a 'science infra-structure'. Given that the level and quality of this infra-structure has suffered budgetary cutbacks and has, arguably, become sub-standard in recent years, it is not surprising that medical research charities have been outspoken in their criticism of such government policies. Conversely, it is true that the state has in turn come to rely on charities to play a more active role in funding bio-medical research as well as providing important patient services (see chapter eight). Consequently, the inter-
dependency between charity and state has meant that when the policies and actions of either charity or state is perceived to adversely affect the other, the potential for conflict is present. However, medical research charities argue that, from a legal viewpoint, they are disadvantaged in that many methods of expressing dissatisfaction with government policies come into conflict with charity law. They further make the point that, in order for charities to reach their objectives, they must lobby aggressively to change the direction of government policies. This means that medical research charities would like to see the boundaries of permissible political involvement expanded. Prior to concluding whether this demand is justified it is necessary to address the question whether the activities in relation to government in which these charities presently engage (as described throughout chapters five to eight) violate existing laws.

In posing this question it must first be restated that the courts, not to mention the charities themselves, find it difficult to determine whether particular political activities are illegal, given the vagueness of British and Canadian law in this general area. Another problem relates to the fact that there are very few legal precedents where charities (and, particularly, for the purposes of this thesis, medical research charities) have had their charitable status revoked for engaging in impermissible political activities. Indeed, of the 44 charities interviewed (26 British and 18 Canadian) not one had even been cautioned by the Charity Commission or Revenue Canada for engaging in unlawful
This raises two points. First, it is certain that most of the politically-related activities of British and Canadian medical research charities described in this study - ranging from lobbies against (B)MRC cutbacks to charities participating in the anti-smoking campaign - are acceptable under existing law. But second, it is also true that neither the Charity Commission nor Revenue Canada have the resources to detect and prosecute charities that over-indulge in their political involvement. This is not an unrealistic conclusion since, as was shown in chapter two, section I. C. (iii), many types of financial frauds are being committed by charities in both Britain and Canada which remain undetected.

For those non-medical research charities that have come into conflict with the law such as Oxfam, War on Want and MIND, the central issue under dispute has had more to do with the style and stridency of their lobbying rather than the amount of lobbying conducted or the objectives they have been pursuing. This sheds light on why British and Canadian medical research charities have avoided serious legal confrontations with, respectively, the Charity Commission and Revenue Canada. So far, their approach to influencing government has utilized more formal channels of communication, rather than the alternative vocal and confrontational approaches that rely on the mass media and public demonstrations.

In applying the specific rules regarding the ban on political activities outlined in chapter three, it seems clear that most
medical research charities would not come into conflict with the law. However, this is only true of the law since 1948 when it was ruled in the National Anti-Vivisection case to accept as a valid 'charitable purpose' any political activity that is ancillary and in furtherance of an organisation's main charitable purpose(s).

Had this study been conducted prior to the addition of the 'ancillary' clause, when the Bowman decision of 1917 was being applied on its own, it is certain that much of the political activities of British and Canadian medical research charities would violate the law. For it was Lord Parker in the Bowman decision who first enunciated a four-fold classification regarding impermissible political activities listed in chapter two, section I. C, as including:

1) attempts to bring about or oppose changes in the law;
2) furthering the aims of political parties and promoting political doctrines;
3) affecting foreign relations;
4) propagandizing, including attempts to persuade the public to adopt a particular attitude towards some broad social question.

We have seen no evidence presented in this study to suggest that medical research charities have engaged in activities having the potential to affect foreign relations. However, this is not the case in regard to the remaining three categories outlined by Lord Parker. Examples of attempts at bringing about or opposing changes in the law are numerous: a short list would include those British medical research charities, discussed in chapter eight, section II. B, that lobby for increased statutory payments for the
physically disabled under the government's 'Aid for Daily-Living Programme', 'Mobility Allowance Scheme' and 'Attendance Allowance Programmes'. Likewise in the same section it was shown that Canadian medical research charities have lobbied for amendments to construction codes to facilitate the access of wheelchair patients in newly-built and renovated buildings and for state subsidies to defray the cost of home nurses for disease sufferers.

In this thesis, fewer examples were provided of lobbying activities of British and Canadian medical research charities directly furthering or dampening the electoral fortunes of one political party. Nevertheless, a good example of this, given in chapter eight, section II. B involves both the British and Canadian diabetes research charities' lobby to require food-processing companies to include the sugar and caloric contents on the outside packaging of their products. This has been a proposal strongly rejected by Conservative governments in both countries where the policy to reduce excessive regulatory costs to the food industry have been advocated. Furthermore, in the case of the anti-smoking movement, dealt with in chapter eight, section III, the Canadian Cancer Society has not hesitated to publicize its strategy to support a Private Member's Bill sponsored by the New Democratic Party as a means of pressuring the governing Conservative party to introduce more progressive legislation to limit the manufacture and marketing of tobacco products. This, again, is a measure which runs counter to the Conservative government's general policy of not intervening in the provision of
goods and services by the market.

British and Canadian medical research charities have also been active in their lobbying campaigns to propagandize, including attempts to persuade the public to adopt a particular attitude towards broad social issues. Again, the most obvious example is given in chapter eight section III in describing the Canadian Cancer Society's programme to distribute public education literature on the hazards of smoking. However, smokers, not to mention tobacco manufacturers, argue vehemently that such literature fails to provide a balanced assessment of the pleasures derived from tobacco products as well as accurate data on the 'real' side-effects associated with the various products being sold. Since each of the examples of lobbying described above do not consume a major proportion of charities' resources and because such lobbying is in furtherance of their main charitable purpose(s), they are regarded as operating within the law. This raises the question that, if the law now permits charities to lobby in a 'limited' way, combined with the fact that the Charity Commission and Revenue Canada are under-resourced and incapable of making such decisions, is there an increasing need to preserve the distinction between charity and politics? The answer to this question might be said to vary depending on the area of charitable activity under discussion. Third world relief charities, anti-abortion and anti-vivisection charitable organisations frequently engage in excessive political activities. From our case study of British and Canadian medical research charities we conclude that
funding scientific investigations and supporting patient service programmes are not politically sensitive areas under normal circumstances. However, in a climate where statutory services are being cut back and where governments have 'off-loaded' a number of their services to charities, it is not surprising that chapter seven was able to list numerous examples where organisations have been drawn increasingly into the political process to resist such efforts. While one might conclude that their lobbying activities have increased dramatically over the last ten years, not one of the organisations included in this study expressed great concern over the possibility of being deregistered as a result of such changes. Again, with the present law permitting a blurring of the distinction between charity and politics it might be asked whether legal reform to preserve the non-political nature of charity is overdue.

In the light of the evidence presented in chapter eight, section I, the urgency of such reform is indeed heightened by the revelation that some British and Canadian medical research charities have forged close economic alliances with pharmaceutical companies and, consequently, have been obliged to support a number of that industry's lobbying campaigns. In these circumstances corporate contributions to charities should not be viewed as purely philanthropic gestures but rather as *quid pro quo* transactions in return for commercial services. Since charities in both countries have been granted a privileged tax exempt status, there is a strong case to be made that collaborative
charity/industry lobbies could, in effect, provide corporate interests with financial subsidies from the state. While there is no evidence to suggest that British or Canadian pharmaceutical companies have created their own charities exclusively, or at least principally for this purpose, the potential does exist for this to occur on a much larger scale. This is especially true given conclusions, reached in chapters two and three, concerning the general ambiguity of the prohibition on political activities combined with the law’s poor enforcement. From a slightly different perspective it may be asked whether those who first decided to extend a tax exempt status to charities foresaw the possibility that government might be financially supporting a lobby of itself. It is clear from the evidence presented in chapter two, section II. A, concerning late 19th century legal decisions, that judges were particularly interested in making charities accountable to the state for their tax deductible revenue. However, the application of such funds by charities towards political activities was not perceived by the courts at that time to be a significant problem.

Given the extent to which British and Canadian medical research charities now pressure their respective governments on a wide-range of issues the case can be made for rethinking the traditional justification for extending such tax exemptions. If reforms to tax laws are contemplated the argument likely to be advanced against them is that the increasing freedom to lobby has permitted charities to articulate the views of otherwise
unrepresented interests and to integrate these views in the policy process. However, in chapter six, section III. A, we concluded that there are a number of important pressures—excluding the law—that have affected British and Canadian medical research charities, and which have created great disparities in the amount and types of campaigning that different organisations are able to engage in. Consequently, it is frequently the case that only a few of the larger, more wealthy, charities are able to conduct effective lobbying campaigns and achieve substantive policy victories in their bid to defend these otherwise unrepresented interests. Despite these disparities the defence supplied by those supporting a greater lobbying role for medical research charities as listed in chapter six, section III. A, is that their resources are manifestly inadequate to deal with the problems they seek to address: finding the cause and cure of specific disease(s). Charities have lobbied government to spend more on researching their disease areas because they recognise that it is perhaps more prudent to spend part of their voluntary income to initiate or augment (B)MRC/(C)MRC research programmes that are capable of making a more sizable impact. This is preferred to simply restricting themselves to ‘tinkering’ at the edges of a problem. The potential achievements of the state with its enormous resources, are obviously far greater than any charity is now able to accomplish on its own. This is even true of the largest British and Canadian cancer research charities whose income represents a comparatively small fraction of the total
income of either the (B)MRC or (C)MRC. Figure 7.4 illustrates that the combined research expenditure of all 35 British medical charities belonging to the AMRC is still smaller than that of the (B)MRC's. In the historical context of relations between medical research charities and the state this is a dramatic turn of events from half a century ago when charity saw itself, rather than government, as better suited to funding scientific research.

It must be emphasized that, while present circumstances have drawn British and Canadian medical research charities into the political process, only the larger organisations have been able to affect public policy change to their advantage. This raises two points. First, in light of the fact that the law and its poor enforcement has permitted charities to engage in political activities, some might argue that the barriers to access in influencing the policy process should be reconsidered. This, it is argued, would permit small medical research charities representing less popular diseases, like alzheimers, to compete equally with the cancer and heart charities. Second, and a more realistic viewpoint, is that legal reforms aimed at preserving the distinction between charity and politics should be tailored specifically to address the problems of lobbying associated especially with larger British and Canadian cancer research charities. As shown in chapter five, section II, most British and Canadian medical research charities were established in the 1950s and 1960s, although others, like the major cancer research charities, were established much earlier - in the 1920s and 1930s.
respectively. The cancer research charities in each country are clearly the most cohesive and stable organisations included in this study. Their incomes are not only the largest, by far, but their networks of volunteers who sustain the activities of local branches, regional offices and national headquarters are much more developed and sophisticated than those of the smaller research charities. Consequently, it is not surprising that their lobbying activities are also more sophisticated than the smaller more recently established organisations. For example, it was noted in chapter six, section III. A, that the Canadian Cancer Society is an anomaly in that it employs a full-time Ottawa lobbyist. Other smaller British and Canadian charities have met resistance from volunteers and the donating public when more formalized lobbying arrangements - such as paid lobbyists - have been proposed by permanent paid staff members. The major complaint by the 'rank and file' in these charities has been that lobbying serves to 'water-down' an organisation's philanthropic contributions by diverting funds away from its main objective - to fund research.

For those medical research charities that have adopted a less formalized lobbying approach, the tensions between paid staff and the volunteers is an important force mitigating against a more sophisticated representation of interests to government. In chapter five, section II we concluded that in smaller medical research charities, which naturally represent less popular diseases, volunteers (frequently disease sufferers themselves) often restrict their paid executives from lobbying government-
even in influencing the (B)MRC/(C)MRC to spend more on researching their disease area. As a result, there is often an under-supply of qualified scientists in these less popular disease areas for whom charities are later able to provide research grants. This is because young investigators define their areas of expertise in relation to the availability of (B)MRC/(C)MRC research funds, which are skewed in favour of the popular diseases. The lobbying activities that are sanctioned by the volunteers in these smaller research charities tend normally to be in the area of personal advocacy and patient services (which in many cases are issues tied to more general lobbying campaigns orchestrated by the pharmaceutical industry). However, even with this type of lobby, a frequent complaint of volunteers is that money should not be 'wasted' on what is perceived as the 'exotic' business of lobbying but rather should be devoted to its main charitable purpose: funding bio-medical research.

A less significant factor in determining the extent of a charity's lobbying activities but nevertheless one worth considering, relates to the nature of the disease being represented. In chapter five, section IV. B, it was seen that some organisations, such as those representing cancer and heart diseases, are more actively involved in lobbying government since the causes of these afflictions are largely known - for example the correlation between smoking and lung cancer. As a result, the involvement of these charities in seeking a wide variety of legislative reforms is a natural extension of their main purpose,
to control the incidence of the disease they represent. The nature of a disease is significant in determining the extent of a charity's lobbying activities in a different way. For those charities that represent diseases such as cerebral palsy, Parkinson and cancer, where individuals tend to spend much of their lives with an affliction, albeit in a disabled state, charities are increasingly drawn into the lobbying process to represent their membership’s needs. In chapter eight, section II. A and B, this was shown to include personal advocacy and more general patient service lobbying to secure greater statutory benefits. As a result, lobbying is formally incorporated within the charity’s organisational structure. With charities representing diseases where the period of convalescence is short (for example, cot-death and AIDS) the number of comparable patient-service-oriented issues which a charity can negotiate with government are comparatively few in number. Consequently, the organisational structures of these charities reflect non-formalized characteristics that are principally geared towards maintaining a fund-raising base in order to support bio-medical research.

In considering the need for legislative reform to preserve the distinction between charity and politics (at least in the context of medical research charities) it is also concluded that the need varies between Britain and Canada. Charity law reform and increased supervision of the political activities of British medical research charities is especially necessary given their
effective use of a national association (the AMRC) to articulate and represent their views to government. For example, in chapter seven, section I. A and B, it was noted that, in acknowledging the government's shared responsibility for funding bio-medical investigations, British medical research charities have been able to define their responsibilities vis-a-vis the (B)MRC's and publicize their views to government through the AMRC. Distinctions between British charities and the (B)MRC have been drawn in relation to the type of research each funds, the type of support each provides and the duration of their research awards. These distinctions are highlighted in AMRC publications where it is argued that medical research in Britain is serviced best through a division of responsibility between government and charity. In doing this, the AMRC have been drawn into the political process, arguing that government cutbacks to the (B)MRC budget translate into an increasing burden on charity to deliver a service presently defined as a shared responsibility.

In Canada, this blurring of the distinction between charity and politics is less of a problem, particularly in relation to issues of collective concern to medical research charities, given the absence of a comparable national association. This is symptomatic of the fact that lobbying activities are greatly affected by the federal structure of the Canadian political system. If governmental jurisdiction in a policy area is shared, as is the case of medical research, then the lobbying activities must be tailored to address 11 governments rather than just one-
as is the case in Britain. As concluded in chapter five, section I. D, this is not only expensive but also difficult to co-ordinate since parallel provincial offices would be required, at great expense, to lobby effectively. Consequently, Canadian medical research charities have had no 'single-voice' to represent their views on issues of common concern. This has benefitted federal politicians who have preferred dealing with individually weak organisations as opposed to a single strong collective association of interests. Not surprisingly, those Canadian medical research charities with comparatively large incomes, operating in prosperous provinces like Ontario and Quebec, have been more effective at lobbying government for legislative reforms. This is true to the extent that the level and quality of services available to their constituency (specific disease sufferers) varies considerably among different regions of the country. In an effort to correct this disparity we concluded in chapter five, section III, that the federal government has offered financial support to medical research charities under their 'Sustaining Grants for Voluntary Health Organisations' programme if they developed a national profile. Accepting this grant includes a commitment by medical research charities to broaden and standardize the level and quality of their patient services being offered in each region of the country. However, the limited government funding of both British and Canadian medical research charities is reflective of the fact that accepting such funds takes an 'edge-off' their fund raising appeal (by appearing to be
'Quango-like') and also restricts their freedom to lobby government for legislative and regulatory reform if in the future the need arises.

In summary, we conclude that a charity's income, the nature of the disease being represented, the role of volunteers and the participation of formalized interest groups are key factors which determine both the amount and style of lobbying that is conducted. Any future attempts at legal reform to preserve the distinction between charity and politics would have to take account of the fact that not all charities confuse their philanthropic role with their public policy role. For those that do, it is also concluded that not only would more specific guidelines, as to what constitutes impermissible political activities, need to be included in the law, but more importantly that the Charity Commission and Revenue Canada be given adequate resources to enforce the law. At present it appears to be the case that 'self-regulation' by both volunteers and to a lesser extent the donating public, play a greater role in preserving the non-political features of charity than does either the Charity Commission and Revenue Canada.
Appendix I

The Conduct of the Research in Britain and Canada

The research for the case-study of medical research charities was conducted in two stages. The first included 32 personal interviews in Canada between 19 November 1986 and 11 February 1987. The second included a further 36 interviews in Britain between 17 February and 6 March 1987. In all there were 68 personal interviews with charity executives, non-elected government officials, pharmaceutical spokesmen, research scientists and interest group representatives. Fifty-two of these interviews were with charities and of this figure 44 respondents (26 British and 18 Canadian) were from different charitable organisations. Where multiple interviews with the same organisation occurred the objective was to gain a more detailed understanding of its total operation by meeting with respondents working at the national, regional (in the case of Canada—provincial) and local levels. Twenty-one Canadian interviews were carried out in Toronto, seven in Ottawa and four in Hamilton. Thirty-one British interviews were conducted in London with single interviews being conducted in Teddington, East Grinstead, Bromley, Colchester, and Horsham. Response rates to written letters of introduction and requests for interviews was 100 per cent.

Although one Canadian charity initially declined to be interviewed it later reversed this decision when informed it would be identified in this thesis as 'unavailable for comment'.

All interviews were tape recorded and later transcribed. The
average length interview lasted approximately 70 minutes, with the shortest being 30 minutes and the longest being 3 hours. In discussing 'sensitive topics' respondents often requested the tape-recorder be switched-off. In one instance a Canadian respondent requested a portion of our tape-recorded conversation be erased. Information provided by respondents 'off-the-record' which is re-produced in this thesis is cited as showing the country but excludes their name as well as the organisation they represented.

In selecting the charities to be interviewed three criteria have been satisfied. First, the sample of organisations almost constitute a 'complete' list in that all large and medium sized British and Canadian medical research charities have been interviewed, but several very small charities were not. These were all charities which had no paid staff and often no national organisation. Their exclusion should not distort the reliability of the data compiled on this sub-sector of charities or make any of the generalizations made about this policy area less valid. This is true since their financial contribution to the total charitable research effort in both countries is calculated to be less than one per cent. Second, 16 of the 18 Canadian medical research charities interviewed can be directly compared in terms of the disease(s) they represent to those included in the British interview schedule. This facilitates cross-national comparisons of organisations where the 'disease' being represented plays a significant role in shaping relations between medical research
charities and the state. Third, the list of organisations interviewed in both countries includes a good mix of large, medium, and small charities representing both popular and unpopular diseases. This facilitates charities to be compared and contrasted with each other and allows for precise conclusions to be drawn about how an organisation's size, and the type of disease being represented, affects its relationship with the state.

List of Interviews in their Chronological Order

<table>
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<th>Date</th>
<th>Organisation</th>
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<tbody>
<tr>
<td>19 November 1986</td>
<td>Canadian Foundation for Ileitus and Colitis (Hamilton Chapter)</td>
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<tr>
<td>28 November 1986</td>
<td>National Cancer Institute of Canada (National Office)</td>
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<tr>
<td>28 November 1986</td>
<td>Canadian Cancer Society (National Office)</td>
</tr>
<tr>
<td>28 November 1986</td>
<td>Canadian Cancer Society (National Office)</td>
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<td>3 December 1986</td>
<td>Multiple Sclerosis Society of Canada (National Office)</td>
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McMaster University Medical School,  
Department of Immunology  
20 January 1987  
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(National Office)  
20 January 1987  
The Arthritis Society (National Office)  
26 January 1987  
Canadian Heart Foundation (National Office)  
27 January 1987  
Federal Government, Secretary of State,  
Voluntary Action Programme  
28 January 1987  
Federal Government, Department of Health  
and Welfare, Medical Research Council  
29 January 1987  
Federal Government, Secretary of State,  
Promotion of Official Languages Programme  
30 January 1987  
Federal Government, Department of Health  
and Welfare, Sustaining Grants for National  
Voluntary Health Organisation Programme  
30 January 1987  
Canadian Cancer Society (National Office)  
10 February 1987  
Alzheimer Society of Canada  
(National Office)  
11 February 1987  
Connaught Laboratories (Head Office)  
17 February 1987  
Back Pain Association (National Office)  
18 February 1987  
Development Trust for the Young Disabled  
(National Office)  
19 February 1987  
Muscular Dystrophy, Group of Great Britain  
(National Office)  
19 February 1987  
Imperial Cancer Research Fund  
(National Office)  
20 February 1987  
Chest, Heart and Stroke Association  
(National Office)  
20 February 1987  
Mental Health Foundation (National Office)  
23 February 1987  
Spastics Society (National Office)  
23 February 1987  
The British Digestive Foundation  
(National Office)  
24 February 1987  
Cystic Fibrosis Research Trust  
(National Office)  
24 February 1987  
Department of Health and Social Security,  
Chief Scientist  
25 February 1987  
The Iris Fund (National Office)  
25 February 1987  
Multiple Sclerosis Society  
(National Office)  
26 February 1987  
Blonde McIndoe Centre for Medical Research  
(National Office)  
26 February 1987  
Ciba Foundation (National Office)  
2 March 1987  
Brain Research Trust (National Office)  
2 March 1987  
British Diabetes Association  
(National Office)  
3 March 1987  
Arthritis and Rheumatism Council  
(National Office)  
4 March 1987  
Association of Medical Research Charities  
(National Office)  
4 March 1987  
National Fund for Research into Crippling
<table>
<thead>
<tr>
<th>Date</th>
<th>Year</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
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<td>5 March</td>
<td>1987</td>
<td>Diseases (National Office)</td>
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<tr>
<td></td>
<td></td>
<td>Association for Spina Bifida and Hydrocephalus (National Office)</td>
</tr>
<tr>
<td>6 March</td>
<td>1987</td>
<td>Foundation for the Study of Infant Deaths (National Office)</td>
</tr>
<tr>
<td>6 March</td>
<td>1987</td>
<td>Astro Pharmaceuticals</td>
</tr>
<tr>
<td>9 March</td>
<td>1987</td>
<td>Migraine Trust (National Office)</td>
</tr>
<tr>
<td>10 March</td>
<td>1987</td>
<td>Foundation for Age Research (National Office)</td>
</tr>
<tr>
<td>10 March</td>
<td>1987</td>
<td>Asthma Research Council (National Office)</td>
</tr>
<tr>
<td>11 March</td>
<td>1987</td>
<td>Cancer Research Campaign (National Office)</td>
</tr>
<tr>
<td>12 March</td>
<td>1987</td>
<td>Charity Christmas Card Council (National Office)</td>
</tr>
<tr>
<td>19 March</td>
<td>1987</td>
<td>Wellcome Trust (National Office)</td>
</tr>
<tr>
<td>31 March</td>
<td>1987</td>
<td>Charity Commission</td>
</tr>
<tr>
<td>2 April</td>
<td>1987</td>
<td>Department of Education and Science, Medical Research Council</td>
</tr>
<tr>
<td>3 April</td>
<td>1987</td>
<td>LEPRA (National Office)</td>
</tr>
<tr>
<td>3 April</td>
<td>1987</td>
<td>LEPRA (National Office)</td>
</tr>
<tr>
<td>8 April</td>
<td>1987</td>
<td>British Union for the Abolition of Vivisection</td>
</tr>
<tr>
<td>9 April</td>
<td>1987</td>
<td>Association of British Pharmaceutical Industries</td>
</tr>
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</table>
# Appendix II

Charity Christmas Card Council, 1985 Shop Sales

<table>
<thead>
<tr>
<th>PLACE</th>
<th>CHARITY</th>
<th>TOTAL GROSS SALES</th>
<th>% OF TOTAL SALES</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>Royal Academy</td>
<td>11,761</td>
<td>4.52</td>
</tr>
<tr>
<td>2</td>
<td>Save the Children</td>
<td>10,424</td>
<td>4.01</td>
</tr>
<tr>
<td>3</td>
<td>World Wildlife Fund</td>
<td>9,209</td>
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<tr>
<td>4</td>
<td>NSPCC</td>
<td>8,974</td>
<td>3.45</td>
</tr>
<tr>
<td>5</td>
<td>British Diabetic Association*</td>
<td>7,579</td>
<td>2.95</td>
</tr>
<tr>
<td>6</td>
<td>Cancer Relief</td>
<td>7,408</td>
<td>2.85</td>
</tr>
<tr>
<td>7</td>
<td>Cancer Research</td>
<td>7,078</td>
<td>2.72</td>
</tr>
<tr>
<td>8</td>
<td>Imperial Cancer Research Fund*</td>
<td>6,986</td>
<td>2.69</td>
</tr>
<tr>
<td>9</td>
<td>Held the Aged</td>
<td>6,875</td>
<td>2.64</td>
</tr>
<tr>
<td>10</td>
<td>Queen Elizabeth’s Foundation</td>
<td>6,480</td>
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<tr>
<td>11</td>
<td>Multiple Sclerosis Society*</td>
<td>6,398</td>
<td>2.49</td>
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<td>12</td>
<td>Dr. Barnardo’s</td>
<td>6,027</td>
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<tr>
<td>13</td>
<td>British Heart Foundation*</td>
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<td>Guide Dogs for the Blind</td>
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<td>2.10</td>
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<td>British Red Cross Society</td>
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<td>Family Welfare</td>
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<tr>
<td>17</td>
<td>Leukaemia Research</td>
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<td>1.90</td>
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<tr>
<td>18</td>
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<td>1.89</td>
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<tr>
<td>19</td>
<td>Cystic Fibrosis*</td>
<td>4,882</td>
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<td>20</td>
<td>Christian Aid</td>
<td>4,790</td>
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<td>22</td>
<td>Richmond Fellowship</td>
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<td>23</td>
<td>RNLI</td>
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<td>24</td>
<td>Missions to Seamen</td>
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<td>25</td>
<td>RNID</td>
<td>3,922</td>
<td>1.51</td>
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<td>Malcolm Sargent Cancer Fund for Children</td>
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<td>Blackfriars Work Settlement</td>
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<td>ASBAH</td>
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<td>30</td>
<td>Bone Marrow Research</td>
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<td>31</td>
<td>MIND</td>
<td>3,267</td>
<td>1.26</td>
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<tr>
<td>32</td>
<td>Sue Ryder</td>
<td>3,251</td>
<td>1.25</td>
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<tr>
<td>33</td>
<td>SENSE</td>
<td>3,169</td>
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<td>35</td>
<td>RAF Benevolent Fund</td>
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<td>Aid to Russian Christians</td>
<td>3,101</td>
<td>1.19</td>
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<tr>
<td>37</td>
<td>Samaritans</td>
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<td>38</td>
<td>Harwell Zoological Society</td>
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<td>39</td>
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<td>CARE</td>
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<td>Handicapped Children’s Trust</td>
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<td>Parkinson’s Disease Society</td>
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<td>45</td>
<td>Birthright</td>
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<td>SOS Children’s Villages</td>
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<td>John Groom’s</td>
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<td>48</td>
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<td>International Voluntary Service</td>
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<td>Gardener’s Royal Benevolent Society</td>
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<td>51</td>
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<td>Army Benevolent Fund</td>
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<td>National Autistic Society</td>
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<td>British Trust for Ornithology</td>
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<td>Brain Research*</td>
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<td>56</td>
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<td>57</td>
<td>CRUSE</td>
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<td>0.63</td>
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<td>58</td>
<td>Inland Waterways</td>
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<td>National Canine Defence League</td>
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<td>Queen Charlotte’s Fund</td>
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<tr>
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<td>King George’s Fund</td>
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<td>62</td>
<td>Population Concern</td>
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<td>63</td>
<td>Oxfam</td>
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<td>64</td>
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<td>Sea Cadets</td>
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<td>66</td>
<td>Methodist Homes for the Aged</td>
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<td>67</td>
<td>Royal Agricultural Benevolent Fund</td>
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<td>0.29</td>
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<td>68</td>
<td>Nat Assoc of Leagues of Hospital</td>
<td>747</td>
<td>0.29</td>
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<tr>
<td>69</td>
<td>Friends</td>
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<td>70</td>
<td>Friedreich’s Ataxia Group</td>
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<tr>
<td>71</td>
<td>RUBKA</td>
<td>638</td>
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</tr>
</tbody>
</table>


Note: *indicates charities included in interview schedule.
MEDICAL RESEARCH COUNCIL UNITS IN THE UNITED KINGDOM

Appendix III
Appendix IV

The 1924 Ministry of Health/Medical Research Council Concordat

Ministry of Health

1. To survey existing knowledge with a view to its applications or applicability to practical uses.

2. To survey by statistical or other means existing states of national (and international) health and environment, both absolutely and in relation to past history.

3. To provide investigation (by use of existing knowledge and recognised methods) of scientific problems arising in the current administrative work of the Ministry.

4. To initiate research by reference to the Medical Research Council or by encouraging local authorities or other agencies to direct and carry it out, and to initiate and themselves to direct research by such investigations as can best be carried out by the Ministry, in the interests of public health administration, applied knowledge or medical services.

5. To propagate the results gained under all the foregoing heads by publication, by suitable information to local authorities or to the general public, and in general to promote the applications or the results in practical life.

Medical Research Council

1. To survey existing knowledge with a view to right direction of new research efforts.

2. Medical research by statistical methods (primarily for the development of new methods).

3. To give assistance to current medical research investigations, whether pathological, biochemical, or other kinds (including studies made into the better standardisation of materials or methods).

4. To promote new knowledge by the initiation and organisation of research in the medical sciences.

5. The publication of the results of research work in such a form as to aid research workers in general and to secure available application.
Appendix V
Membership of the International Cystic Fibrosis Association and their Dates of Accession.

A. Countries whose national associations are in membership of the ICF with dates of accession:

<table>
<thead>
<tr>
<th>Year</th>
<th>Countries</th>
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</thead>
<tbody>
<tr>
<td>1964</td>
<td>Argentina, Australia, Canada, Republic of Ireland, Italy, United Kingdom, United States of America</td>
</tr>
<tr>
<td>1965</td>
<td>Belgium, France, German Federal Republic, Switzerland</td>
</tr>
<tr>
<td>1966</td>
<td>Denmark, Israel</td>
</tr>
<tr>
<td>1968</td>
<td>Austria, Greece</td>
</tr>
<tr>
<td>1969</td>
<td>German Democratic Republic, Netherlands, New Zealand, Spain, Sweden, Yugoslavia</td>
</tr>
<tr>
<td>1970</td>
<td>Czechoslovakia, Norway, Poland</td>
</tr>
<tr>
<td>1973</td>
<td>Cuba, Hungary</td>
</tr>
<tr>
<td>1975</td>
<td>South Africa</td>
</tr>
<tr>
<td>1980</td>
<td>Brazil, Uruguay, Mexico</td>
</tr>
<tr>
<td>1981</td>
<td>Puerto Rico</td>
</tr>
</tbody>
</table>

B. Countries who are associated members:

<table>
<thead>
<tr>
<th>Year</th>
<th>Countries</th>
</tr>
</thead>
<tbody>
<tr>
<td>1969</td>
<td>Finland</td>
</tr>
<tr>
<td>1972</td>
<td>India</td>
</tr>
<tr>
<td>1973</td>
<td>USSR</td>
</tr>
<tr>
<td>1979</td>
<td>Iceland, Portugal</td>
</tr>
<tr>
<td>1980</td>
<td>Egypt, Iran, Jordan, Kuwait, Turkey</td>
</tr>
<tr>
<td>1981</td>
<td>Pakistan</td>
</tr>
</tbody>
</table>

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Nature
"The Relationship Between Charity and the State in Britain and Canada, with Particular Reference to the Case of Medical Research"

AUTHOR

Tom Deane

INSTITUTION and DATE

University of Warwick, July 1988.

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