

Original citation:

Szczepura, Ala, Roberts, Jean, Biggerstaff, Deborah, Fagan, Rose and Clay, Diane (2005)
Optimising the use of ICTs by health & social care professionals in the community. Coventry ;
London: University of Warwick ; Department of Health.

Permanent WRAP URL:

<http://wrap.warwick.ac.uk/83340>

Copyright and reuse:

The Warwick Research Archive Portal (WRAP) makes this work by researchers of the University of Warwick available open access under the following conditions. Copyright © and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable the material made available in WRAP has been checked for eligibility before being made available.

Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

A note on versions:

The version presented in WRAP is the published version or, version of record, and may be cited as it appears here.

For more information, please contact the WRAP Team at: wrap@warwick.ac.uk

Optimising the Use of ICTs by Health & Social Care Professionals in the Community

FINAL REPORT

January 2005

Address for correspondence:

Professor Ala Szczepura
Warwick Medical School
University of Warwick
Coventry
CV4 7AL

Telephone No: 02476 – 522 - 958

E-mail: Ala.Szczepura@warwick.ac.uk

Contents

ACKNOWLEDGEMENTS	I
EXECUTIVE SUMMARY	II
GLOSSARY	VI
1. INTRODUCTION	1
1.1 STUDY AIMS AND OBJECTIVES	1
2. STUDY CONTEXT	1
3. STUDY METHODS	2
4. INFORMATICS PERSPECTIVE	3
4.1 PRELIMINARY ICT OVERVIEW	3
4.2 MAPPING ICT CONFIGURATIONS (IT TERMINALS & SYSTEMS)	3
4.3 OVERVIEW OF LOCAL INFORMATICS CONTEXTS	4
4.3.1 Warwickshire: Overview of Local Informatics Context	5
4.3.1 Leicester: Overview of Local Informatics Context	6
4.4 IDENTIFYING SPARE CAPACITY AND ACTIVITY PROFILING	8
4.4.1 Activity Profiling	8
4.4.2 Electronic Activity Data Capture	9
4.4.3 Interviews with NHS and Social Services IT Leads about Activity Profiling Statistics	10
4.4.4 Surveys to Gather Activity Profiling Data	10
4.4.5 Results: Estimation of Spare Capacity	11
4.5 CONCLUSIONS: INFORMATICS PERSPECTIVE	15
4.5.1 Inventory of Terminals and Applications	15
4.5.2 Profiling of Activity Using Electronic Data Capture	15
4.5.3 Profiling of Activity Using Site Surveys & Interviews	15
5 PROFESSIONAL PERSPECTIVE	17
5.1 INTRODUCTION	17
5.1.1 Methods Used	17
5.2 POSTAL QUESTIONNAIRE SURVEY	17
5.2.1 Postal Survey Scenario Development	17
5.2.2 Development of Professional Survey Questionnaires	19
5.2.3 Conduct of Surveys	20
5.3 SURVEY RESPONDENTS	21
5.3.1 Response Rate	21
5.4 IT TRAINING AND ACCESS TO COMPUTERS	27
5.4.1 Professionals' Self-rated IT Competence Levels and IT Training	27

5.5	INFORMATION ACCESS & SHARING IN SCENARIO SITUATIONS	34
5.5.1	Choice of Scenario	34
5.5.2	Access to Local Procedures or Guidelines for Scenario Situations	34
5.5.3	Access to Information via Other Professionals in Scenario Situations	36
5.5.4	Sharing of Own Information with other Professionals in Scenario Situations	38
5.6	GENERAL VIEWS ON INFORMATION ACCESS & SHARING	41
5.6.1	Key Areas of General Information Needs	42
5.6.2	Key Areas for General Information Sharing by Professionals	42
5.6.3	Professionals' Overall Rating of Inter-Agency Communication	43
5.6.4	Professionals' Reasons for Inter-Agency Communication Ratings	44
5.7	IN-DEPTH INTERVIEWS	44
5.7.1	Introduction	44
5.7.2	Interview Methods	45
5.7.3	Analysis	46
5.8	RESULTS: PROFESSIONALS' PERSPECTIVES ON INFORMATION SHARING IN THE COMMUNITY	47
5.8.1	Information Technology	48
5.8.2	Teams	54
5.8.3	Change	56
5.8.4	Confidentiality	58
5.8.5	Theory	63
5.9	CONCLUSIONS: PROFESSIONAL PERSPECTIVE	65
6.	USER/CARER PERSPECTIVE	68
6.1	INTRODUCTION	68
6.2	SURVEY METHOD	68
6.3	CARER SURVEY RESULTS	68
6.3.1	Description of survey respondents	68
6.3.2	Views of general information needs and accessing information	72
6.4	CONCLUSIONS: USER/CARER PERSPECTIVE	79
7.	DISCUSSION	81
7.1	A CHALLENGING CONTEXT	81
7.1.1	Health and Social Care Integration	81
7.1.2	Informatics	83
7.1.3	Older People and their Carers	84
7.2	CRITICAL ISSUES UNDERPINNING STUDY FINDINGS	85
7.2.1	Spare ICT Capacity & Access	85
7.2.2	ICT Environment	86
7.2.3	Professional Perspective	87
7.2.4	Older people and public access	90
8	CONCLUSIONS	91
	BIBLIOGRAPHY	93

APPENDIX 1	112
Description of Study Areas	112
APPENDIX 2	114
Overview of Local Informatics Contexts	114
2A: Warwickshire Overview	114
2B: Leicester: Overview of Local Informatics Contexts	115
2C: Example of Activity Profiling Tool (Main Surgery)	118
APPENDIX 3	119
Survey Questionnaire	119
APPENDIX 4	135
Information Sharing (Professionals' Survey)	136
APPENDIX 5	137
In-Depth Interviews (Professionals)	137
APPENDIX 6	142
Survey Questionnaire (Users/Carers)	142

Acknowledgements

The evaluation team would like to acknowledge the co-operation and support of a number of individuals. First, we would like to thank all the people who agreed to be interviewed and those who responded to our postal questionnaire surveys, all of whom provided valuable information required for our report. Thanks are also due to senior management in the two localities without whose support the study would not have been possible. Finally, thanks to Wendy Brown, Caroline Conneely and Julia Hyde for their administrative support.

Study Team

- **Professor Ala Szczepura** Centre for Health Services Studies (CHESS), University of Warwick: *Responsible for co-ordination of project.*
- **Jean Roberts** Phoenix Associates, Church Meadow, Ipstones, Staffordshire ST10 2LS UK & Associate Fellow, CHESS, University of Warwick: *Responsible for Informatics perspective.*
- **Debbie Biggerstaff** CHESS, University of Warwick: *Responsible for Professional perspective and jointly with RF Carer perspective.*
- **Rose Fagan** CHESS, University of Warwick: *Responsible for Carer perspective.*
- **Diane Clay** CHESS, University of Warwick): *Responsible for literature review searches.*

Executive Summary

Introduction:

- It is recognised that there is a need for improved inter-agency working across health and social care in order to deliver integrated care that can best meet patients' / clients' needs. This is especially important for vulnerable and disadvantaged groups of the population, such as older adults and their carers, who are more likely to have complex care needs.
- Sharing information and enhanced communication is a necessary part of providing and managing provision of care in both health and social services. It is also a vital part of care for both carers and clients/patients.
- This research was part of a Department of Health Research and Development Directorate project to identify the potential for improved use of existing information and communications technologies (ICTs) to support health and social care convergence.

Study:

- Two geographical areas were studied, Warwickshire and Leicester, representing an urban/rural and inner city environment. A specific cohort of professionals, those supporting older people, was chosen as the focus for the study.
- ICT support to these professionals typically presents all the challenges collectively that may be observed for other client/patient groups individually. Informal carers were also included in the study. Many of the overall findings of this study can therefore be used as a proxy for general reuse of ICTs at the interface between health and social care.
- The study adopted an approach that included profiling existing ICTs in the two localities, using scenarios as a tool to help survey health and social care professionals (N = 686) to explore their views of communication and information sharing with colleagues. In addition, in-depth interviews with a purposive sample of participants (N = 10) were conducted to further examine professionals' views and lived-experiences of IT and information sharing in inter-agency work. Information needs of carers were explored through interviews and a survey (N = 150).

Informatics Perspective:

- Providing a comprehensive profile of *existing* ICT configurations in both sectors in the two localities (i.e. an inventory of the number of terminals and types of applications available) proved to be problematic. This was mainly due to a lack of complete and up to date centrally held information.
- Inventories are not in themselves a means of determining *how* the equipment is being used. They cannot provide information on important aspects such as: end-user access, Internet use etc. The value of an approach which profiles activity in more detail is increased under these circumstances.
- A systems monitoring approach (i.e. electronic data capture) was of limited value, principally because it could only be used to determine switch on and switch off times; and transaction logs only recorded transactions that altered data i.e. not enquiry or report transactions.

- Instead, an activity profiling tool was developed and used in surveys and interviews to capture information on real-time usage in different locations (e.g. GP practices, Health Centres, Social Services offices), local configurations, and (indirectly) 'spare capacity'. The findings indicate significant under utilisation of some terminals.
- The 'spare capacity' calculated ranged from 20% to over 90% in individual GP practices. However, the method we used to estimate spare capacity can, at best, only capture *notional* spare capacity i.e. the time equipment is not directly in use. In reality, *useable* spare capacity will be lower. Staff use will be governed by a complex mix of: equipment at hand; availability of appropriate software applications; permission to use; personal competence; and local policy.
- Our study indicates that Internet-enablement of end-user access points and the training of potential users in effective Internet use will help facilitate data sharing.

Professional Perspective:

- The 686 professionals replying to the survey represented a cross section of staff providing care for older people in the community spread across six staff groups. Staff provided care in several locations, with community nursing staff and social workers reporting the widest range of settings.
- All staff, apart from some auxiliaries, had face-to-face contact with other professionals in the course of their work. GPs, other practice staff and nursing auxiliaries were much less likely to report contact across the professional 'divide' i.e. with social care staff.
- Virtually all staff used telephone, letter and fax for communication. Day books/ message books were also used by 88% of professionals. Email was far less likely to be used, especially by community nursing staff and social workers (15%). Its use was most widespread among GPs (40%). Even where the users indicated the availability of computer systems, they did not feel secure enough to terminate their paper-based message books. Work is still needed to demonstrate that informatics is safe not threatening.
- Most staff (85%) had access to a computer at work. Almost all GPs had access to their own computer and over half of social workers, but only 10% of community nursing staff. The intensity of computer use reported varied significantly. Health care staff were much more likely to report using a computer at home for work purposes (67% of GPs, 47% of community nursing staff) than were social care staff (33% of social workers).
- GPs were the most intensive users with only one in ten spending < 2 hours per day using a computer. This figure was 20% for social workers, and 90% for community nursing staff. Over 40% of those who used a computer for only 1-2 hours per day had their own computer, as did nearly 70% who used it for 2-4 hours. This confirms the presence of significant 'notional' spare capacity in the system.
- Only 6 professionals (<1%) considered themselves to be 'expert' users, and only 15% of community nurses rated themselves as 'competent'. General practice staff were least likely to report having received any formal IT training; ca 15% of GPs and 30% other staff. Training was limited and 45% of professionals had received their training 'over three years ago'. For the most intensive users (>8 hours per day), ca 80% had either received no training or were self taught.
- Access to the Internet at work was highest for practice staff (80% of GPs), lower for community nursing staff (ca 50%), and lowest for social workers (<10%).
- Most professionals had asked other professionals for information in the scenario situation; 88% of GPs, 75% community nursing staff and 93% of social workers. A wide range of

information had been requested. Information was most likely to be accessed by telephone or face-to-face.

- Professionals identified information they themselves held that would be of value to other professionals in scenario situations. The vast majority of staff (91%) said that they would be able to share this information with other professionals. The main reasons for being unable to share information were confidentiality issues or lack of responsibility. Even for those who could share information, consent issues were important.
- Very few professionals (< 10%) said that information access was easy, although most thought it was acceptable. GPs and other practice staff were most likely to report that it was difficult (59% and 45% respectively). GPs were the most isolated in terms of experience of information sharing across the 'divide' in scenario situations. The preferred means of sharing information in scenario situations were verbal; very few professionals (<5%) would use email.
- Many professionals felt that communication in multi-disciplinary teams worked best when people knew each other. Factors such as sharing office buildings or meeting regularly led to better sharing of information ("You know who communicates well because we're a small team"). Professionals also considered that communication was rather variable outside their 'own' multi-disciplinary team.
- GPs were most likely to report unmet information needs (60%), predominantly involving information from social services. Community nurses (25%) and social workers (10%) were far less likely to identify an unmet need for information from the other sector.
- Professionals were generally positive about the benefits that information sharing could provide. Communication between the two sectors, although not excellent, was rated as 'good' or 'reasonable' by the majority. Results show that information sharing between professionals in health and social care is experienced as both a challenge and a frustration. Professionals have to struggle to manage information exchange in a rapidly changing environment. Most issues centred on human communication, with technology related issues presenting far less frequently.
- Other elements centred on conflicting interests and priorities of different professional groups, education and training. Issues for ICT use included computer access for staff and maintaining confidentiality in the sharing of e-information across different systems. Results also show that some participants perceived increased computer use as reducing the time they had available to deliver care to their clients/ patients. The facilitation of any data sharing in this complex socio-technical environment needs to take account of the multiple stakeholders in each sectoral environment.

User/ Carer Perspective:

- The 150 carers surveyed had several years of experience (average 8 years). Even so, they reported the need for a broad spectrum of information. Much of this related to services (e.g. respite care, benefits, carer support, OT/adaptations, housing, transport, day care etc) or information on the illness of the person for whom they are caring.
- Carers looked to various professionals for information and advice; the most important ones being GPs, followed by social workers and nurses/health visitors. Carers' support groups are also important.
- Carers reported difficulties in getting information at the time they needed it. They also found that it was difficult to ask for information, suggesting that a *proactive* approach is required to meeting carers' information needs. The most important stage for such information is when someone just begins informal caring.

- The means most strongly preferred by carers for accessing information were through the GP surgery/ health centre, via brochures/ information leaflets, or through a carers' support service. Only one in ten would prefer to use a computer.
- The preference of older carers (>75 years old) was for accessing information via the GP's surgery or by telephone; rural carers preferred access via carers' support services or telephone. Computers were preferred by younger carers (<65 years), by women and by urban carers. One in four carers expressed an interest in training in computer skills.
- Voluntary carers' groups are an important source of information and support. As well as providing 'someone who listens' and links with other carers, they also supply valuable information on benefits, respite care etc. plus providing concrete administrative help (e.g. in filling in forms) and help with aids and adaptations.
- From the perspective of carers, information provision could best be improved by access to a support worker based in the GP surgery.

Conclusions:

- Some of the main themes to emerge, from both quantitative and qualitative analyses, highlight much good will and many attempts to find a way to share information across the professions and improve communication in teams. However much of this is currently fragmentary in nature and different groups hold separate pieces of the puzzle.
- From our analysis, we can make a strong case for the added value of cross-sectoral sharing of non-person-specific data. In addition, there is evident demand for sharing of person-identifiable data, subject to further privacy issues being resolved. The competency gap amongst professional end-users should urgently be addressed through work-based or recognised initiatives in order to achieve equity and consistency, currently being challenged by sporadic official learning activities, home-based computer access, and self-learning.
- Benefits will be realised by informing current professionals of the wider value of their data, in addition to meeting their expressed needs for further joint access to existing data in a controlled cross-sectoral way. There is a demonstrable demand, articulated in this study, for increased access to technologies in the workplace by both sectors, and the demand for establishing a technologically robust environment, conducive to collaborative working, is increasing.
- The project identified much information that, once shared between professionals, could also be usefully made public.
- The informatics issues form part of wider cultural, organisational and personal communication and sharing issues. These have implications for how health and social care, within the UK and internationally, may best be delivered in the future to provide a more seamless approach to care for clients and professionals.
- The facilitation of any data sharing in this complex socio-technical environment should be carried out sympathetically taking account of the multiple stakeholders in each sectoral environment separately. Pressures from citizens for like data are emerging rapidly so these demands should be addressed sequentially, rather than as separate disjoint exercises.

GLOSSARY

ACTION	European Commission sponsored project Assisting Carers using Telematics Interventions to meet Older person's Needs. www.hb.se/action/ ACTION aimed to 'maintain or enhance independence, autonomy and quality of life for frail older and disabled people and their family carers through the application of modern information and communication technology.' Its actions were taken forward in CarePlus.
ADSS	Association of Directors of Social Services
Back office functions	The facilities and services of an organisation which are usually not seen by a customer. In the case of health and social care this will include financial and staff management, audit, monitoring and corporate governance.
BIC	Building the Information Core - Implementing the NHS Plan (Jan 2001) 'considers the implications of the NHS Plan for the necessary information and IT infrastructure that will support the patient centred delivery of care and services.'
C21	Delivering 21 st Century IT Support to the NHS: National Strategic Programme (June 2002) – document issued by the Department of Health indicating a new direction/mode of informatics support to the NHS in England.
Care Direct	The social welfare equivalent to NHS Direct, frequently operated from same base; currently only addresses information for and about services for the older person.
Care Trust	In overall management control of a combined service for health and social welfare in a geographic area
CarePlus	NHS Executive Trent funded project, based in Sheffield University, School of Nursing and Midwifery (www.careplus.info) developing a pilot one-stop information service targeting older people and their carers in 4 areas of the Trent region. Developed on from the previous European Commission ACTION project
carers	Loose term usually meaning informal carers (that is unpaid and probably family members)
CATCH / CATCH II	European Commission funded projects addressing informatics issues for the Older Person.
CDSS/CALAIB	Project in Scotland that captured decision support information about clinical investigations by staff group. Sponsored by Merke Sharpe Dohme www.calaib.co.uk .
CISS	A Warwickshire NHS in-house Community Information Support System (CISS), addressing referrals, waiting times, episodes of care and the utilisation of care plans. It replaced the earlier FIP Community system.
Client / patient	The subject of social welfare or community health/ hospital and/ or primary care services respectively.
Clinical history	(Structured) record of all (health professional) interventions affecting an individual. Similarly a clinical record may address just one episode of care and the clinical history may be on paper / fragmented or held electronically in linked or cohesive form.
Cross-sectoral	Typically activity which involves participation by both the health sector and social services, but could equally well be social welfare and education or housing
dumb terminal	End-user access point to computer system, no functionality inherent in it (as oppose to a 'PC' that can stand-alone and has in-built applications to run locally)
e-business	Conducting any process that affects the (financial) status of the organisation by electronic means
e-government	Conducting the processes of government (any or all) by electronic means

EHR	Electronic health record. Typically a longitudinal record containing all the key clinical milestones for an individual, regardless of location of the intervention. It will ultimately represent a ‘birth to death’ record and will usually cover all clinical conditions experienced by that patient (though this is subject of some discussion at present). Transient data, for example held for individual care and treatment within a hospital acute episode will have a certain lifecycle within an HER.
Electronic data interchange (EDI)	The passing of standardised ‘messages’, for example about pathology test results, between two locations purely over robust networks electronically.
EMIS	GP Application system supplier in the localities studied
EPR	Electronic patient record. The key data items that identify an individual patient or client and describe in detail the interventions, test results etc. applicable to their current clinical condition, on going chronic condition and/or current episode of care (under one consultant for one cause). For example an EPR may describe all that goes on to and for a patient during the course of an acute inpatient episode of hospitalisation.
ERDIP	Electronic Records Development and Implementation Programme – an NHSIA work programme looking at content, structure and architecture of patient and health records and how they might be achieved [www.nhsia.nhs.uk].
ETD Strategy	NHS Information Authority Strategy describing key actions in terms of education, development and training for (clinical and management) health professionals
Functionality	The activities within a computer programme that describe and support a capability to carry out a certain function, for example ‘appointment booking’.
HA	Health Authority. Previously the body coordinating health care activities in a geographic area containing a number of primary care groups and / or Trusts. Now replaced by Strategic Health Authorities covering several old HA areas.
HAZ	Health Action Zone – a government initiative to classify a particular area as giving cause for concern relative to the national picture and in need of additional investment and actions due to some factors of deprivation or special circumstances relating to the health of the local population.
HealthPOINT	An initiative, started in Glasgow, providing general information for citizens (for example - sexual health and limited lifestyle information) through information kiosks in public locations.
Healthy Cities	An international initiative started in 1985, now involving WHO, that recognises that health is a result of much more than medical care. It targets and solves local problems by getting many parts of the community involved; then shares the findings.
Herefordshire Partnership	A project located across Herefordshire and Worcestershire, led by the local authority in conjunction with the local health organisations. It has developed a web-based gateway to all local services.
Hot desking	Working from one of many possible locations, usually implies a requirement for computing facilities and functionality to be available for a particular individual from all locations where they may work.
I4SC	Information for Social Care May 2001
ICT	Acronym used by many in Europe - Information and Communication Technologies, part of informatics.
IMHER	National initiative for Integrated Mental Health Electronic Records, inclusive of multi-sectoral content.
Informatics	Portmanteau word covering ICT (information and communications technologies), IM&T (information management and technology), IT (information technology) and all others aspects of information quality and information handling.

Information Society	A Directorate General of the European Commission particularly addressing issues including the deployment of informatics to support health, as one of its themes.
InPractice Systems interface	GP application system supplier in the localities studied. Device (probably software) to enable communication, data transfer etc between legacy or best of breed systems and other applications - as oppose to integrated systems that interwork (or are interoperable) by design.
intranet	Network infrastructure that is local to (within) a group or organisation – such as the NHSnet.
LAN	Local area network – where all local terminals within an organisation (or say hospital campus) are inter-connected onto (usually) a ring, and then connected as an entity to any external WAN (wide area network).
Legacy systems	Computer application systems that have been in operation for some time and could be superseded by newer architecture or offerings, but are retained until their useful life has expired/ amortisation (financial write-down) is completed; they are probably bespoke (customised) systems which will necessitate a complex interface with contemporary systems
LIFT	NHS initiative (2002) relating to commissioning, in conjunction with the private sector under PPP terms) large polyclinics in geographic areas to include minor surgery and other traditionally hospital processes (Local Implementation of Financial Trusts)
LIP	Social Services Local Information Plan, nearest equivalent to NHS LIS (Local Implementation Strategy) that describes all aspects of informatics actions to support health in a Health Authority area.
Local Compact	Initiative involving health, housing and social welfare
MAIDeN	A project to develop Multi-Agency Information Database for Neighbourhoods (MAIDeN) around Gloucester to support the many service partners.
Neighbourhood Renewal Area	Under Local Strategic Partnership
NHS Code of Connection	Contains mandatory practice when deploying computer equipment and functionality through the NHS intranet and connecting to the Internet
NHS Number	The unique patient identifier that is issued to all England & Wales residents at birth (similar numbering concept in other home countries), recently changed to be unstructured and compliant with European Law on anonymity of sensitive data.
Non-application-specific training	Covers training and awareness in informatics principles, not in the explicit operation and requirements of a named piece of software.
NSF	National Service Frameworks – define collective ‘good practice’ for addressing a specified clinical area like cancer, coronary heart disease, services for the older person, or children’s services
OLA CRMS	Social Services Client Referral Management System developed by the company OLA, now superseded in the study areas by an enhanced product CareFirst from the same company.
One Stop Shop	In this study, it refers to the location through which advice, guidance and information about both health and social welfare issues, and perhaps other local public services, can be acquired.
PAS	Patient Administration System, precursor of HIS in hospitals, mainly addressing administration of inpatients and outpatient clinics
PC	Personal computer
PCG	Primary Care Group – administrative grouping of general practitioners, nurses and primary care teams, addressing the needs of local people by developing primary care and arranging hospital and community services

PCT	Primary Care Trust – a locally managed community NHS organisation, responsible for improving health, and commissioning and delivering health care for local residents.
PDA	Personal Digital Assistant – a small hand-held computer with advanced functionality.
Person-identifiable	Synonymous with personal data, refers to unique identification points such as demographics, retinal patterns, finger-prints and DNA.
PHR	Patient-held record, where the subject may or may not be able to add their own observations pertaining to their health. The record is available, typically at home, but also can be made available directly to professionals of the subject's own choice – for example in ante-natal care.
PPP	(in this context) public-private partnership, usually for a scheme requiring significant capital investment.
PRIMIS	A DH-funded project to training GPs to make better use of the information they hold on their patients and activity; based in Department of Primary Care, Nottingham University.
RFA	Requirements for Accreditation - A detailed textual specification of core functionality that should be provided in a primary care application system in order for it to be awarded Accreditation by the DH and become eligible for some financial reimbursement to users.
Single Assessment Process (SAP)	A process undertaken collectively by multi-disciplinary professionals (health and social care or clinical specialists in different disciplines) to determine the overall interventions to be carried out within the care programme for an individual patient/ client
Single Assessment Programme	Whereby all relevant care groups (health and social welfare) develop a plan of interventions and actions to support individuals in the community. It is initially particularly addressing cohorts such as Older People, children and those with mental health conditions.
Smart card	Credit card sized unit. Carried by citizens to identify either where health information is held about them, or containing clinical detail about them (prescribing, chronic conditions and the like). Also similarly used by professionals, containing all the relevant information and credentials to identify them to health informatics applications that they wish to use.
SHA	Strategic Health Authority, introduced under the Modernising the NHS: Shifting the Balance of Power reorganisation, September 2001. Proposed as the bridge between the DH and local NHS services. Provide strategic leadership to ensure the delivery of improvements in health, well being and health services locally.
Telecare	The delivery of care with some element of remoteness between the recipient, carer and the professionals involved in its delivery.
Torex Health vendors	GP Application system supplier in the localities studied Both suppliers and those who sell third party products.
Wanless Report	Treasury-commissioned report on the strategic investment needed in the NHS (2002 onwards).
Web-enabled	Applications that can be accessed through an intranet or the Internet (may have been previously operated directly).
WHO	World Health Organisation

1. INTRODUCTION

This research was commissioned as part of the Department of Health's Information and Communication Technology (ICT) Research Initiative, to identify ways in which ICTs might provide benefits to health and social care professionals working across boundaries and to the clients/ patients that they serve. The project aimed to examine the use of *existing ICTs* in supporting isolated users in the community (principally professionals but also lay users), and to consider ways in which use of such ICTs might be improved, focusing initially on non-person identifiable information. A single patient group was selected as the main focus of the study - older people (and their carers). This group was chosen because the needs of older people and their carers reflect those of the wider isolated populations served by health and social welfare professionals in terms of their clinical, psychological and social care needs. Other isolated groups might include the physically disabled, the mentally ill, or those socially and potentially service isolated through geography, lifestyles or other factors. Older people would be represented in all these categories. Therefore, a study focusing on the information needs of professionals who support older patients or clients should provide findings that are generalisable to other groups, such as those mentioned above. Furthermore, it was evident that this is an important group on which to focus in terms of inter-agency working because of the various policy initiatives that aim to enhance working between professionals across the health and social care interface in relation to older people.

1.1 STUDY AIMS AND OBJECTIVES

The main aim of the study was to examine use of existing ICTs and consider possible improvements required to provide:

- better communication and co-ordination of care delivered by health and social services professionals in the community; and
- better dissemination of information to isolated client/ patient groups.

In terms of health and social care professionals, the study objectives were to:

- establish access to, and use of, information technology by these professionals;
- map the information needs of professionals, focusing on their delivery of care to older people;
- examine current information and communication practices by these professionals;
- place an equal emphasis on the front and back ends of the topic - how to develop an appropriate model for improving communication and co-ordination and how to implement it.

As well as examining the information needs and practices of professionals caring for older people, a secondary objective of the study was to:

- explore the information needs of older clients/ patients and their informal carers.

The study therefore set out to provide improved knowledge to support the development of joint information strategies, including determination of current patterns of use and collective requirements across existing (multi-disciplinary) boundaries, and the definition of optimal approaches to meet future information needs for professionals and users.

2. STUDY CONTEXT

The two sites in which the study was undertaken were: one location (Warwickshire) selected as representative of an urban/ rural site and a second location (Leicester) selected as representative of an inner-city site. Further details on both locations are provided in Appendix 1.

During the period of the study there were major organisational changes in the community and primary care sectors, including the introduction of Primary Care Trusts and Strategic Health Authorities. Apart from these nationally driven organisational changes, this was also a period of local re-structuring of service delivery for both health and social care in both localities. The changing organisational context and developments in IT features and functionality during the study period meant that the project was inevitably undertaken within a constantly changing environment.

3. STUDY METHODS

Meaningful assessment can be problematic in an organisation which is constantly undergoing change [Øvretveit, 1999]. Since our research was being conducted in a complex research area at a time of considerable and rapid change, an action research approach was adopted [Hart and Bond, 1995; Giliham, 2000]. This approach enabled us to identify and assess various possible strategies for providing enhanced information to professionals working with older people and their patients/clients or carers. Firstly, a framework was devised to enable the research team to identify and consider changes that might be key in terms of improved information. Secondly, we undertook a pragmatic assessment of current utilisation of ICTs, required improvements, and the best way in which improvements of the type required could be carried out in a timely and appropriate manner. Throughout there was an emphasis on ensuring optimal use of *existing* ICTs and a focus, in the first instance, on non-person-identifiable information requirements, but not to the exclusion of person-identifiable data.

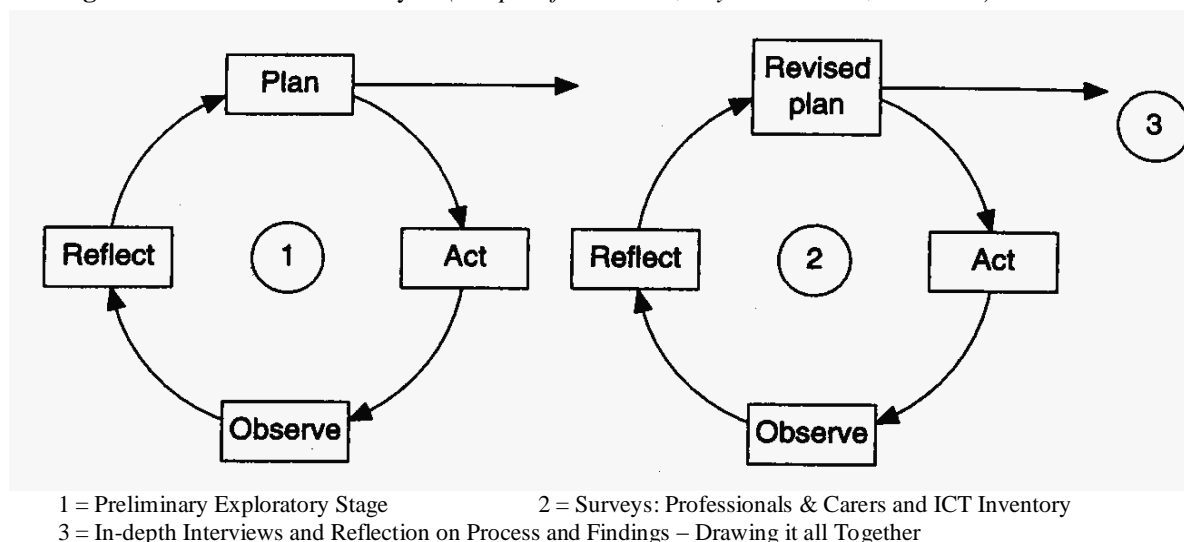
The study aimed to provide findings from three different perspectives, using slightly different methods:

- **Informatics Perspective:** methods used included interviews, inventory performance (terminal numbers/ types of applications), profiling of terminal use on a geographical basis, and identification of spare capacity in a cross-section of locations.
- **Professional Perspective:** the methods used included scenario development (for the elderly patient/ client group), surveys of professional groups, and in-depth interviews.
- **User/Carer Perspective:** the research utilised interviews followed by surveys of users/ carers in one locality.

Findings from each of these three perspectives are presented separately in the following sections, including a more detailed description of the methods used, as well as the main research findings.

The over-arching approach involved a collective process of self-reflective inquiry, as shown in Figure 3.1.

Figure 3.1: Action Research Cycle (Adapted from Curtis, Bryce & Treloar, 1999:206)



This was an evolving and cyclical process conducted through a number of inter-linked stages. Each research stage included preliminary planning, observation and final reflection on what was reported, and each provided the basis for the next stage of the research. The subsequent stage was then better informed and could lead to more effective action.

4. INFORMATICS PERSPECTIVE

Various approaches were used in order to explore the informatics perspective:

- initial interviews with key informatics staff (health and social care) and suppliers;
- extraction from local implementation strategy inventories;
- analysis of other inventories (where existing);
- discussion with system suppliers about the configurations purchased;
- survey of equipment use in a representative sample of primary care locations;
- follow-up with selected representative sites about terminal usage.

4.1 PRELIMINARY ICT OVERVIEW

A preliminary ICT overview was developed for each geographical area through interviews with key systems and computer professionals working within health and social welfare, and with existing applications systems suppliers. The objective was to describe what existed currently in each location in terms of information technology and joint working. At the same time, methods were established for maintaining contact and providing on-going updates during the course of the study. The ongoing individuals interviewed were also consulted in the design of an ICT activity profiling tool that would be of relevance to both health and social care. This would collect information on current ICT use and identify any spare capacity on existing IT systems.

The individuals interviewed were also asked to identify any projects in their locality that were relevant to the care of older people and/or information sharing by the NHS and local government. Key players in informatics in Warwickshire were interviewed at the start of the research, and contact was maintained by using e-means to approach them for updated information throughout the study. In Leicester, interviews were conducted with the Head of Information at the Health Authority and the Head of Information for Social Services towards the end of the study.

In Warwickshire only a small number of projects were identified in baseline interviews. There was little evidence of joint working at the outset of the study, and this situation did not change significantly during the course of the project.

In Leicester this site also demonstrated few examples of joint working; typically the challenges of progressing informatics in their own domain was considered to require significant effort by both sectors.

Following the baseline interviews, a more detailed overview of both localities from the informatics perspective was built up as follows:

- (i) *Mapping ICT configurations*: this included a stock-take of existing (and planned) IT terminals and systems, an overview of the local informatics context, plus other relevant ICT descriptors.
- (ii) *Estimating spare capacity*: this included profiling ICT use at specific locations in order to record levels of activity, identifying any barriers to accessing terminals, and estimating 'spare capacity' in existing systems.

4.2 MAPPING ICT CONFIGURATIONS (IT TERMINALS & SYSTEMS)

The main locations for terminal usage in the community were GP Practices, Health Centres, and Social Services offices. Manufacturers and service delivery organisations (health and social care) were approached for information on the number and location of the end-user points in these various locations. Interviews were undertaken with relevant industry vendors (i.e. Torex Health, InVision, EMIS for primary care; and Hyder/ IBA for Warwick Acute) and with representatives of health (community and primary care) and social care. NHS interviews were conducted with informatics leads in both study areas and with the operational head in the community in the first study site. Exploration of the Social Services systems was carried out with dedicated IT Department staff. As the informatics operation in the Social Care sector is very centralised and hierarchical, interviews were exclusively with those with high level management responsibilities rather than field workers.

Interviews with manufacturers indicated that, in practice, it would not be possible for suppliers to provide accurate information on terminal numbers in the study sites. The suppliers reported that because organisations bought and withdrew equipment over time, up to date figures were not available to them. System vendors also considered that it would be inappropriate and inaccurate for them to attempt to give details of the current number of end-user points in each client site, as clients may be using equipment bought at different times and for different purposes relative to their organisational layout. For example, there was a likelihood that some end-user points might be being utilised for separate Internet access to satisfy the NHS Code of Connection (necessary at the time because of firewall concerns), but it was not known which these were.

Interviews with service delivery (health and social care) staff were slightly more productive. Data were eventually provided by the NHS and Social Services Informatics Departments within the user organisations. However, whilst both study locations maintained an inventory, for example, of which systems were in which GP practice locations, this information was only periodically (and rarely) updated. Over the study period there were a number of in-practice changes in staff, mergers, openings and closures and one demerger of a practice. There was therefore a question over the currency of any GP practice inventory data from these sources or from published documentation such as the local implementation strategy inventory. The Community Trusts in both locations were supported by the same health informatics groups, so data on the placement of technology in other locations was subject to the same caveats described above. Because the inventory in the local strategy documentation was recognised to be outdated in both health localities, steps were being taken to determine a more up to date inventory in each area. It was indicated that inventories were usually only reviewed when an update was required for external reports, not as upgrades are made. It was also reported that considerable effort is required to collate and update this data, together with other relevant information such as named practice contacts with IT responsibility.

Both study locations also stated that, because the economic life of PCs is relatively short, equipment could be relocated on an 'as required' basis. The research team identified this as a major complication limiting the currency of any stock-take approach. Furthermore, such movement of equipment made the specification of equipment in particular locations difficult to track. For example in Leicester Social Services, the IT lead indicated that PCs were all configured with a core desktop of applications and, under the Code of Connection of Leicester County Council, no other applications were to be loaded locally without central permission and involvement. However, as new staff came on board end user desktop PCs were replaced and introduced on a rolling (as required) basis. Thus, any equipment figures provided for our study could only represent generic end user desktop PCs of 'at least the basic specification'.

In addition to attempting to gather information on current equipment, information was also requested on any *planned equipment* i.e. equipment that was on order. There was even less centrally held data on this. Few detailed implementation plan documents were readily available for Social Services in the two localities; plans for NHS locations, as stated before, were only updated periodically when required for purposes such as audit or business plans.

4.3 OVERVIEW OF LOCAL INFORMATICS CONTEXTS

During the course, both localities experienced major changes to their systems, their organisations and in some cases, their application supplier. Because the distribution and use of available computing resources proved to be labile in both locations, this clearly limited the value of a simple equipment stock-take. In this situation, a *broad overview of the informatics context* needed to be acquired in each locality. Structured interviews were used to build up for each locality information on the following aspects:

- available computer terminals/equipment;
- applications software in use;
- end-user access;
- Internet access;
- IT training;
- handling of associated privacy issues;
- future IS plans.

An overview of the local informatics context is presented below separately for health and social care in each study site, with more details provided in Appendix 2.

4.3.1 Warwickshire: Overview of Local Informatics Context

Warwickshire's ICT strategy at the outset of the study included a strong commitment to the application of IT to improve patient/ client care. This strategy emphasised that health and social care agencies were committed to using ICTs to address certain priorities which were relevant to the study, including:

- taking action to make people feel less isolated or excluded from society;
- improving the mental health of the population;
- promoting independence by providing services to help adults achieve and sustain the maximum independence in their lives, and especially improving the independence and quality of life for older people.

When the study commenced, the existing NHS technological infrastructure was acknowledged to be variable across Warwickshire. Most general practices, NHS Trusts and the Health Authority were connected to the NHSnet (the secure network shared between NHS organisations in England). Electronic data interchange (EDI) across this network had concentrated on administrative data but pathology results were also flowing from South Warwickshire General Hospitals Trust to some local general practices. Connection to NHSnet enabled access to services such as the Cochrane database (of evidence-based medicine) and offered a secure gateway to the Internet for some professionals. At the outset of the project, systems still had a mix of dumb terminals ('green' screens) and personal computers attached to the network. South Warwickshire General Hospitals NHS Trust had recently implemented a new Patient Administration System (PAS) in order to enable progress to be made with implementing the national and local strategies of developing Electronic Patient Records (EPRs) and the eventual holistic Electronic Health Records (EHRs).

However, it was reported that *sharing information between health and social care was still in its infancy* for technical reasons and, more significantly, because of issues around professional practice.

4.3.1a Health Care

At the outset of the study (1999) there were 350 terminals in South Warwickshire community locations and approximately 300 in GP surgeries (total 650 primary care terminals). North Warwickshire community locations (excluding Rugby which was part of the then North Warwickshire Trust) had 200 terminals, with a further 290 in GP practices (total 490 primary care terminals). Services covered a population of 500,000.

By 2002, there were of the order of 560 terminals in the South Warwickshire community NHS domain plus 360 GP terminals (an increase of 50% on the number of terminals at the start of the study); and just over 800 in North Warwickshire community locations and 390 terminals in GP practices (more than doubling the initial figure of 490 terminals). Thus, there was a significant increase in the IT infrastructure over the study period.

In 1999, the Acute Trust in South Warwickshire was estimated to have of the order of 600 terminals in personal offices, wards etc. By August 2002, this figure had increased by nearly 50% to 850 terminals. Informatics support for the NHS across Warwickshire was being revised during the study period, and by 2002 covered acute hospital, non-hospital and community locations.

4.3.1b Social Services

In 1999, Social Services in Warwickshire had 870 terminals in both back office management locations and some team bases. By August 2002, there were reported to be 1,200 terminals (a 30% increase), all of which were personal computers. Managers, senior social workers and administrative/ support staff were all reported to have their own PC; other social workers were reported to share in a ratio of approximately one terminal to two members of staff. All these terminals had access to email facilities. Warwickshire ran all its Social Services work from its own servers.

The informatics context in Warwickshire is described in more detail in Appendix 2A, covering application system types used, end-user access to systems, Internet access, training and privacy issues

4.3.2 Leicester City: Overview of Local Informatics Context

Leicester City's ICT strategy included a strong commitment to improving patient/ client care through the application of information and communications technology, similar to Warwickshire's. Both city PCTs (Leicester East and Leicester West) supported these IT developments and both had identified information sharing across health and social care as a priority. The Leicester NHS Strategy for Informatics was under the management of a Health Informatics Service that had responsibility across the hospital sector, the community and primary care collectively. The March 2001 strategy update stated that the 'planning' stage would be moved into 'doing' in the 2002/2003 period which would 'represent a significant step in investment' and be 'in line with the IM&T funds included in the HA allocations'

The local strategy was being developed through five main programmes of work, each of which had multi-professional and cross-organisational representation:

- Primary, Community and Social Care EPR – previously the Leicester Royal Hospital Trust IM&T Strategy Group;
- Acute EPR
- Education, Training and Development Strategy
- Information for Patients and the Public
- Communications and infrastructure

Targets of relevance to this study included:

- A Modernisation Executive, comprised of Chief Executives (SHA, Trust and PCT) and Social Service Directors, had been created to oversee the implementation of the overall NHS Plan locally, creating a better climate for cross-sectoral dialogue.
- A proposal to integrate the provision of mental health services across the health and social care community – the Mental Health Information Strategy - was being developed to support the new organisation, delivering cross-sectoral working in action.
- A commitment to integrate the provision of information into care pathways and to continue to develop 'web-based delivery of information', which should demonstrate and facilitate joint working respectively.

The work plan at the time of the study included the establishment of a clinical learning network addressing clinical governance issues, progressing of the mental health information strategy, an upgrade to the network, agreement to develop a multi-agency database to support the local Sure Start programme, and extension of the Knowledge Management service into the Community. These lines of action were expected to have a positive effect on the environment into which shared data concepts could be introduced. In addition, there was a confirmed intention to address the requirements for each NSF underpinned by a national obligation to generate a plan for each NSF within 6 months of its publication.

Unlike Warwickshire, the technological structure in primary care was almost consistent in Leicester in terms of the supplier of the system, although implementation versions were variable. This had been reinforced by practices being strongly encouraged by the PCT to install, and use, one computer system, to facilitate compatibility. Targets were still to be achieved to modernise systems to meet the Primary Care Requirements for Accreditation (RFA) functional specification by 2003/04. A considerable number of practices in Leicester East and West had branch surgeries which still required modernising. The PCT Executive had identified this as an area for improvement and plans were underway to implement these changes. The city also had a higher proportion of single-handed GPs than the national average. All general practices were connected to the NHSnet and had local area networks (LANs), although computer use was still developing in some practices. The PCT had identified the need for education and provision of IT training as the next step forward in encouraging the use of computer technology in these practices.

In March 2001, Leicestershire Health Community had one in three practices receiving electronic pathology results across NHSnet. Connection to NHSnet also enabled access to services such as the Cochrane database and the Internet for some professionals. Systems had a mix of dumb terminals and personal computers attached to the network, but a lower percentage of dumb terminals than Warwickshire due to the different mix of applications supplied in Leicester.

By early 2002, pilot projects were ongoing in areas such as PRIMIS (training GPs to make better use of their information); electronic records and patient registers to meet National Strategic Framework targets; clinical governance and audit; and booking for direct access appointments, initially lung cancer (a national pilot scheme) and endoscopy. These were being rolled out over the near future. The national requirement for integrated records for mental health (IMHER) were to be met in 2002. The transfer of data to support NHS Direct operation during out of hours working was pending, as were projects to look at the infrastructure for dentists, pharmacists and optometry and the extension of hospital-type informatics into the community sector. Other electronic records work was ongoing but as yet *little of this had involved cross-sectoral working within the City*. Some general clinical information for patients/ carers was available on the Internet and accessible through project and personal Internet connections. All the above were expected to enhance the likelihood of acceptance of multi-disciplinary working and *pave the way to cross-sectoral action*.

It was interesting to note that despite apparent slippage in the timetable for health actions that had a cross-sectoral impact, the e-government response and the general County Council plans in Leicester still stated, for example, a 2003 date for the introduction of Citizen smart cards and a 2005 date for integrated back office services to support health, social services and other local government departments jointly. It was felt by interviewees that there was little likelihood of these targets being achieved.

4.3.2a Health Care

The two PCTs in Leicester City (East and West) between them had of the order of 200 terminals in GP practices and 80 in the community (total 280 terminals) in 2002. Services covered a population of 320,000. A programme of replacing the dumb terminals ('green screens') with PCs was almost complete for the team offices of district nurses, health visitors, and their administrative staff and managers.

4.3.2b Social Services

In 2002, Leicester Social Services reported that they had of the order of 1,000 terminals. Each Social Work team had 1 end-user point for their Manager, 1 per Clerk, and at least 1 per 2 social workers (in their team office not at clinics). All staff had an email address.

Different from Warwickshire, Leicester did not run all its Social Services work from its own servers. Instead, it used both its own equipment and shared resources with other local authority departments such as Housing and the Arts. There were 18 servers owned by Social Services and others were shared or were directly connected to a central server via modem link. Social Services worked within the Corporate IT policies of Leicester City Council, who also purchased, installed and maintained all hardware and software on behalf of the Social Services IT Group.

The informatics context in Leicester is described in more detail in Appendix 2B, including aspects such as applications used, end-user access to systems, Internet access, training and privacy issues

4.3.3 Summary of Two Local Informatics Contexts

In both study sites, it was reported that information sharing between health and social care was not well developed; in fact, the perceived task of advancing informatics in their own domain was thought to require major effort by both sectors. Thus, although plans for joint or collaborative working were included at a strategic level, these were less often incorporated in action plans.

The overview of the two health informatics contexts shows that deployment of ICTs during the course of the study was volatile in both locations. In health, there was a range of suppliers in both locations, although Leicester was encouraging all practices to migrate to accredited systems, predominantly from the EMIS vendor. In terms of core functionality, all solutions were RFA accredited, but with extensions. In social care, the two local contexts were similar, but both were also waiting for informatics changes to be proofed in health before implementation in social care.

Thus, for health the models of use were similar in both locations. But, these were different from those in the social care locations, which were also similar to each other. All locations adhered to necessary Data Protection and other (e.g. Caldicott) guidance.

Interestingly, the study sites had chosen to open up their end-user points for Internet use in different ways [see Appendix 2]:

- by additional permissions attached to the individual user code (Warwickshire);
- by enabling various end-user PCs rather than the people who used them (Leicester).

The organisations interviewed did not necessarily recognise the need for additional training to be undertaken before access was granted. For social care staff, access was allowed in both locations after management sanction for the connection; and in the case of Leicester Social Services after a licence fee per required end-user had been paid (by internal transfer) by the departments requiring access for their staff. For healthcare staff, access was password protected and training was required in Warwickshire; in the case of Leicester, there was no mandate to complete the formal training before using the Internet.

4.4 IDENTIFYING SPARE CAPACITY AND ACTIVITY PROFILING

The interviews, designed to build up an overview of local informatics contexts, were followed by an examination of use of IT systems in more detail (activity profile) and identification of any ‘spare capacity’ that might exist. The objective was to first record available IT systems in a particular location and then to gain a measure of the intensity of use of these systems. Comparison of the two should allow the size and characteristics of any spare capacity in local systems to be identified.

When examining the issue of spare capacity, or potential extended use of existing ICTs, we were aware that there might be a number of inhibitors that could limit use of any apparent spare capacity. For example, *technical constraints* could limit extended use and also pose considerable constraints on implementation of any information sharing. In addition, there might also be *organisational or professional inhibitors* that would limit actual usage of spare capacity. Other inhibitors which have been identified by studies such as the European Commission Information Society Initiative project G8-ENABLE include lack of user training, requirement for standards, and perceptions of the performance and quality of the Internet [Rogers and Reardon 1999]. The activity profile exercise could only examine some of these. The remainder were incorporated into the survey of professionals (see section 5).

4.4.1 Activity Profiling

A review of the literature was undertaken to identify any validated activity profiling tools for IT systems use and ‘spare capacity’. This demonstrated that a limited literature on profiling of activity, and no tools available for identification of spare capacity that had been validated in the community setting for health or social care.

The research team therefore devised a simple activity profiling survey tool. In developing this, we first considered the data capture frame from the European Commission DG13 HIST study funded by the CEC R&D Telematics Application Programme (Health Sector) and the NHS Information Authority Electronic Record Development and Implementation Programme (ERDIP) inventories [www.nhsia.nhs.uk]. Building on these, and similar survey instruments we devised questions for use in the present study. Consideration of the coding frame from the multi-national Deloitte and Touche HIST study (a European survey by Deloitte and Touche addressing the context of the emerging European Health Telematics Industry) was not helpful; the range of incompatible and non-standard ways of defining configurations across Europe did not provide a useable model [EC Directorate 2000].

A framework was mapped out to cover IT system use i.e. activity profiling, including the following items:

1. what equipment¹ is presently available;
2. who uses the equipment, for how long and for what purposes;
3. what might the equipment be used for;
4. any constraints on access or use of the equipment.

The literature did not go into detail about data capture forms for levels of usage (item 2), so those questions had to be developed by the project team and validated with our potential respondents. For item 3, a list was produced of the main functional task areas that might be used to classify the types of

¹ Including hardware and software

transaction carried out by health and social welfare professionals when using information systems. The main types of staff carrying out these transactions were also identified. The resulting classification had to be appropriate for mapping how existing computer equipment is utilised by current users in a particular location. After discussion with end-user professionals, questions were also selectively incorporated into the large scale postal questionnaire surveys of professional groups (see section 5). Electronic activity data capture was also explored.

4.4.2 Electronic Activity Data Capture

The study team aimed to use electronic capture of data on actual usage of terminals (including time of day, duration of use, types of activities, and professional users) in selected locations. Subsequent analysis of this data, together with survey activity profiling information on the numbers of terminals and patterns of use in particular locations, would enable spare capacity to be estimated on a quantitative basis.

Early in the study discussion were held with relevant NHS vendors (Torex Health, InVision, EMIS for primary care; and Hyder/ IBA for Warwick Acute) and IT Managers for the CRMS (subsequently CareFirst) application in Social Services in order to determine the feasibility of developing electronic capture of data on actual usage of a system by scrutiny of the transaction logs.

In Warwickshire, interviews with GP systems suppliers (Torex Health, InPractice Systems, In4Tek (general control) and EMIS) identified that their applications were unable at that point in time to give profile information for primary care. Similarly, interviews with the main hospital application vendor (Hyder/ IBA) indicated that they were in transition and unable to provide much information or commit to deliver any statistical profile of usage at the acute/ primary care interface.

It was consistently identified by all those interviewed that there would be major shortcomings in any approach based on electronic data capture, and that data acquired in this way would inevitably produce inaccurate estimates of what was being done, when and by whom (or under what password). The main difficulties reported were as follows:

- *systems reports* could only be used to determine switch on and switch off. Thus, where a user switched on when they entered their place of work and off when they went home, the system would be notionally 'live' all the time. This observation was borne out by some of the comments in response to the activity profiling survey, described in section 4.4.5 below ("All computers are switched on all day. Cannot guess how many hours are actually spent on each one"; "[we use our computers] nearly all the time"). This factor would mean that any systems monitoring approach could significantly *under estimate* spare capacity in the system;
- systems suppliers also reported that no *intermediate transactions* are logged unless personnel create, add, or amend data. Transactions which *alter data* are logged to facilitate disaster recovery and backup processes. However, *enquiry and report* generation transactions, which may form a large part of actual activity, are not logged. Since all these transactions *would* make the terminal unavailable for other users, the information that could be extracted from the operational management software integral to the applications was therefore of limited use in terms of the aims of the study. This factor would mean that a system monitoring approach could significantly *over estimate* spare capacity in the system;
- finally, suppliers stated that, as technology is getting cheaper in terms of power, it was highly unlikely they would in practice ever investigate the transaction profile at a particular site. Even in a case where degradation in performance threatened contract performance, it would be more cost-effective to simply add hardware to improve the performance.

Based on these responses, we concluded that it would not be possible to accurately monitor actual usage of terminals using a systems monitoring approach. We subsequently determined that monitoring activity profiles were reported for a project in Scotland (referred to as CDSS-CALAIB) that captured some clinical decision support information about clinical investigations [www.calaib.co.uk]. This study was able to gather similar information to that we envisaged originally, but only from the Scottish national system GPASS. The study recorded nearly half a million GPASS 'sessions' in a year amongst 45 practices and broke them down by user type e.g. GP, nurse, administrative staff etc. The figures, once collated, equated to about 26 'sessions' on average per practice per day (with a 'session' defined

as ‘logon to logoff’ over an unspecified length of time). Therefore, as noted above, this is a statistic that one would not necessarily be able to relate with any great accuracy to *spare capacity*, since many of our respondents reported leaving their computer switched on all day, without the computer actually being in use all this time. Interestingly, the CDSS-CALAIB study also reported considerable use of decision support functionality on top of general GPASS patient administration work, mostly by nursing users in specialist activities like asthma clinics. This would not have been captured in the transaction logs, resulting in an over-estimate of spare capacity.

4.4.3 Interviews with NHS and Social Services IT Leads about Activity Profiling Statistics

Since it was clear that data on terminal usage and spare capacity could not be accessed electronically, interviews were next held with health and social care leads on IT in both Warwickshire and in Leicester and representative users with the aim of identifying any available data that might help activity profiling and identification of spare capacity. Following discussion with IT managers in social care, statistics were produced using both the application software CRMS and via SQL query language *ad hoc* enquiries. A series of non-standard *ad hoc* reports was generated for us to seek to determine the profile of activities amongst the professionals supporting the elderly. In the event these statistics were of limited use.

4.4.4 Surveys to Gather Activity Profiling Data

The study team next undertook a *survey of a sample of sites* using the framework described in section 4.4.1. This gathered information on current ICT configurations and activity in terms of end-user access points, types of users, reasons for use, and time of day/ duration of time in use. An important aspect that emerged in interviews, in both health and social care, was use of the Internet. Our focus therefore changed during the course of the study to incorporate ability to access the Internet as a necessary capability and therefore an important additional factor.

Contacts in Community Trusts and Social Services questioned the practicality of surveying certain field locations (e.g. clinics) where no one person had responsibility for the management of the systems and staff were frequently on the road and using various bases for systems enquiry and data input. In these instances, therefore, it was agreed that activity profiling data could best be provided by the senior officer for the locality. Site surveys were therefore confined to a sample of general practices since these were the field locations in which many of the community professionals in whom we were interested actually worked and accessed ICTs.

4.4.4a Sample Frame

A sample frame was identified for Warwickshire to be representative of practice characteristics (e.g. large and small practices, and technological leading and lagging practices) and for equipment and applications used (i.e. suppliers). For Leicester the location survey was carried out using a similar approach although the application vendor was in an almost monopolistic situation.

Partnerships in the two localities ranged from 1–10 GP principals; the survey sample similarly included practices with 1-10 GPs. A mix of rural, urban and city practices was also included in the sample. Certain other characteristics were difficult to identify prospectively. For example, there were no typical IS configurations for primary care and practices could have varying functionality in operation. Therefore, the practices were evaluated *post hoc* in terms of these parameters. Practices were also identified *post hoc* as leading or lagging either by their own assessment or a judgement based on interviews and their declared scale of system usage. Where necessary, the survey sample was supplemented by further approaches to ensure an appropriate range of practices. In Warwickshire, a total sample of 21 practices was selected out of 62 partnerships. In Leicester, a similar size sample (17) was drawn from the 60 partnerships in Leicester East and Leicester West PCTs.

There were three main systems vendors (Torex Health, EMIS and InPractice Systems) who had a range of systems in place in the two localities. These companies had also taken over other suppliers and were in the process of replacement or migration of the operational systems into their main stream offerings. For example, Torex were migrating their AAH Meditel clients forward to System 6000 and Premiere Synergy functionality. Torex had also acquired Aremis during the period of the study. This situation was one that was common nationally and whilst the market movement might be expected to settle down there would never be homeostasis. The changing context was pertinent in health because of the

requirements for systems to change, in technology and in client functional and accreditation requirements, with NHS strategic changes. Therefore, over the period of the project there was a considerable migration between systems vendors, and whilst every effort was made to select representative GP practices (by vendor) for the surveys, the coverage was fluid.

For Community Trusts and Social Services, activity profiling of ICT use and 'spare capacity' was undertaken through interview with Senior Officers, because of the factors described in Section 4.4.4 above.

4.4.4b Activity Profiling Tool

The activity profiling tool was piloted with potential respondents in GP practices, and slight modifications to content made as a result. The final instrument [see Appendix 2C] was presented in a tabular format as the end user advice was that otherwise responses would not be forthcoming from practices. The table was designed to enable practice staff:

- record the number of available computer screens and their location;
- identify whether these were networked or stand-alone;
- record what systems were in use;
- provide an estimate by (staff group) of how much time was spent using the computer system in an average working week.

The survey collected data separately for the main practice premises and each branch surgery.

For Community Trusts and Social Services, the ICT profiling tool was used as the basis for questioning senior staff in the Health Informatics Services. The same types of questions were therefore posed to these staff, rather than field staff as in the surveys. Finally, the profiling tool was also used in a similar manner for face-to-face follow up interviews with a sample of GPs.

4.4.4c Conduct of Survey

Initially, it was anticipated that the survey could be circulated through standard NHS email services to each practice. In reality, whilst email was available in most locations it was not readily used. The survey form was therefore faxed rather than emailed. Because distribution of the survey occurred at a period of major change, considerable effort was made to ensure an adequate response rate at a time when contacts might feel themselves to be 'surveyed out'. Fax reminders and telephone follow-up were used to increase the number of responses, and also to clarify the reason for any non-response. In cases where practice managers replied on behalf of their practices, if their knowledge of the use of the local systems was limited, further clarification was sought in some instances. A full response rate was achieved.

Because of the lack of electronic data (see Section 4.4.2), we also aimed to record more detailed on-site data on actual usage at a number of representative terminals. Utilisation sheets attached to these terminals would capture a range of information on usage including time of day, duration of use, types of use, type of professional user, and reasons for use. In practice, analysis of survey responses demonstrated a considerable lack of clarity about what was being done on which terminals and by whom, so that terminals could not easily be selected for further detailed study. Instead, follow-up face-to-face and telephone interviews were carried out with selected GP practices (both high and low use, leading and lagging in systems use) to ascertain the range of informatics deployment across the study area. Interviews covered two leading / one lagging practice in Warwickshire, and one mid-range practice in Leicester.

4.4.5 Results: Estimation of Spare Capacity

4.4.5a GP Practice Spare Capacity

In order to estimate spare capacity, the following two assumptions were made:

- that total capacity can be estimated as the product of the number of terminals and the number of working hours per week. A conservative estimate was used for the latter (37.5 hrs per week) in order to ensure that the level of spare capacity would not be *over-estimated*;
- that any time remaining, after deducting the recorded total sum of 'time in use' from available capacity, would provide a measure of spare capacity.

Estimates of *percentage spare capacity*² were analysed to detect any relationship with the following parameters:

1. *size of practice* by total list;
2. *patient list size* by GP partner;
3. *access to terminals* by professionals other than GPs, such as practice nurses, practice managers, district nurses, health visitors and midwives, and attached staff such as pharmacists & physiotherapists.

No discernible patterns could be detected in terms of those parameters. This might, at least partly, be attributable to the fact that the estimates provided of time in use were either unclear, or the claimed period was suspect respondents might assume that because the equipment was switched on all day it was always in use. If a particular practice wrongly claimed a full day's use this would result in a low estimate of spare capacity. Conversely, a respondent's under-estimation of how long 'visiting' staff like District Nurses usually spent on computers would be reflected in an incorrectly high figure for spare capacity. The time computers were reported to be used varied from the whole of 'the working week' to an estimate of 2 hours per week.

Although the situation was clouded by a lack of credibility for some of the survey responses, particularly where continuous use was indicated, reported ranges were similar for both the localities studied as shown below.

Warwickshire GP practices

Intensity of terminal showed no consistent pattern across practices in this locality. Spare capacity estimates ranged from 20% (a practice with 7 GPs and 17 terminals) to 97% spare capacity (a similar sized practice with 7 GPs and 19 terminals).

Leicester City GP practices

Intensity of terminal use for practices with no branch surgeries in the second location also showed no consistent pattern across practices. Estimated spare capacity for practices with no branch surgery ranged from 39% (e.g. practice with 5 GPs and 16 terminals) to 83% (i.e. practice with 5 GPs and 14 terminals).

Because a considerable number of responding practices had branch surgeries, this further complicated any estimation of spare capacity. Reported usage patterns for terminals in these branch surgeries proved particularly difficult to relate to the notion of spare capacity. In some cases, GPs and their administrative staff carried out limited sessions at the location so that the assumed working week of 37.5 hours was inappropriately high, although that could in principle have been adapted in the formula. In other cases, however, there was a reception facility available when GPs were at their other location(s) so there was potential access to branch surgery terminals. In the event, spare capacity for the practice as a whole was calculated by aggregating the figures for all locations. The range for practices with branch surgeries was similar to that for single location practices (40% to 92%).

Benchmarking GP practice spare capacity

Unfortunately, there are no reported norms for comparable organisations or businesses against which to benchmark these figures and identify whether reported levels of spare capacity (i.e. 20% - 90% plus) are unusual. However, it would appear that there is *considerable spare capacity* in many GP practice systems, even allowing for the fact that some of this may actually be due to inaccurate estimations of the time spent on computers by certain staff groups. In particular, bearing in mind that a conservative estimate was used for terminal availability (37.5 hrs per week), it would appear that practices have considerable *potential* for more intensive use of their existing IT terminals.

² The percentage spare capacity in a practice was calculated using the following calculation:

$$\% \text{ spare capacity} = \frac{[(\text{No terminals} \times 37.5 \text{ hrs}) - (\text{Total hrs terminals in use})]}{[\text{No terminals} \times 37.5 \text{ hrs}]} \times 100 \quad \text{..... } \textit{Equn 1}$$

Actual spare capacity was calculated by multiplying the total number of terminals by the % spare capacity.

4.4.5b Community Trust Spare Capacity

The concept of 'spare' capacity was particularly unclear in the context of Community Trusts due to perceptions of terminal 'ownership' through custom and practice. Interviews with senior officers in NHS community locations using the activity profiling tool identified that terminals were for team use, and in some cases had team support clerks/ administrators to do the processing for the field professionals. Also, terminals could only be used by staff when they were 'back at base' so usage was once again dependent on working practice, and this would be a crucial factor limiting actual use of any identified spare capacity. Some staff went into the office before starting their clinical rounds, others preferred to go back afterwards and therefore 'close' their day by data entry and any necessary computer use. As all these staff were predominantly making home visits and running clinics, any spare capacity identified at their home base when they were off the premises was likely to be 'notional' because it could not be taken up by other staff who were also undertaking similar field activities.

The complex activity patterns reported for Community Trust staff made it extremely difficult to estimate any 'spare capacity' in locations used by these staff. Difficulties in identifying spare capacity might perhaps be less following the planned introduction of new hand-held devices in Warwickshire, in which an individual's access should be clearer, although any spare capacity would not be accessible to others.

4.4.5c Social Services Spare Capacity

Social Services operated a similar pattern of team usage to that reported by NHS community staff and, whilst there was typically one terminal per two field professionals (in both Warwickshire and Leicester), any calculated spare capacity might once again be 'notional' if it occurred when the professionals were out of the office carrying out their duties. It was considered by the senior officers interviewed that one terminal per two professionals should support the custom and practice necessary for current usage, and that equipment could be made available for relevant applications on an 'as and when required' basis. Like Community Trust staff, some Social Services staff undertook their paperwork/ reporting at the beginning of the day before going out on calls and some before they went off duty. Although the metric of 1 terminal per 2 field workers seemed to be suitable for current applications activity, it was indicated that this was under review and any demonstrable request for increased equipment (based on increased workload or a larger range of applications) would probably be viewed positively without further investigation.

In conclusion, exploration of the 'informatics perspective' uncovered highly variable patterns of IT use and large differences in estimates of spare capacity. At the same time, this element of our research also highlighted that it is as critical (if not more so) to identify the information access and exchange use to which systems are being, and could be, put by professionals. Gaps between information provision and use on the one hand, and information requirements on the other, were therefore explored through surveys of professional groups in health and social care in the two localities.

4.4.5d Modifiers of Spare Capacity

The difficulties associated with identifying *useable* spare capacity were not only due to uncertainties in survey responses. The *notional* spare capacity calculated from these was modified or constrained by a number of factors, as subsequent interviews identified.

The capacity modifiers which we identified fall into three main groups and operate through various mechanisms as follows:

(i) Physical Factors

A number of physical factors will limit any uptake of notional 'spare capacity'. Considering a general practice location where many community staff work, as an example, these will include:

- *The location of terminals* - terminals are often tied to certain staff by virtue of their physical location. For example, terminals in GP consulting rooms or terminals on the reception desk are viewed as not available for other uses or users. Therefore, any notional spare capacity on these terminals would, in practice, not be useable by other users for other functions.
- *Multi-professional use* – access to terminals designated for multi-professional use may be constrained by the fact that most staff spend a considerable time in the field, thus limiting their ability to take up any notional spare capacity. For example, midwives, health visitors, district nurses and physiotherapists attached to a practice will not have their own personal terminal and are

also often physically removed while working in the field. This means that spare capacity will be difficult to estimate accurately from the 'time spent' claims for such multi-use terminals outside GP consulting rooms;

- *Multi-functional use* - the study did identify some end-user points as 'multi-functional', for example in the administration areas of smaller practices. However, the usage of terminals and different functions in such areas is *ad hoc* and covers activities such as practice correspondence, clinical audit reports and practice accounts. It may therefore be relatively difficult to identify consistent spare capacity in these areas.
- *Split practice site locations* – the existence of two or more practice bases (e.g. branch surgeries) with staff working across these may also limit uptake of any notional spare capacity. It was apparent that responses for branch surgeries were only indicative; these locations were either open at limited times, therefore the expectation would be that computers would not be available outside those hours to anyone; or only a sub-set of the staff were on-site at any one time. Therefore, although a three-doctor practice might have a branch surgery, it is unlikely that there would be three full time people on site against which to evaluate spare systems capacity.

(ii) Functional Factors

Even if staff can physically access a terminal, the actual use of any 'spare capacity' on this terminal may be constrained by other 'functional' factors. For example:

- terminals may be only capable of performing certain functions and unavailable for other purposes (e.g. the terminals on the front reception desk in a practice or dumb terminals);
- local policy on who is allowed to use terminals for what purposes (governed by password permissions and after what training) may act as a barrier to use of apparent spare capacity, as may privacy limitations for person-specific data and systems;
- staff may be reluctant to attempt any functions that are not in their main job requirements, or for which they have no specific training or capability, thereby limiting the activities carried out through certain terminals.

(iii) Organisational Environment and Emergent Factors

Changes occurring in the organisational and technology environment may also have a profound influence on the concept of spare capacity and any potential extended use of existing ICTs. Although the focus of our research was on *existing technology*, in reality the situation as first envisaged became further complicated during the period of the study because of changes in the environment such as:

- movement in both the supplier base and the applications portfolios they offered;
- acceptance of the Internet as a mainstream vehicle for information sourcing, communication and presentation in the NHS, and for communication of general governmental information to the public [www.Ukonline.gov.uk] demonstrated by statistics on general usage by the population [www.statistics.gov.uk].
- changes in policy affecting the propensity to share data and the means by which such exchange may be facilitated;
- organisational changes in deployment and co-ordination of technology, including the strategic environment;
- wider policy changes with an effect on Informatics perception, delivery and utilisation.

As a result, during the study the meaning of the term 'existing technology' also came to be challenged due to various changes, typically:

- ubiquitous technology had moved on from dumb terminals to PCs as end user access points for the same existing applications in both health and social care;
- the common generic basics of many organisations increasingly included Internet-enablement;
- portals were being introduced (using existing equipment) for a number of different applications from one end-user access point, as reported by Leicester Social Services.

Therefore, a further important (emergent) factor during the course of the study limiting the use and usefulness of any notional spare capacity was *Internet access*. Whether a terminal had access to the

Internet could also limit uptake of any notional spare capacity. This increased in importance as accessing information placed on the web or held with other users became more important, and more facilities were becoming portals to all the applications that were operational in a health or social care organisation.

4.5 CONCLUSIONS: INFORMATICS PERSPECTIVE

4.5.1 Inventory of Terminals and Applications

Providing a comprehensive profile of *existing* ICT configurations in different sectors in the two localities (i.e. an inventory of the number of terminals and types of applications available) proved to be problematic. This was mainly because of a lack of complete and up to date centrally held information. Any information that was available was usually based on historical data. Furthermore, over the research period all localities in health and social care had experienced changes to their systems, their organisations and, in some cases, their application supplier. Within this volatile setting, there was even less robust information available on *planned* equipment and applications. Both professionals and manufacturers reported that it would require considerable ongoing effort to record and update inventories to provide robust information, and this might not prove worthwhile.

Inventories are not in themselves a means of determining *how* the equipment is being used. An equipment stock-take can only provide information on availability. It cannot provide information on other important aspects such as: end-user access, Internet use, IT training, and associated privacy issues.

Thus, we concluded that there is no cost-effective way of producing a robust inventory based on existing data. Instead, we would recommend that a mechanism for maintaining the accuracy of the periodic inventories carried out for local strategy reviews (health and social care) should be devised in order to, as a minimum, provide a basic picture of what equipment is available for use. This should prove to be a more cost-effective strategy than the types of *ad hoc* survey undertaken in the present study. Furthermore, the usefulness of a detailed inventory of IT equipment is limited and the value of an activity profiling approach is increased under these conditions.

4.5.2 Profiling of Activity Using Electronic Data Capture

In order to consider the issue of spare capacity, or potential extended use of existing ICTs, it is necessary not only to record the types of IT systems available, but also important to gain some measure of the intensity of use of these systems (profiling activity).

From our results, it appears clear that determination of how equipment is used in different locations (e.g. GP practices, Health Centres, Social Services offices) using a systems monitoring approach (i.e. electronic data capture) is of limited value. Interviews with vendors and IT Managers in NHS and Social Services clearly indicated that the feasibility of developing a useful profile through scrutiny of transaction logs was limited. This was principally because systems reports could only be used to determine switch on and switch off times; and transaction logs only recorded transactions that altered data i.e. not enquiry or report transactions. Therefore, this approach would be unable to give adequate profile information on real-time usage.

4.5.3 Profiling of Activity Using Site Surveys & Interviews

A survey instrument (ICT profiling tool) was developed once it was clear that it would not be possible to analyse activity through direct systems interrogation. This profiling tool captured information on local configurations, ICT use and (indirectly) 'spare capacity' at specific sites through surveys and interviews. The findings demonstrate considerable differences in the number of terminals and their utilisation in different sites, indicating substantial apparent underutilisation of some existing terminals.

However, our findings also indicate that the concept of 'spare capacity' is complex. The formula we used to estimate this can, at best, only capture *notional* spare capacity, i.e. the time when equipment is not physically in use. It may not be sufficient to consider this as the sole constraining factor. In reality, the factors that limit *useable* spare capacity will consist of a complex mix of equipment at hand and availability of appropriate software applications, permission to use, personal competence, and local

policy (including financing of licences). The *useable* spare capacity available will be dependent on a range of factors that will further limit any *notional* spare capacity recorded. Even so, 'spare capacity' calculated using the activity profiling tool ranged from 20% to over 90% in individual GP practices.

A constant issue in both the health and social care domain was reported to be access to the Internet. During the course of the study Internet use had increased exponentially in both public use and the number of health-related sites. It had therefore become a viable medium for cross-sectoral data sharing, subject to privacy regulations, the strength of the protective firewall around sensitive procedures and data, the robustness of the 'service', and the commitment to broad band (fast) access in the near future. However, returns from our surveys and interviews showed that many existing end-user access points and potential users were not Internet-enabled.

5. PROFESSIONAL PERSPECTIVE

5.1 INTRODUCTION

The issue of ICT access by professionals and the use to which information systems are, or could be, put was further addressed through the development of a postal survey and interviews of professionals in the two locations. The research team held a number of initial meetings with health and social welfare personnel in each study site in order to explore existing inter-working and any emerging issues before survey and interview instruments were developed. In accordance with the action research methodology adopted, information regarding findings on the informatics context were shared with key stakeholders as the study progressed giving them the opportunity to comment on and clarify aspects of research findings.

Due to fragmentation of organisational knowledge, the research team also had to invest considerable effort initially in the development of networks of contacts across health and social services in both sites. This was necessary in order to identify, and gain access to, the relevant professional workforces providing services for older people and their carers. This ground work also proved invaluable in the design of survey scenarios (see section 5.2.1) and the development of questionnaire instruments relevant to the groups of professionals involved (section 5.2.2). It also ensured that appropriate health and social services professionals were included in the in-depth qualitative interviews (see section 5.7).

5.1.1 Methods Used

As discussed in section 4.5, it was not possible to produce real-time profiles of professionals' use of information systems or to explore the factors which limited use of any apparent spare capacity in different settings. There might also be sensitivity and privacy issues related to scrutinising the use made of systems for named old patients/clients. In order to avoid such issues, an approach focused on professionals' needs for, and use of, health and social welfare information in the context of caring for older patients/ clients was adopted.

Firstly, the project team developed a series of generic but realistic 'scenarios' for consideration by professionals working with the chosen client group. These scenarios were incorporated into a postal questionnaire designed to capture wider data on information needs, working practices, and experiences of information sharing. Some questions on access and (indirectly) spare capacity for particular professional groups were included in the survey. However, analysis of responses could only provide data at the professional group level; this could not be linked to specific locations (e.g. practices).

Next, emergent themes and comments provided by answers to open ended questions contained in the questionnaire were explored further through in-depth interviews (see section 5.7). This element of the research provided a breadth and depth of data [Huberman, & Miles, 1998], particularly in relation to the professionals' viewpoints on information technology use and information sharing in the context of inter-agency working. The emphasis in the questionnaire surveys and in-depth interviews was on identifying ways of optimising the use of information to provide benefits to patients/clients and to professionals working across boundaries. Issues involved in the provision of health and social care for older people could then be viewed from both perspectives [Murphy and Dingwall, 1998] rather than adopting a single and hence more limiting view.

5.2 POSTAL QUESTIONNAIRE SURVEY

5.2.1 Postal Survey Scenario Development

Scenarios were created as a research tool to 'prompt' professionals in their survey responses. The aim was to encourage the professionals surveyed to reflect on the realities of their practice, rather than encouraging questionnaire responses that reinforced 'social desirability' i.e. that respondents would over-report what they thought they *ought* to be doing regarding information sharing in the workplace, rather than what they *actually* did [Tourangeau, Rips & Rasinski, 2000]. These 'real-life' vignettes or scenarios were specifically designed to reflect commonly occurring or 'generic' situations encountered by professionals providing care for vulnerable people, especially those relating to older people.

Scenarios were also able to address the potential problems of patient confidentiality issues around possible use of real-case studies. Although our research plan allowed for the fact that the scenarios used would not necessarily be identical in both study locations, in fact the same scenarios were selected by staff in Leicester and Warwickshire.

In terms of existing and potential use of (shareable) information, the scenarios were designed to enable professionals to consider this in the context of ongoing support and care, as well as for emergency situations. The aim was to determine (among other things):

- what information is already available in such situations?
- who holds it and how is it accessed?
- what information would professionals like to have available?
- what access do professionals have to ICTs, and what forms of communication do they use?
- how intensely do professionals use computers, and how are they trained?

5.2.1a Designing the Scenarios

Scenario development included the researchers undertaking a preliminary review of the literature. Observations and documentation from the preliminary exploratory interviews were also included among the source texts. Other academics working in the area were approached for advice, and literature was sought and obtained that was unlikely to be available elsewhere (e.g. internal, unpublished reports, local documents). Using these various resources, the research team identified a number of possible topic areas considered to most accurately reflect 'situations of care'. The following topics were selected for potential inclusion in the scenarios, as most likely to reflect inter-agency professional issues regarding information sharing:

- mental health issues, related to ageing as well as those likely to occur at any age;
- acute illness and 'crisis' situations;
- underlying chronic health issues;
- financial issues;
- housing and adaptations to the home;
- support and the carer's perspective;
- hospital discharge;
- accessing social and health care;
- the journey through the care process.

Outline scenarios were developed with a careful focus on the 'user' and the individual's journey through the care process to tease out the explicit actions and information requirements of service professionals. Once the scenarios had been developed in outline form, they were extensively piloted with invited field workers and managers. Individuals were carefully chosen to represent the full spectrum of professionals involved in the provision of care. The views of both the 'non-technological' and the 'technology-rich' were canvassed both at this first stage of scenario development and in the later, validation stage.

5.2.1b Scenario Validation

A further process was undertaken to validate scenario relevance for both groups of professionals. Initially, health professionals' comments and suggestions were incorporated and then social care professionals were approached. Using this cyclical process, the scenarios were further refined into two examples meeting the main points identified from the literature and other resources. Any differences of professional opinion that emerged at this stage were discussed and debated with the research team until a consensus was achieved. Once a position of convergence and agreement was reached with both health and social care professionals, two scenarios were selected for inclusion in the questionnaire. The scenarios then underwent a final validation stage as part of piloting of the questionnaire. The final scenarios are summarised below in Figure 5.1 [see Appendix 3: Section 3 (A) for full text].

Figure 5.1: Scenarios developed for use in questionnaire survey

Scenario 1: ‘Coming home’. This encompassed issues relating to an inappropriate hospital discharge for ‘Gwen’, who suffers from chronic illness (diabetes), with an acute complication (leg ulcer). It included issues associated with accessing care (delay in hospital discharge information reaching primary care team), social issues (woman living on her own), carer issues (her daughter working full time), and housing issues (wheelchair access).

Scenario 2: ‘Developing crisis of care’. This focused on rural isolation and the problems encountered by ‘Fred’ and ‘Jean’. Health and social problems included a complex mix of social, psychological and health related issues. The scenario focused on the lived experience of dementia (Fred’s problems with memory and his history of gradual cognitive changes), a developing health problem for Jean (recent diagnosis of angina), carer support (stress and symptoms of depression), rural isolation (living in a small rural community), housing (maintaining their home in the face of progressive illness), and accessing care (approaching an advice centre and ongoing health and social care needs).

For each scenario, questionnaire respondents were given a list of some of the main services that might possibly become involved. By listing likely services the research team aimed to help professionals reflect on cases they had dealt with personally and help them to think through any implications for information sharing in inter-agency working. The services listed included: primary care, district and community nursing, home help, physiotherapy, housing benefits officer, council tax, voluntary sector, counselling, and social services assessment care management [see Appendix 3: Section Three (A)].

5.2.2 Development of Professional Survey Questionnaires

The aim of the questionnaire survey was to capture, as realistically as possible, the reality of information sharing in inter-agency working. The research team was interested in *all* information sharing, whether it be ‘high tec’ methods, such as PCs, palm-tops and similar, or technology that is more commonplace (e.g. telephone and fax). The objective was to collect reliable and valid data from various professional groups involved in the provision of care for older, disadvantaged client/patient groups. The focus was on the ICT needs of professionals working across boundaries.

Although questionnaires have some disadvantages (i.e. the potential for a lower response rate than other methods such as interviews, inability to ensure target receives it or completes it) it was thought that the advantages to using a questionnaire in this study outweighed any potential disadvantages. These advantages included: less expensive than running large numbers of interviews or focus groups; possible to target a greater number of professionals; and greater anonymity for the respondent [see McColl et al., 1998, for detailed discussion of these issues].

5.2.2b Questionnaire Development

Questionnaire development involved the same iterative process used to develop the scenarios. Members of the research team held exploratory meetings with key informants in each locality. These meetings (face-to-face, by telephone and e-mail discussion) were undertaken to identify what inter-agency activity was currently going on in the location and to inform the professionals of the survey. This was an essential component of the research process both as an information gathering exercise and to plug into health and social care professionals’ expertise in each area.

The researchers also met other professionals and voluntary groups involved with care of older people (e.g. local housing initiatives, one-stop advice centre staff, adults’ community initiative for computing and web page design. Feedback and suggestions from these meetings were incorporated into the questionnaire. A provisional mapping of the information needs and preferences of different professionals was undertaken. It was recognised that some information might only be of use and relevance to one professional group or in certain situations. Differences in information needs could be recorded through the surveys, but a more important objective was to identify a core shared information set necessary to support professionals operating with the defined populations.

5.2.2c *Questionnaire Content*

The final questionnaire [see Appendix 3] consisted of four sections designed to capture information on:

- Descriptive and professional background, including whether professionals had a caring and/or management role (Section one of the questionnaire)
- Contact with other professionals and client/ patient group(s) (Section two)
- Accessing information to help clients/patients (Section three)
- Communication issues and information technology in relation to information sharing i.e. access to computers, data entry and data management issues (Section four)

Two versions of the questionnaire were prepared: one for health professionals and one for social services staff (incorporating minor changes in style appropriate for each professional group). A shorter form of the questionnaire was also designed to send out to home care staff/ home-helps. However, the research team established, during the consultation process, that these care staff and nurse auxiliary staff wished to complete the same version of the questionnaire as other staff. It was decided therefore to use the same questionnaire for all categories of health and social care professionals, apart from some minor adjustments to language (e.g. 'client' versus 'patient'). This would improve the representativeness and overall generalisability of the survey findings [Gomm, Needham & Bullman, 2000].

The research team paid particular attention to issues of design and the saliency of questions proposed to ensure that all professional groups would find the questionnaire acceptable. High priority was given to questionnaire layout and survey administration to encourage a good response rate [Oppenheim, 1992]. As well as a number of closed questions, the questionnaire included areas for personal free text comments. The code numbers for all completed questionnaires were also entered into a series of prize draws for department store gift vouchers (value of each prize £25) as a small incentive to encourage return of the questionnaires.

5.2.3 *Conduct of Surveys*

5.2.3a *Samples*

In each location the study needed to identify relevant professionals engaged in caring for older people. These individuals were located in co-operation with executive officers in health (community and primary care) and social care.

In Warwickshire, all 76 general practices were surveyed; the geographical area covered included North and South Warwickshire, but excluded the city of Coventry. Community health staff were accessed via the South Warwickshire Combined Care Trust; this Trust covered rural locations, likely to reflect aspects of isolation, as well as urban areas. In Leicester, community health staff dealing with older patients in City East PCT and all 31 GP practices were surveyed. The Social Services surveys in both locations covered all staff in teams dealing with older people.

Questionnaires to community health and social services staff were not mailed out directly by the research team to potential participants. Instead, the relevant management team officers acted in an intermediary role were asked to identify those members of their staff whose work involved caring for older adults and forward questionnaires to them. Completed questionnaires were returned direct to the research team. Therefore, unless respondents chose to reveal their identity to the research team (e.g. if volunteering to help further with the research) their identity remained anonymous. For primary care staff, the research team mailed directly to all staff (general practitioners, practice managers and practice nurses). The same approach for questionnaire distribution was used in Warwickshire and Leicester.

Using this approach, it was possible to survey a broad range of health and social care staff involved in providing care for older adults, both full and part-time. A total of approximately 1,452 staff were surveyed in Warwickshire and Leicester; this figure is an estimate since final mailings were performed by a number of intermediaries.

5.2.3b Method of Survey Data Collection and Analysis

Letters of support and endorsement from key health and social care management personnel were enclosed in each questionnaire mailing. These letters served to emphasise to the professionals concerned that their replies were anonymous and would not be seen by management. Information on the purpose of the study was also given. All questionnaires were mailed out with a pre-paid (freepost) return envelope. To manage the survey, and to monitor returns efficiently, the survey mailing was carried out in stages.

The first survey sample included all social care and health care professionals involved in providing care for older people across Warwickshire. Each professional group received *two reminders* for those members of staff who had not replied. With the second reminder, a further copy of the questionnaire was enclosed to encourage a reply. All participants were given the opportunity to formally opt out of the study.

In Leicester the research team sent out only one survey mailing. This was due to the shorter time frame available for follow up in this locality, and also the limited benefit observed from intensive follow up of non-responders in the first location.

To ensure confidentiality, and to monitor response rates, every potential participant was allocated a unique identifying number. A member of the research team, using a coding schedule, coded responses in returned questionnaires. This schedule was drawn up and agreed by the research team. Questionnaire responses were entered into a computerised software package and analysed using Statistical Package for the Social Sciences™ SPSS version 10 and SAS version 8. Any free text written comments were also coded and analysed using a content analysis framework. Data were checked for errors and inconsistencies and edited as appropriate before analysis.

In case those mailed had any queries, the questionnaire included the telephone contact details of a named member of the research team. Further information was requested by only a few respondents. When it occurred, it was usually due to personal interest (e.g. a nurse interested in the study for her personal research; a general practitioner volunteering additional information about a local project).

Questionnaire responses underwent exploratory data analysis using descriptive and inferential statistics [Tukey, 1977]. Results were analysed for three main staff groups (GP practice staff, community NHS staff, and community social care staff) and, where possible, compared. Although responses were initially analysed separately for the two locations, they were then analysed together in order to provide greater power when considering different sub-groups. Throughout, where differences between samples in the two locations reached statistical significance these results are reported.

5.3 SURVEY RESPONDENTS

5.3.1 Response Rate

A total of 686 completed questionnaires were returned. This gave an overall response rate of 47% across both locations although the true response rate was difficult to quantify since the research team received queries from professionals which indicated that staff had been wrongly identified by their management team as dealing with older people. Using an intermediary method to contact personnel inevitably meant that a percentage of professionals had received the questionnaire in error.

5.3.2 Description of Survey Respondents

5.3.2a Roles and Responsibilities

Respondents were asked to describe their job/ professional role. A breakdown is shown in Table 5.1 at three different levels of detail, ranging from the broadest professional grouping (level 3) to more detailed occupational groups (level 1). At level 3, responses were fairly evenly spread across the three staff groups; 212 GP practice staff (GPP), 222 community health service staff (HS), and 252 community social service staff (SS).

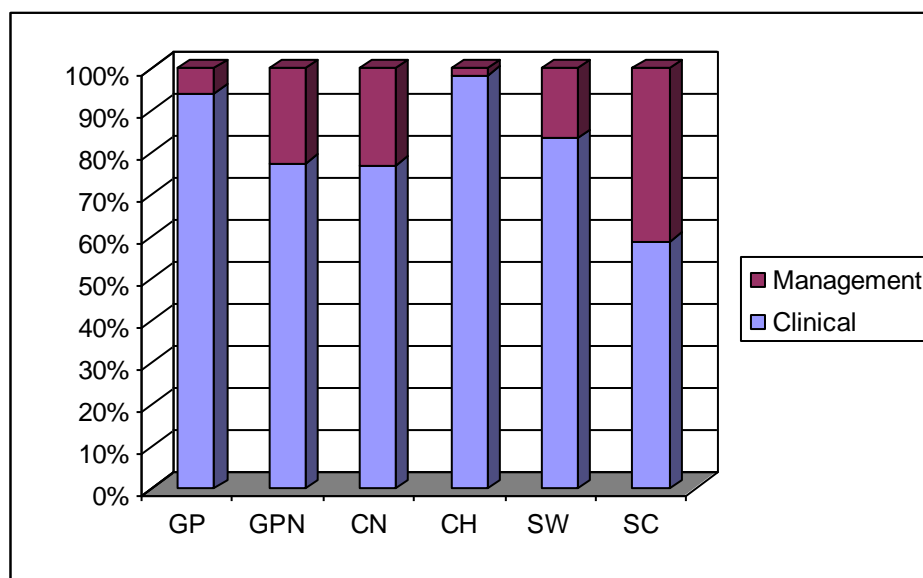
At level 2, community nurses (n=157) represented the largest group of respondents. These included district/ community nurses, health visitors, community psychiatric nurses (CPNs), and community hospital staff. A sizeable sample of practice nurses and managers (n=89) and nursing auxiliaries/health care assistants (n=65) also responded.

General practitioners represented the second largest professional group (n=123) at level 2, followed by social workers (n=90). The social worker category included a few hospital social workers (n=9) but were predominantly community social workers (n=81).

A large mixed group of 'Social care other' staff (162) included home care managers (n=43) and home care supervisors (n=44); community care officers (n=21) and social care managers/ team leaders (n=10); and occupational therapists (n=24), as well as related staff employed by Social Services. A small number of residential or nursing home managers (n=10) also replied.

All staff were asked to indicate whether their responsibility on a day to day basis was mainly patient/client-based or managerial. Figure 5.2 shows a breakdown for the six groups identified at level 2 (see Table 5.1). The community auxiliaries/healthcare assistant group (CH) reported virtually no managerial responsibilities. All the other groups included some staff with managerial responsibilities, although GPs reported the second lowest level of managerial responsibility.

Figure 5.2. Professional role: Respondents' responsibility



The respondents therefore represent a broad range of professionals working in the community.

Table 5.1: Breakdown of Survey Responses by Care Sector and Self-declared Role

Self-declared role	No	Level 1	Level 2	Level 3		
HEALTH SERVICES: Primary care staff						
GP	123	GPs	GPs 123 (GP)	GP practice Staff (GGP) 212		
Practice Nurse / Nurse Practitioner	73	Practice nurses	Practice nurses & Managers 89 (GPN)			
GP Practice Manager	16	Practice managers				
HEALTH SERVICES: Community Trust staff						
District nurse / Community nurse	65	Community nurse (general)	Community Nurses & Other community staff 157 (CN)	Community NHS staff (HS) 222		
Community nurse	46	Community nurse (general)				
Health visitors	12	Health visitor				
Community psychiatric nurse (CPN)	7	Community psychiatric nurse				
Mental health advisor	1	Community psychiatric nurse				
Community information officer	1	Information Officer				
Day hospital co-ordinator / manager	5	Community hospital manager				
Ward sister (Community hospital)	11	Community hospital nurse				
Ward manager (Community hospital)	9	Community hospital manager				
Nursing auxiliary (Community or hospital)	19	Nursing auxiliaries	Community auxiliaries/ assistants 65 (CCH)			
Health care assistant (e.g. day hospital)	46	Health care assistants				
SOCIAL SERVICES						
Social Worker	81	Social worker: Community	Social workers 90 (SW)	Community social services staff (SS) 252		
Hospital Social Worker	9	Social worker: Hospital				
Home care manager/care officer/review officer for home care	43	Social care manager: Home care	Social care other 162 (SC)			
Home care supervisor	44	Home care supervisor				
Home care assistant	2	Home care assistant				
Community care officer	21	Community care officer:				
Team leader / Manager	10	Social care management				
Management - Services for Older People	3	Manager: Older people				
Occupational therapists	24	Therapists				
Customer advisor	2	Advice/ information				
Community information officer	2	Information Officer				
Housing Officer/Housing Project Officer	1	Housing				
Residential/nursing home manager	10	Care homes management:				
Total	686					

5.3.2b Age, Gender and Experience

The 686 professionals in the sample were predominantly women; only 19% were men. Table 5.2 shows that the individuals who responded were highly experienced, especially general practice staff.

Table 5.2: Median number of years in job

	<i>Staff Type (level 2 – see Table 5.1)</i>					
	GP	GPN	CN	CCH	SW	SC
N	115	89	154	64	90	161
Median years	13yrs	10yrs	5yrs	4yrs	5.5yrs	4yrs

Respondents were mostly over 40 years of age, with a similar age distribution for healthcare and social care staff, as shown in Figure 5.3. Within health care there was little age difference between general practice and community staff, although a few GP practice respondents were older (over 60 years old) as shown in Figure 5.4. Younger respondents (less than 30 years) were principally social workers and home care or health care assistants.

Figure 5.3: Age distribution of healthcare vs social care respondents

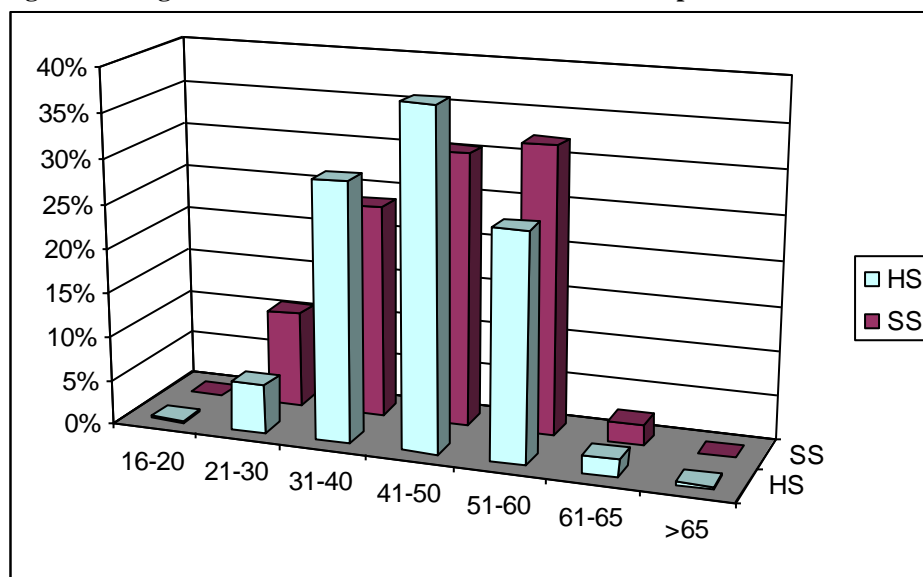
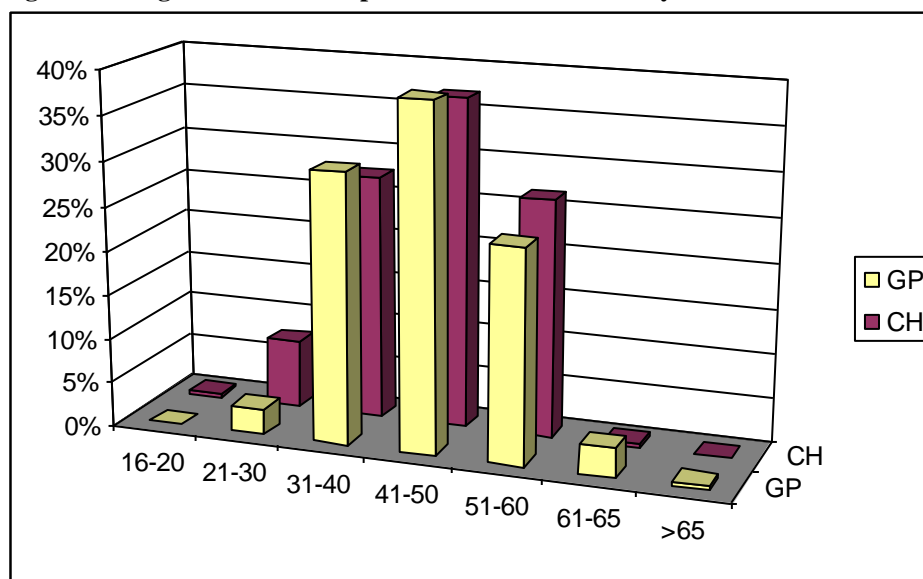


Figure 5.4: Age distribution of practice staff vs community NHS staff



5.3.2c Working Hours

A significant minority of respondents (41%) worked part-time. Women were more likely to work part-time; 94% of the men in the survey reported working full-time and only 51% of the women.

In GP practices, as would be expected nearly all general practitioners (80%) reported that they worked full-time. However, only a minority (19%) of other practice staff i.e. practice managers and nurses similarly reported working full-time. The majority of social care staff work full-time (70% of social workers and 74% of other social care staff). In the community, only half (52%) of community nurses worked full-time, and one third (29%) of nursing auxiliaries/ health care assistants. The mean number of hours worked by these part-time staff was 24 hours per week. This figure was similar for males and females (25 hours men and 24 hours women).

5.3.3. Working Patterns

5.3.3a Professionals' Workload Relating to Older People

Respondents were asked what proportion of their workload related to providing care for older adults (65 years plus); and whether this involved face-to-face contact with older people, indirect contact (e.g. in a management capacity), or both. For two thirds (69%) of the whole sample over half their work involved caring for older people; 55% reported that more than three quarters of their working practice was taken up with caring for older people.

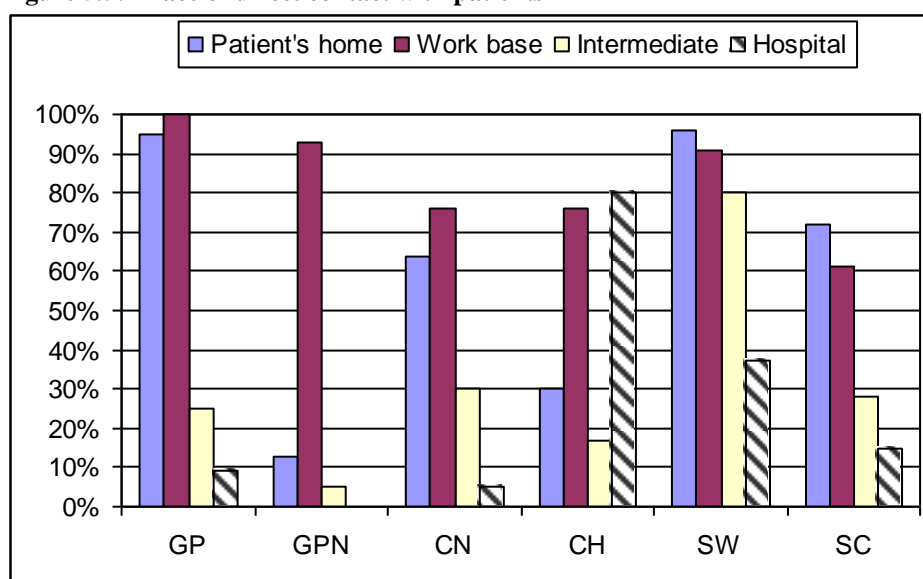
Examination of workload breakdown by professional group showed that GP practice staff were the group which served the widest age range; with very few (<5%) reporting that 75% plus of their workload was related to older people. The reverse was the case for NHS community staff – with most community nurse respondents (71%) and nursing auxiliaries/ health care assistants (89%) reporting that they were mainly working with older people. Similarly, half of the social workers (51%) and nearly all (85%) of other social care staff who responded spent three quarters plus of their time dealing with older people.

Thus, the survey proved to be well targeted and responses should represent the views of a broad range of professionals who spend their time working with older people in the community.

5.3.3b Contact with Patients/ Clients

Almost all of the respondents (99%) had regular contact with patients. Figure 5.5 shows the complex pattern of this contact for most staff groups. Only practice nurses and managers (GPN) reported contact with patients/clients almost exclusively at their main workplace. GPs reported contact in the patient's home as well as their workplace, as did social workers (SW). The latter group were also most likely to report contact in other intermediate locations. Community nurses (CN), community auxiliaries/ assistants (CH), and other social care staff (SC) also report contact with patients or clients in a wide range of settings.

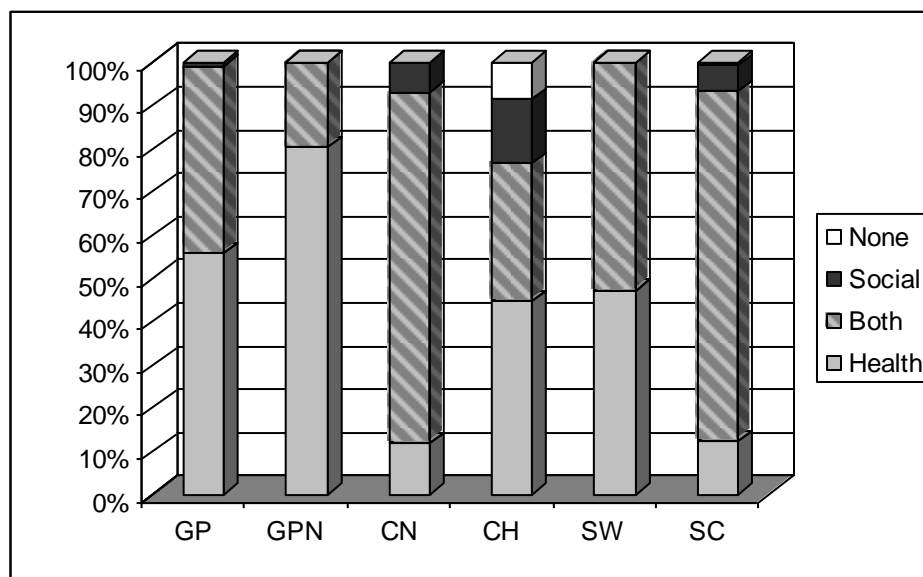
Figure 5.5: Place of direct contact with patients



5.3.3c Contact with Other Professionals

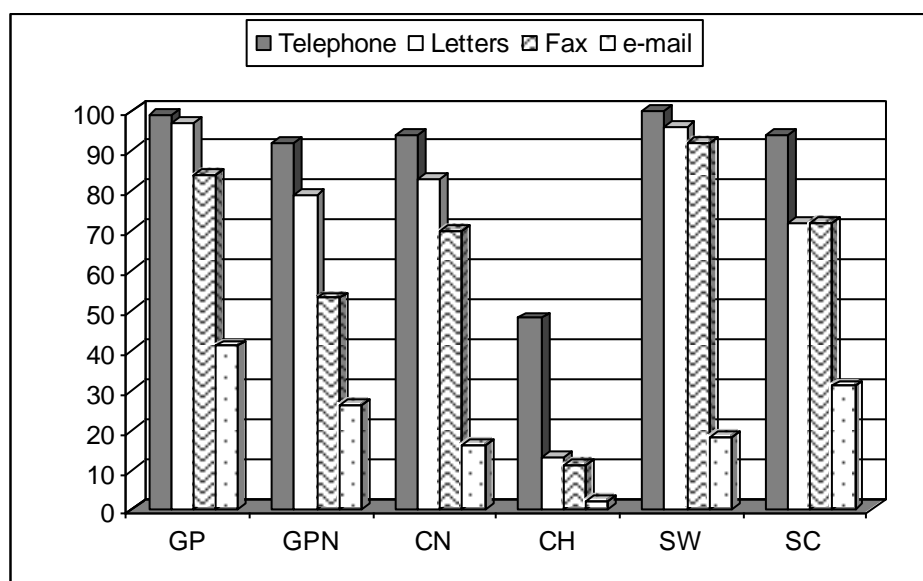
Respondents were also asked whether they worked in isolation or had **direct** contact with other professionals in relation to their own patients or clients. Figure 5.6 shows the groups with whom respondents reported face-to-face contact. Clearly, community nurses (CN) work predominantly with *both* health and social care staff, as do individuals in the social care other (SC) group. GPs, practice staff (GPN), and social workers (SW) appear to be slightly more isolated in their work patterns, with fewer than half reporting work across the health and social care divide. Only community nursing auxiliaries (<10%) reported no direct contact with other professionals.

Figure 5.6: Other professionals with whom respondents have face-to-face contact



Virtually all staff used non face-to-face as well as direct contact; means of indirect contact are shown in Figure 5.7. In all groups, telephone was the favoured form of contact, followed by letter and fax. Email was used by a minority of staff in all groups, with GPs the most extensive users (40%).

Figure 5.7: Means of non face-to-face contact with other professionals



5.4 IT TRAINING AND ACCESS TO COMPUTERS

In order to explore the ICT context for professionals, the survey collected data on what access different professional groups had to PCs, how they had been trained and their competence levels, and how intensely they used their computers.

5.4.1 Professionals' Self-rated IT Competence Levels and IT Training

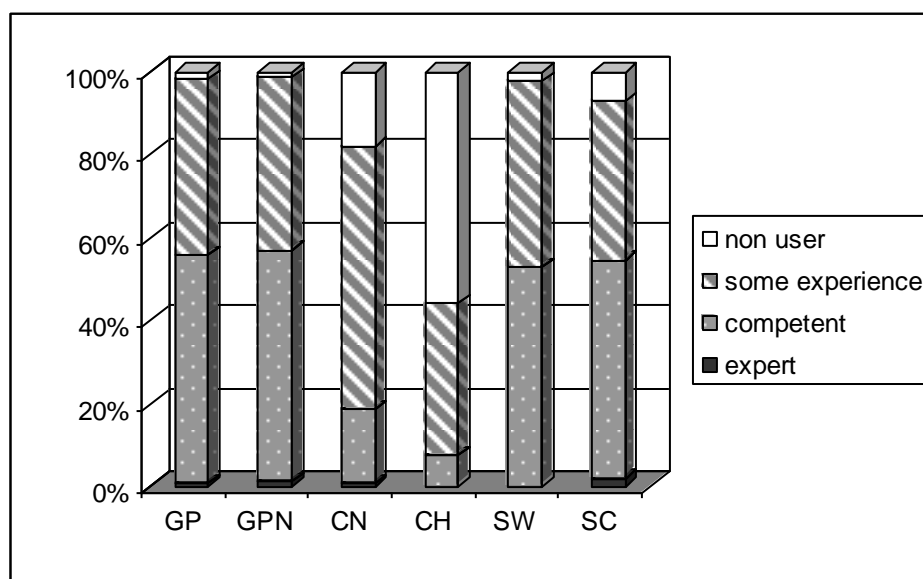
Professionals were asked to rate their own competence in the use of computers; 645 provided a self-rating for their 'ICT competence'. The rating categories professionals could use ranged from:

'Expert' \longleftrightarrow 'Competent' \longleftrightarrow 'Some experience' \longleftrightarrow 'Non user'

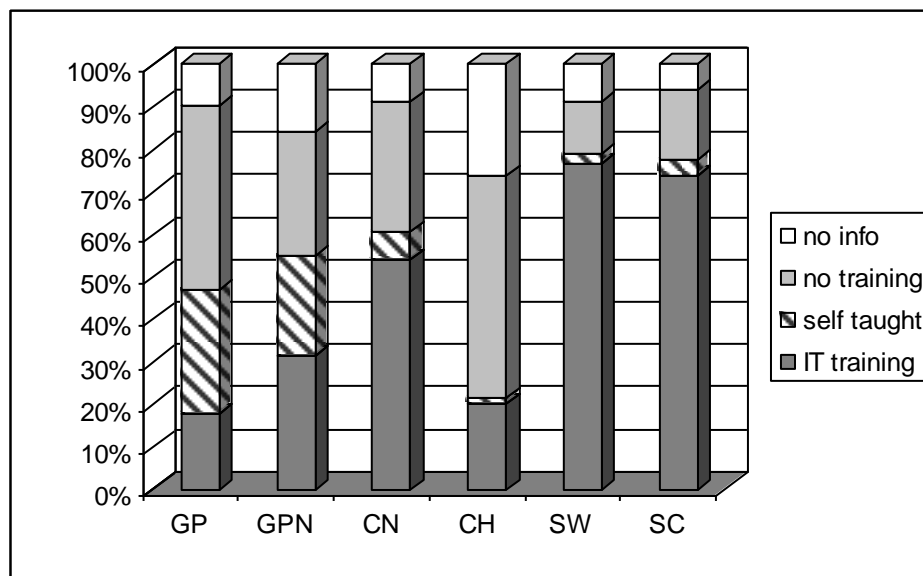
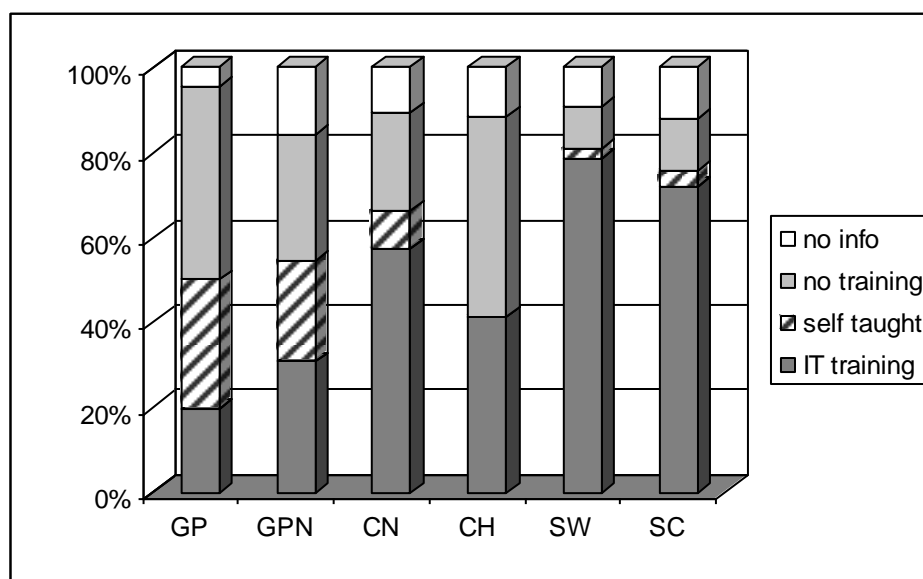
11% stated that they were 'non users' at work; just under half (46%) of the whole sample stated that they had 'some experience'; and 42% rated themselves as 'competent'. Only six professionals (<1%) considered themselves to be 'expert' users, these were either 'other' practice staff or 'other' social care staff.

Responses are broken down by professional group in Figure 5.8. This shows that, as might be expected, the main concentration of non-users is found among nursing auxiliaries and health care assistants (56% of these staff). However, nearly one in five community healthcare staff (18%) reported that they were non-users at work. In terms of their IT competence, generally just over half of all staff groups identified themselves as competent, except for community nursing staff (18% self-declared competent) and nursing auxiliaries/ health care assistants (8% competent). There was no difference in the declared competence levels of those staff who dealt mainly with older people (>75% workload).

Figure 5.8: Self rating of IT competence



Professionals were also asked about any formal IT training they had received, including the year and type of training undertaken. The results are shown in Figure 5.9. Clearly, social care staff record the highest levels of formal training, with very few reporting that they are self-taught. In contrast, very few practice staff reported any training, with large numbers being self-taught. Community nursing staff were more likely than practice staff to have received training, with relatively few self-taught. As might be expected, few nursing auxiliaries/ health care assistants had received IT training. If the analysis is limited to respondents who reported that they use a computer at work, then the pattern remains largely unchanged (see Figure 5.10).

Figure 5.9: IT training received by professional group (all staff)**Figure 5.10: IT training received by professional group (computer users only)**

Where professionals reported training this was mainly in the use of service packages, word processing, or database management. Only 4% of people reported training on Internet use, and 15% on use of email. There was no significant difference in self-rated competence between those who were self-taught and those with some IT training. Just under half of respondents (45%) who reported training had received this 'over three years ago'.

Some professionals who returned the questionnaire pointed out that their ability to attend training courses, if they were to be offered, was limited due to lack of courses that fitted in with their pattern of work (i.e. they worked shifts, or were working part-time). Another problem was linked to staffing shortages; if no one was able to provide cover for them, staff did not feel able to request 'time-out' to attend training.

5.4.2 Professionals' Access to ICTs in their Workplace

Staff were asked to provide information on their use of a wide range of information and communication systems, not exclusively focusing on computer use, in the course of their daily work. Categories were defined through earlier interviews with professionals to include use of the following in support of their work:

- Computer
- Palm top/Psion etc.
- Telephone/fax
- Day book
- Information kiosk
- Other (self declared)

Computer use was reported by the majority of respondents (85%), with 3% also reporting use of palm tops/ Psions. Only 15% of the sample said that they did not use a computer in their job. Almost all respondents (93%) reported use of telephone/ fax, and the vast majority (88%) used a day book/ message book. Only 4% reported use of an information kiosk.

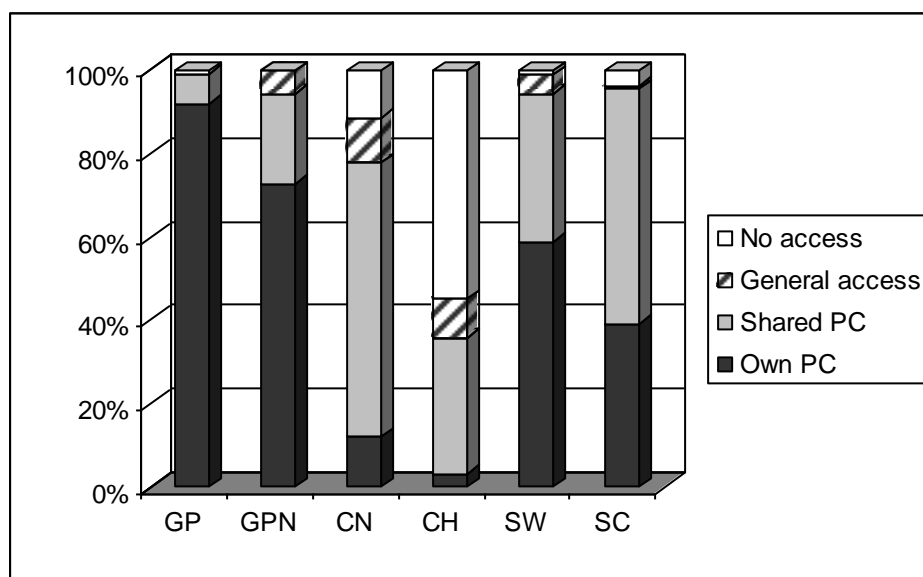
Respondents were also asked to provide data on any work-related use of a computer at home. The highest levels of home use were reported by health professionals with 67% of GPs, 60% of other practice staff and 47% of community healthcare staff using a computer at home for work-related tasks. Far fewer social care staff reported using a computer at home for their professional work; only 33% of social workers and 28% of other social care staff.

5.4.2a Professionals' Access to a Computer and the Internet in the Workplace

Professionals were asked whether they have access to their own computer at work. If not, they were asked if they could access a computer shared with other members of the team/unit or ward, or a computer with general open access to all staff. Figure 5.11 shows responses for different staff groups broken down by the type of access, with the remainder having no access.

Almost all GPs and two thirds of other practice staff reported that they had access to their own computer. In contrast, the vast majority of community nursing staff reported access to a shared PC. Fewer than half the nursing auxiliaries/ health care assistants reported access to a computer, as might be expected, and of those who did, the majority had shared access. Social workers (unlike GPs) did not necessarily have access to their own PC and other social care staff were even less likely to do so.

Figure 5.11: Reported computer access in the workplace

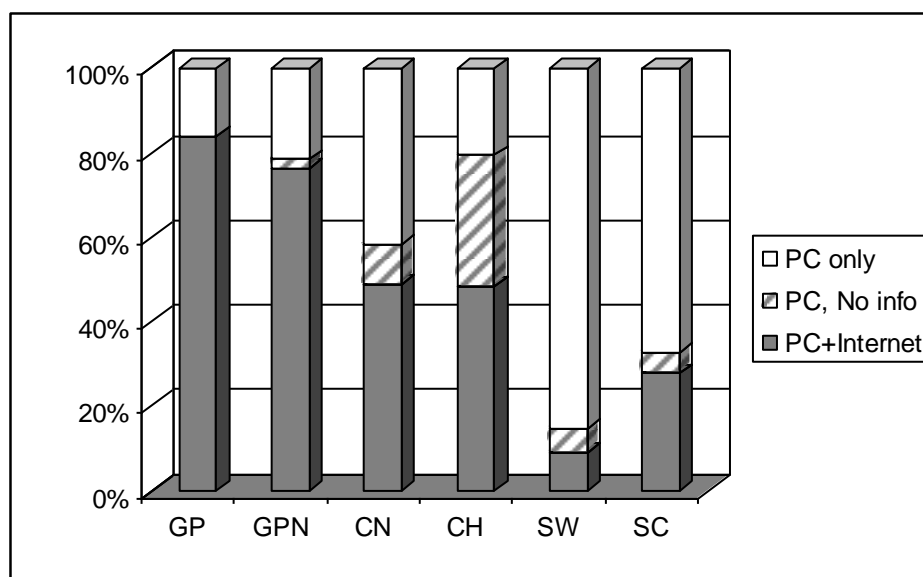


Staff who reported they had no access to a computer were asked whether they thought they would benefit from being able to use a computer at work. Twenty five out of 61 individuals with no access explained how they would benefit. Eighty percent of these (20) said they would like to have faster access to information. Almost half (11) said they would like to share information via computer, and 7 people thought they would benefit from having access to e-mail. Other benefits mentioned were the opportunity of using Web resources and equal access to information for all staff.

Staff who used a computer were asked whether this was networked. Computers were reported to be networked in 96% cases. The percentage was not very different for the various groups of professionals (from 90% for Health Care staff to 98% for Social Care staff).

However, there were distinct differences in terms of whether staff who have access to a computer are able to access the Internet, as shown in Figure 5.12. From this it is clear that primary care staff had relatively good Internet access, with few reporting PC only access. Social care staff (especially social workers) reported very limited (<10%) access to the Internet. In contrast, just under half of community nursing staff with access to a computer also had access to the Internet and so did a similar percentage of nursing auxiliaries and health care assistants.

Figure 5.12: Reported access to Internet in the work-place

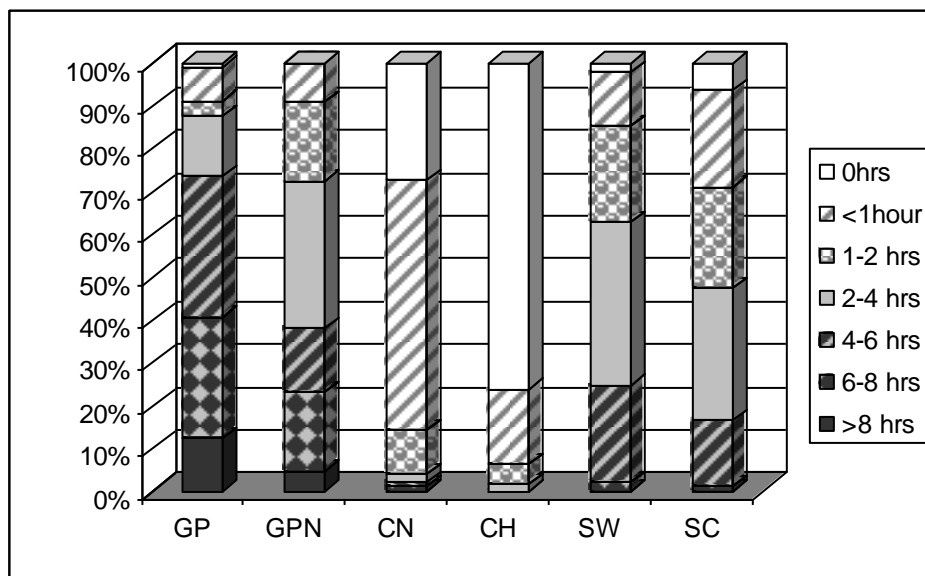


Even if staff who have access to a computer but are not PC users are excluded the number of professionals reporting that they can access the Internet remains high in GP practices, but low in social services. Just over half (54%) of community nursing staff who actively use a PC report access to the Internet.

5.4.2b Professionals' Hours of Computer Use and Functions Used

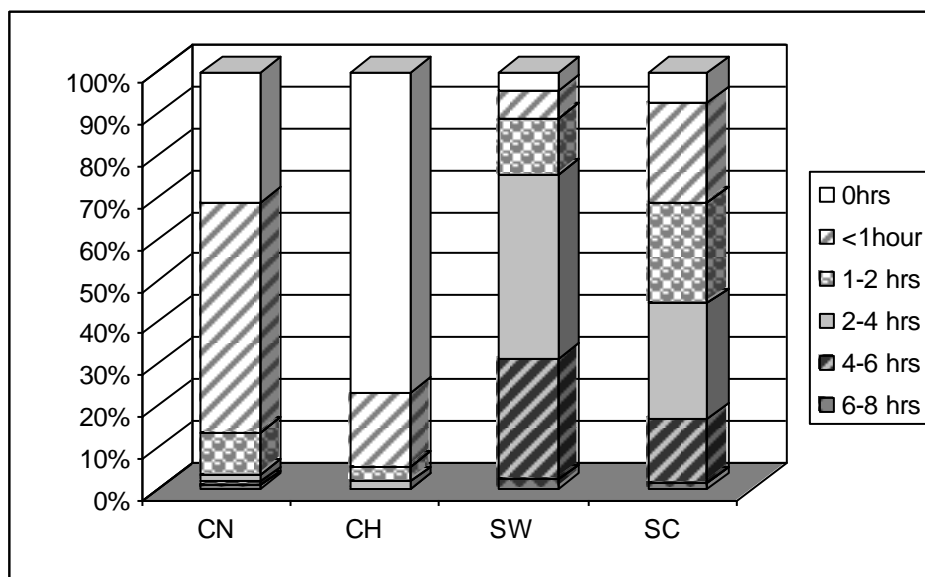
Professionals were asked how many hours on average they used the computer each day. Figure 5.13 shows that GPs are the heaviest users, with only 10% using a computer for less than 1 hour per day and 70% using it for more than 4 hours. The remaining practice staff (nurses and managers) are the second more intensive users. In contrast, community nursing staff spend very little time at a PC, with almost 90% reporting less than 1 hours use per day. Social care staff spend more time, but still only 20% use a PC for more than 4 hours per day.

Figure 5.13: Pattern of computer use by different professional groups

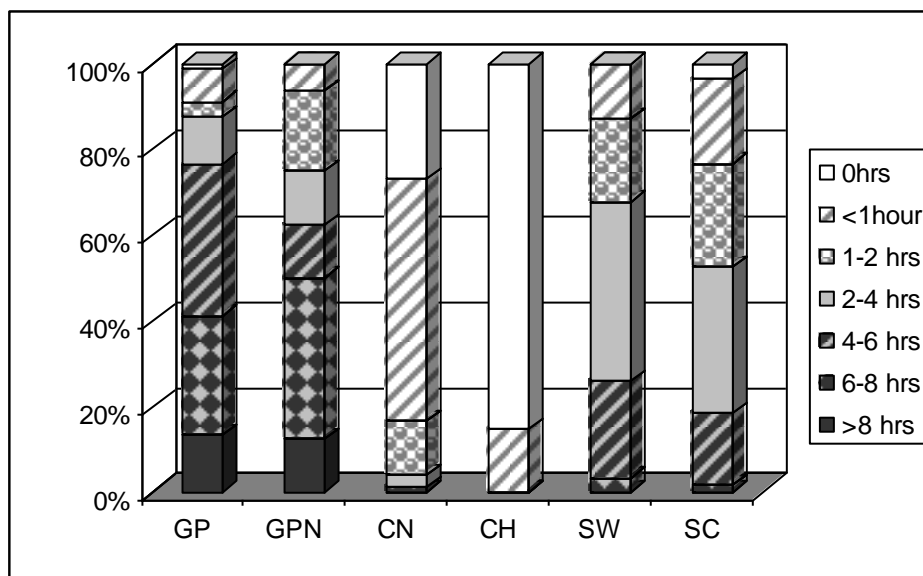


Daily hours of use for staff whose main workload is older people (>75%) demonstrate a similar pattern (see Figure 5.14). GPs and other practice staff (GPN) are excluded from this figure since very few fell into this category.

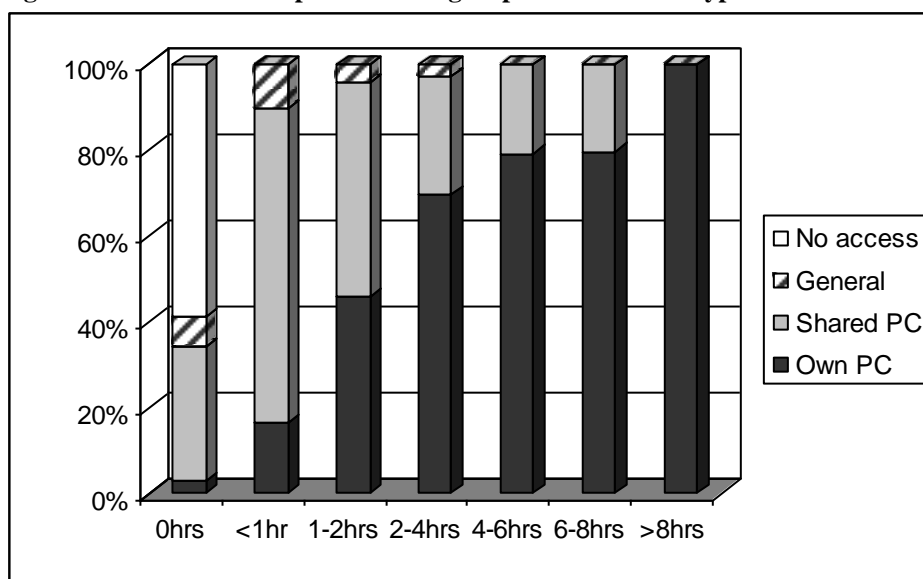
Figure 5.14: Level of computer use for dealing with older people (staff with 75% + workload)



It is possible that the low level of use reported by some groups is linked to the part-time nature of many appointments. However, Figure 5.15 shows that the pattern of computer use is virtually unaltered if full-time staff only are considered.

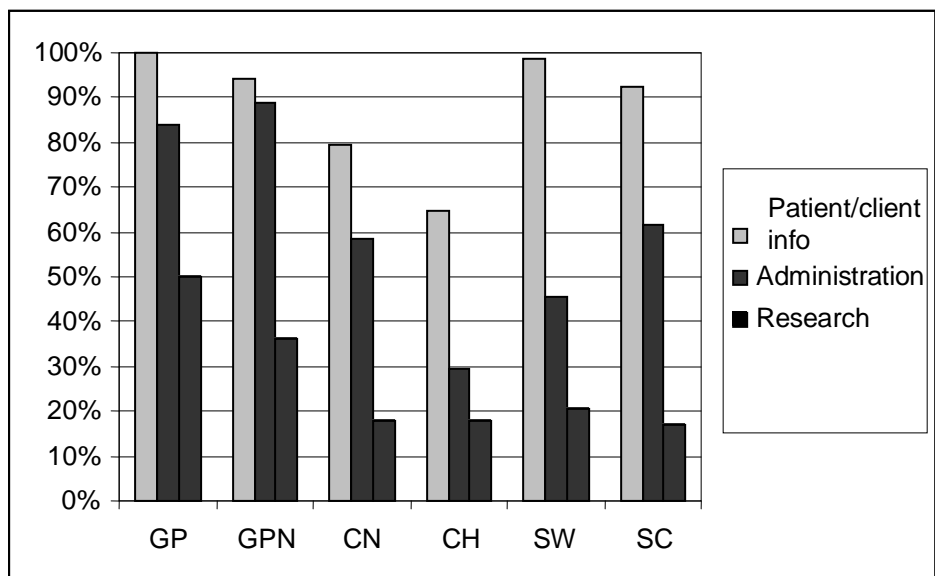
Figure 5.15: Level of computer use for professionals working full-time

It may be that hours of use are linked to whether individuals have access to their own computer. Figure 5.16 shows the daily hours of use versus the level of access that individuals report having i.e. own computer, shared PC etc. It is interesting that in the group of non-users ('0hrs') 41% report they have access to a PC. For other groups, there is a clear tendency for those who use the computer longest to have their own PC. Even so, a large percentage of those who use a computer for only 1 – 2 hours per day have sole access to a PC, reinforcing the suggestion of significant spare capacity.

Figure 5.16: Level of computer use for groups with different types of access

Daily hours of computer use may also be related to whether staff have a direct care role. Analysis shows that those providing only direct care spend less time using a PC and, as might be expected, those with a managerial element to their job use a computer more.

In relation to patient care, professionals were asked to identify the broad functions for which they used their computer system. Figure 5.17 shows responses, limited to people who use a PC at work. Three broad functions were identified: Patient/client specific data, Management/audit/routine administration, and Personal research. Other uses which were mentioned by professionals included 'e-mail' (4%), 'finance', 'CPD', 'Policy information', 'Patient leaflets' - all less than 1%.

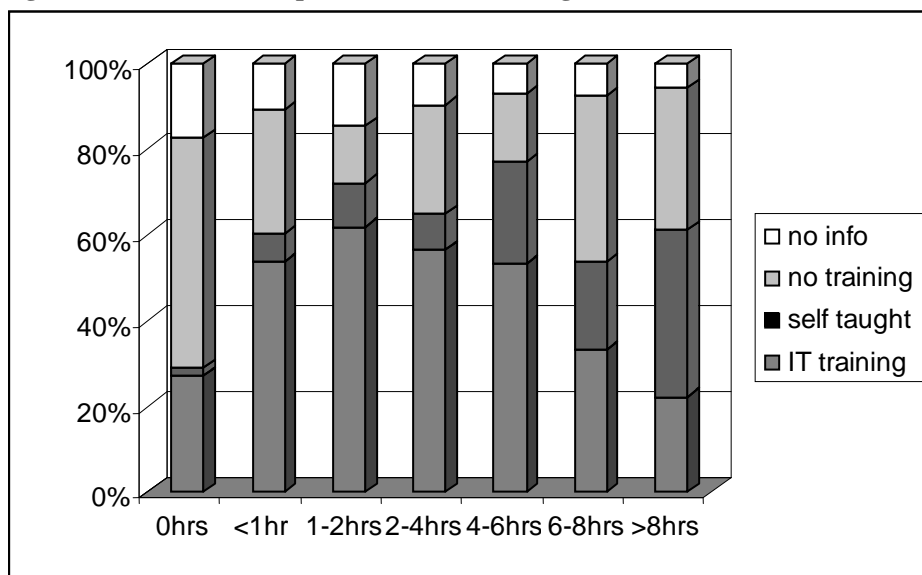
Figure 5.17: IT Functions used in relation to patient care


The percentage of staff in each group who are able to change data on the computer at work is high for practice staff and social care staff, but much lower for community nursing staff as shown in Table 5.3.

Table 5.3: Ability to Change Data on Computer at Work

	<i>Staff Type (level 2 – see Table 5.1)</i>					
	GP	GPN	CN	CCH	SW	SC
N	106	75	60	5	73	106
%	96%	86%	55%	33%	84%	73%

Finally, Figure 5.18 shows the type of training that individuals report having received versus their daily hours of computer use. Among people who currently did not use a computer in their work ('0hrs') 27% had received some IT training. This group recorded the highest percentage (53%) of complaints about the lack of IT training, suggesting that lack of training might be preventing many from using a computer. In the two heaviest user groups (more than 8 hours and 6-8 hours) relatively few are IT trained (22% and 33% respectively). Within both groups there were also relatively high numbers of complaints about the lack of IT training (33% and 38%). Furthermore, the most intensive user group ('>8hrs') contains the highest percentage of self taught professionals (39%).

Figure 5.18: Level of computer use vs. IT training received


5.5 INFORMATION ACCESS & SHARING IN SCENARIO SITUATIONS

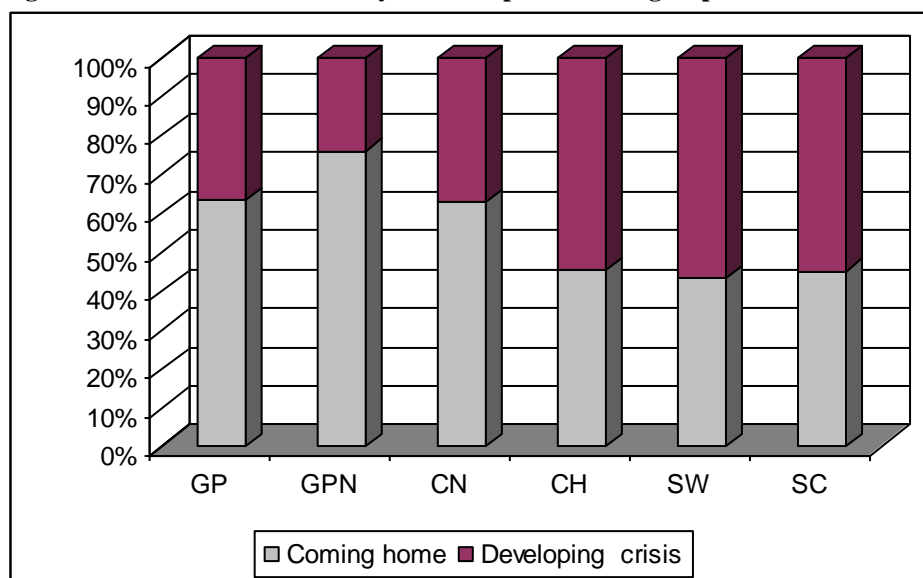
5.5.1 Choice of Scenario

The scenarios presented in the survey questionnaire were developed to help professionals focus on practical issues relating to their use of information and communication systems in complex situations of care. Overall, 637 professionals selected a scenario to use and comment on. Slightly more of these (56%) selected Scenario 1 (*Coming home*), with 44% of the group choosing to comment on Scenario 2 (*Developing crisis of care*). Three out of four professionals (74%) stated that they had personally encountered a 'similar situation' to that depicted in their chosen scenario in the course of their professional practice. A further one in five (20%) chose to use the scenario as a guide for their replies. Although the remainder (n=49) elected not to answer this question, some still commented on the situations contained in the scenarios.

Figure 5.19 shows that primary care staff were more likely to choose Scenario 1, with slightly more GPs selecting the 'developing crisis of care' (Scenario 2). Community nurses similarly predominantly chose Scenario 1. In contrast, nursing auxiliaries/ health care assistants and social care staff predominantly identified with Scenario 2 (the developing crisis).

Nearly all GPs (95%) and social workers (90%) had dealt with a situation similar to that described, as had 75% of community nurses and 85% of other social care staff. Practice nurses and managers (59%) were less likely to report direct experience, as were nursing auxiliaries/ health care assistants (53%). However, even in the latter two groups over half the staff responding could call to mind facing a similar situation.

Figure 5.19: Scenarios selected by different professional group



5.5.2 Access to Local Procedures or Guidelines for Scenario Situations

Respondents were first asked if they had access to any local procedures or good practice guidelines for a situation such as that described in their chosen scenario. It should be remembered that these scenarios focused on situations common in the care of older people, and therefore likely to be encountered by professionals working on both sectors.

Social care staff were most likely to report access to local procedures or guidelines, especially social workers (see Figure 5.20). In contrast, only a small minority of NHS staff who had experience of a similar situation ('experienced staff') reported knowledge of any procedures or guidelines. Even among community nursing staff (CN), who exhibit a working pattern with the highest level of cross-boundary working (see Figure 5.6), fewer than 1 in 5 reported knowledge of local procedures or guidelines.

General practice staff (especially GPs) were least likely to indicate that they had access to any guidelines. Interestingly, other staff such as NHS nursing auxiliaries and health care assistants were more likely to know of local procedures or guidelines. Examination of responses from respondents whose work mostly involves care of older patients/ clients (>75% workload), showed they were *no more likely* to report knowledge of any procedures or guidelines (see Figure 5.21). Data are not presented for GPs or other practice staff because of small numbers. A number of staff did not provide an answer, suggesting that they would probably also fall into the no access category. If staff had no personal experience of a situation similar to the scenario they were more likely to provide no response (29% vs. 5%, $p < 0.001$).

Figure 5.20: Access to guidelines in scenario situation

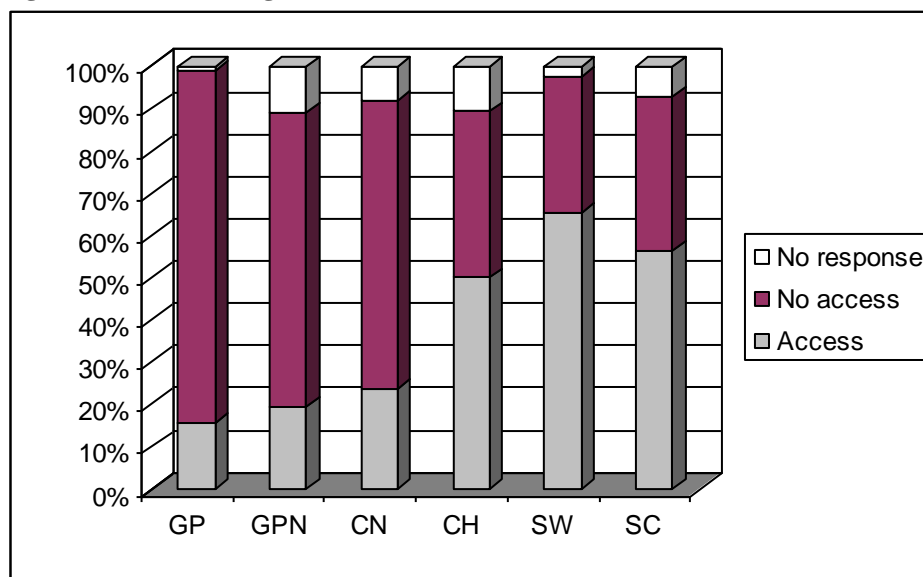
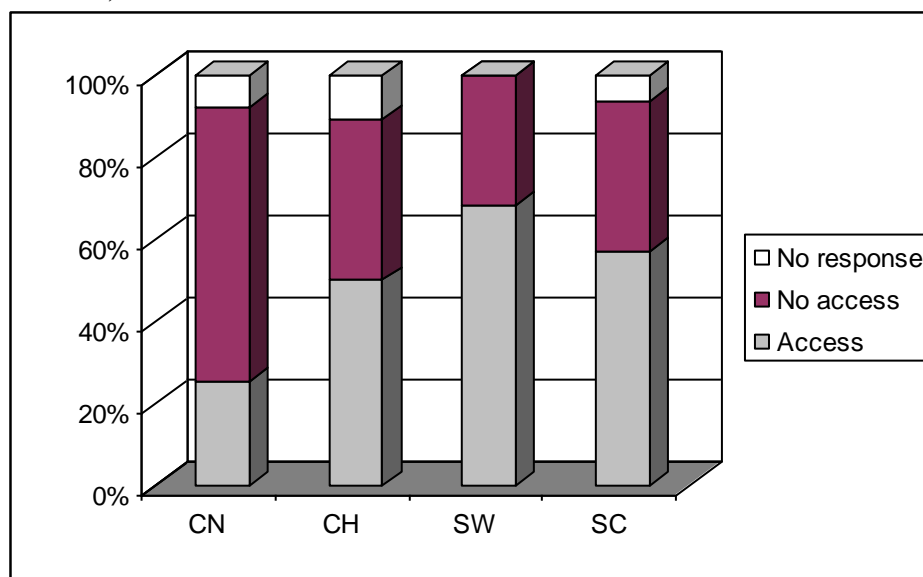


Figure 5.21: Access to guidelines in scenario situations for staff dealing with older people (75% + workload)



For the staff who did report access to information in the form of procedures or guidelines in scenario situations, 21 types of documentation were falling into 5 main groups (See Table 5.4). The main means of accessing this information were via: hard copy; PC; intranet for social services; and telephone. Most procedures (62%) were accessed as paper copies. For this type of generic non-patient identifiable information only 34% were accessible via a PC-based or intranet system. A few documents (mainly policy) were accessed via telephone.

Table 5.4: Scenarios: Main types of documents and means of access

Type of documentation	<i>Means of Accessing Information</i>				Total
	Hard copy	PC	Social Services intranet	Telephone	
1. Procedure policy	30	25	9	5	69
2. Practice protocol	21	1	0	0	22
3. Assessment	23	21	6	1	51
4. Discharge	37	1	1	0	39
5. Carers	14	3	3	0	20
Total	125 (62%)	51 (25%)	19 (9%)	6 (3%)	201 (100%)

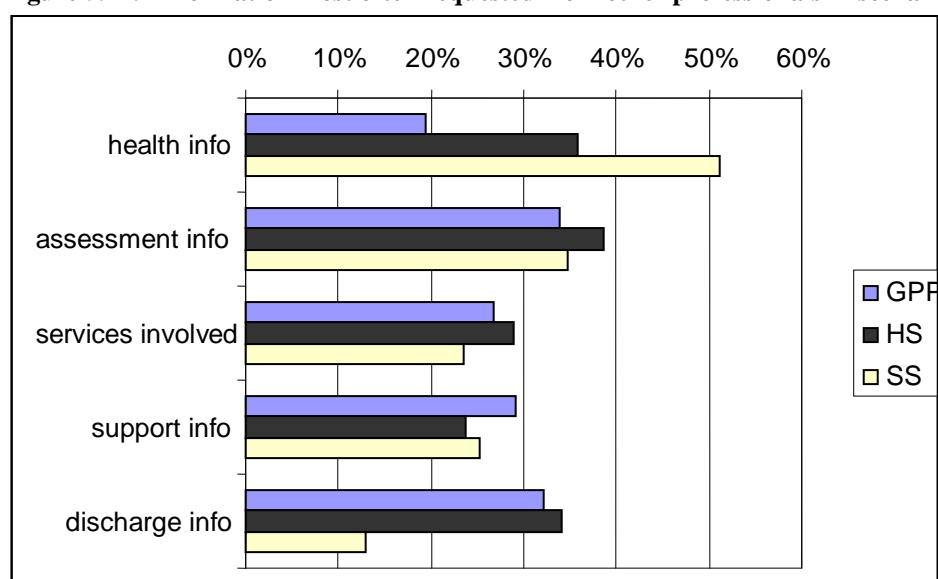
5.5.3 Access to Information via Other Professionals in Scenario Situations

As well as access to local procedures and guidelines, the questionnaire explored whether respondents had ever *asked other professionals for information* in a situation similar to that in their chosen scenario. Overall, 76% reported that they had, with GPs and social workers the two groups most likely to respond positively (see Table 5.5).

Table 5.5: Scenarios: Request other professionals for information

	<i>Staff Type (level 2 – see Table 5.1)</i>					
	GP	GPN	CN	CCH	SW	SC
N	97	47	116	7	84	127
%	88%	64%	75%	14%	93%	83%

When asked an open question about the type of information other professionals might be able to provide in such a situation, respondents mentioned up to 25 different types of information. These fell into 5 broad categories as shown in Figure 5.22, with only slightly different patterns of responses for general practice staff (GP), community NHS staff (HS), and social services staff (SS).

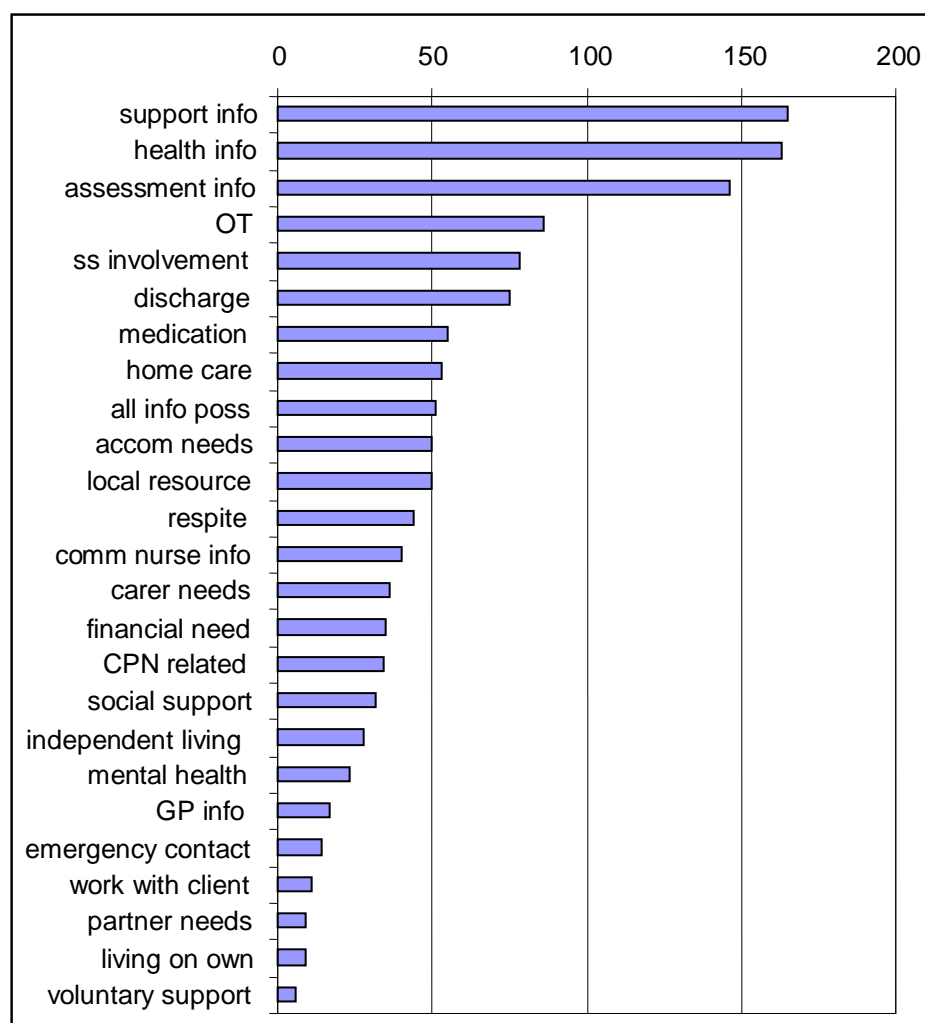
Figure 5.22: Information most often requested from other professionals in scenario situations

As would be expected, social services staff were more likely to request health information. GP Practice staff and community health staff were more likely to request discharge information. The three groups

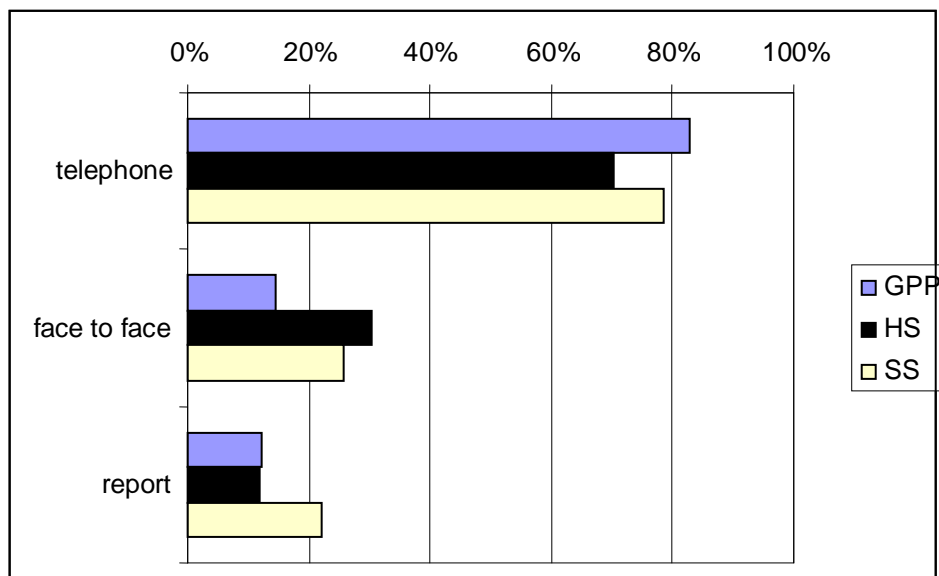
were equally likely to request information from other professionals on an individual's assessment, the services involved, and the home support available.

Individuals who had actual experience of needing to contact another professional in a scenario situation were asked what specific items of information they had requested. Responses covered a broad range of items which clustered into a number of categories (not necessarily mutually exclusive) as shown in Figure 5.23. More detailed information by groups of professionals can be found in Appendix 4 (Figure 1). The type of information accessed was similar to that prioritised by the group as a whole. In general, somewhat more social services staff identified having had to request information than did GP or community health staff.

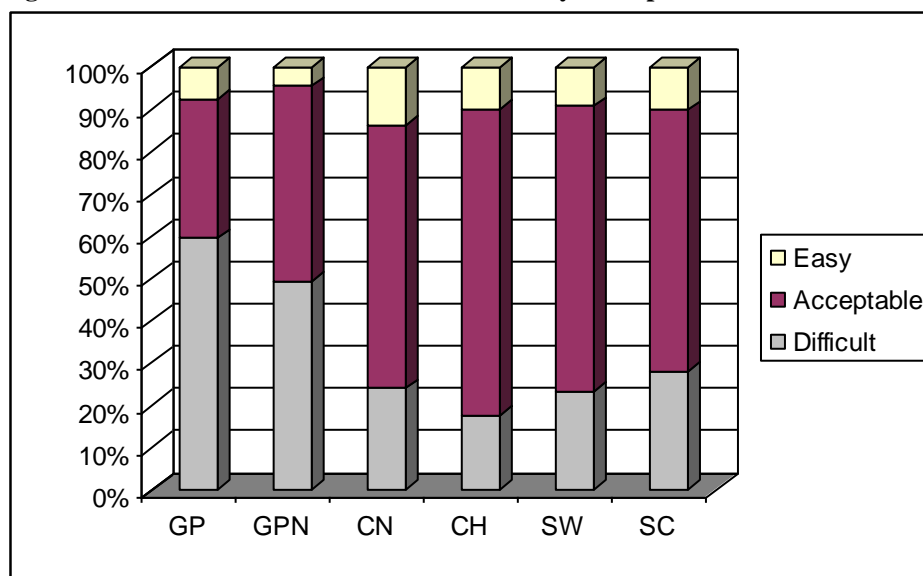
Figure 5.23: Types of information requested from other professionals in scenario situations



Respondents were asked what means they had used to access this information in a scenario situation. The means differed from those reported for accessing guidelines (see Figure 5.24 and Table 5.4). Information was most likely to be accessed by telephone, followed by face-to-face (particularly for community health and social care staff) or via reports (especially social care staff). In total, professionals reported 17 different means of accessing information from other professionals in a scenario situation.

Figure 5.24: The most frequent ways of accessing information in scenario situations

Respondents were also asked how easy it had been to access the required information in the scenario situation in the past. Figure 5.25 shows that only a very small minority (<10%) in each professional group reported that they had been able to access information easily. The remainder among social care and community NHS staff mostly considered access was 'acceptable' although not easy. However, problems were much more evident among general practice staff where 59% of GPs and 45% of other practice staff rated access to information as difficult.

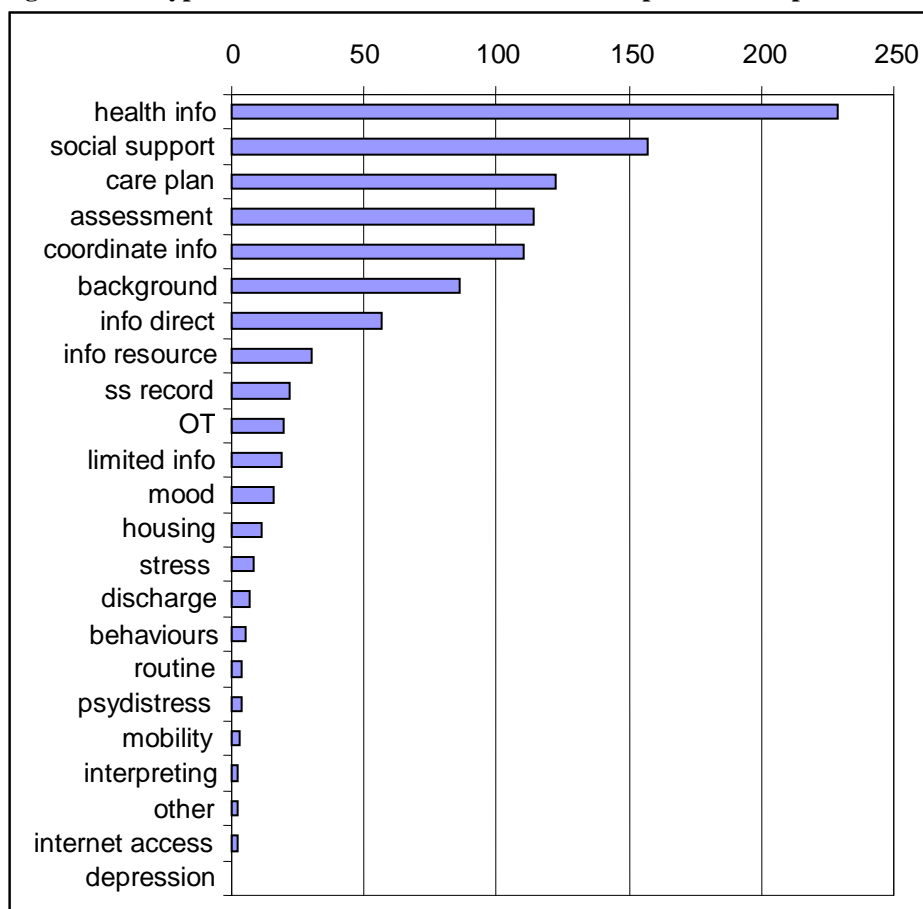
Figure 5.25: Ease of access to information held by other professionals in scenario situations

5.5.4 Sharing of Own Information with Other Professionals in Scenario Situations

As well as identifying what information they might need from other professionals, respondents were also asked to consider information sharing from a different perspective, and to identify what information *they themselves had* that other professionals might find useful in a situation similar to that in the scenario. Overall, 536 offered some response to this open question; the pattern of responses is shown in Figure 5.26. The detailed information by groups of professionals can be found in Appendix 4 (Figure 2). Although the open question categories do not necessarily map across directly to groupings in Figure 5.23, it is evident that social support information, health information, and assessment/care plan information are all requested and identified as useful by both those who hold this information and those who do not have access to it. Certain information was highlighted as needed in the scenario situations, but not identified as information held by respondents. Among others, this included

information on respite care, partner/carer needs, financial needs and emergency contact details. Potentially useful information held by some respondents but not requested in scenario situations included interpreting needs.

Figure 5.26: Types of information held that could be helpful to other professionals



Professionals were next asked whether they *could share* the types of information they held with other professionals in a scenario situation. The vast majority (91%) stated that they would be able to share the information about their clients / patients ('Yes' group); only 8% said that they were not able to share this information ('No' group). A further 1% of professionals considered that it would depend on the situation.

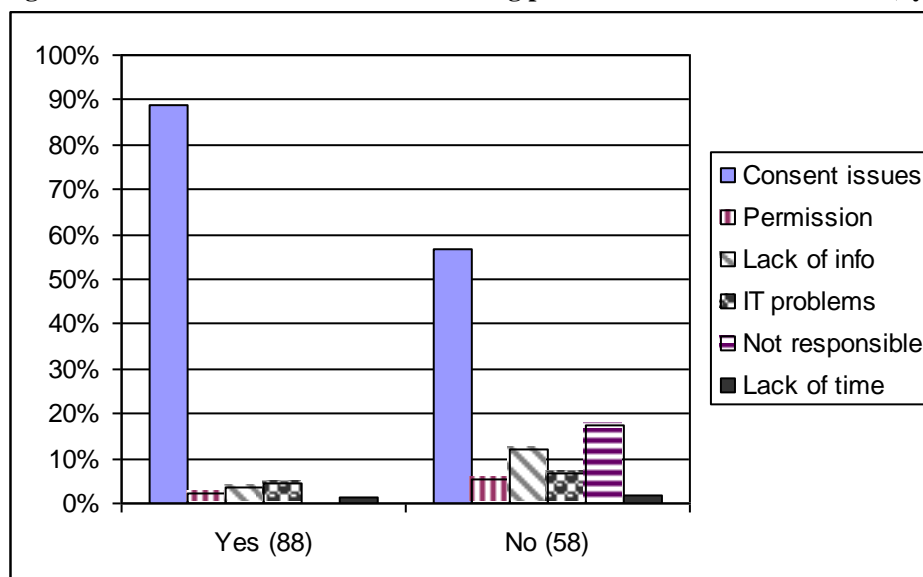
5.5.4a Reasons Why Professionals Unable to Share their Own Information in Scenario Situations

The issues around information sharing across professional groups were not as clear cut as might be first supposed. This became evident when professionals were asked to explain why they felt *unable* to share information. Although this question was targeted at the 'No' group (8%) of individuals who had said that they are not able to share information, 25% of professionals gave further information around their inability to share information in inter-agency working.

The vast majority expressed uncertainty around issues relating to *consent* (76% of this sample). 18% of the sample cited *factors linked to their work role* as reasons for being unable to share information in inter-agency working; these were either 'not their responsibility', 'lack of information', or 'permission needed to share outside professional group' (7% of the sample each for the first two reasons and 5% for the last). Only a small number identified *technical factors* as the reason why they could not share information with other professionals; 6% of the sample identified 'not being on the same information system'. Other work-related factors such as 'lack of time' were given as a reason by only ca 3% of the sample. The pattern of reasons given for being unable to share information differed between professionals who had stated that they felt *unable to share* information and those who had stated that they *were able to share information* in inter-agency working (although this sharing might be constrained). The reasons given by the two groups are displayed in Figure 5.27 for both the 'Yes' (able to share information) and 'No' (unable to share) groups. For both groups 'consent issues' were the main reason given. For those who had reported that they were unable to share, the second most

frequent reason was 'not responsible'. For those who reported that they are able to share information, the second barriers reported to have an effect was 'not on same IT system' (<10%). The first of these (consent) was significantly ($p<0.001$) higher in the 'Yes' than in the 'No' group. No-one in the 'Yes' group cited 'not responsible' as a reason.

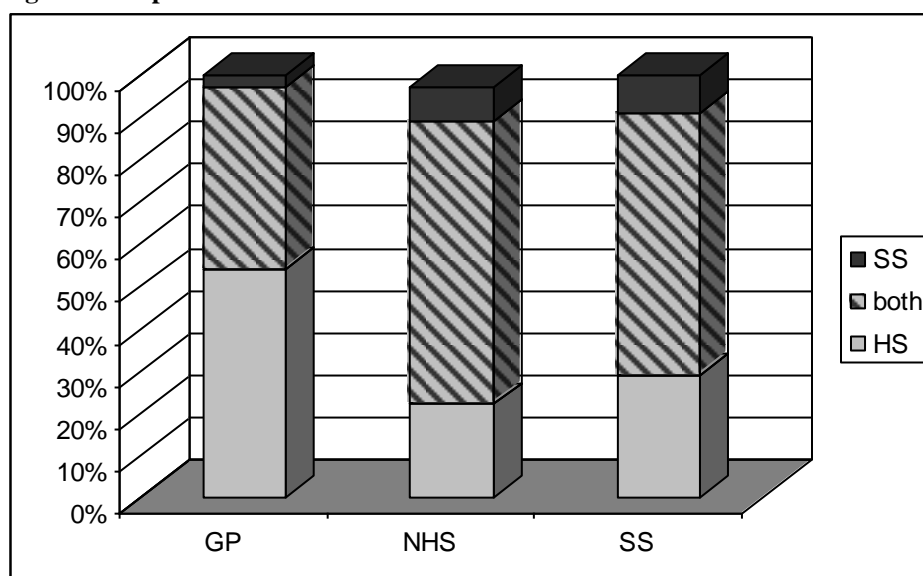
Figure 5.27: Reasons for information sharing problems in scenario situations (by able to share)



5.5.4b Types of Professionals with whom Own Information Shared in Scenario Situations

An open question asked respondents to identify those people with whom they had previously shared information in scenario-type situations. The pattern of responses in Figure 5.28 is shown separately for health care (HC) and social services (SS) staff, with the most frequently named staff being health professionals (including GPs, community psychiatric nurses, mental health workers, and hospital doctors); social workers; or therapists (OT and physiotherapy). Other groups mentioned less frequently, predominantly by social care staff, included voluntary sector, housing, care home staff, benefits agency and relatives. In terms of other staff, healthcare professionals were more likely to mention discharge or support teams. Only social care staff mentioned incontinence advisors, local authority staff, or police/ legal staff. Thus professionals providing care for older people have considerable experience of sharing information with a spectrum of other agencies. In this context, also, it is easy to understand why uncertainty relating to issues of consent would be the main constraint on information sharing.

Figure 5.28: professionals with whom own information shared in scenario situations

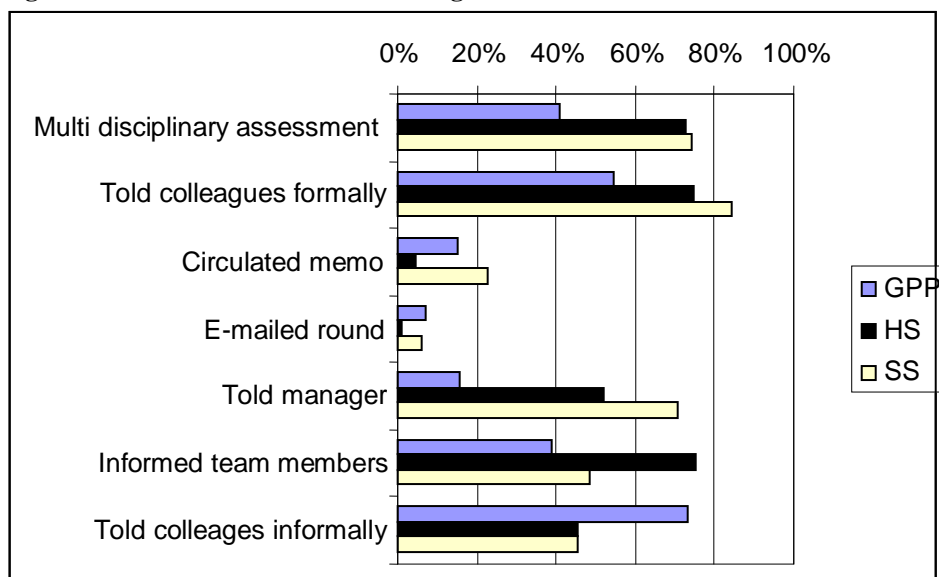


The extent to which professionals actually had experience of sharing information across the health-social care interfaces was also analysed. This showed that nearly every respondent in the social care sector (91%) reported some experience of sharing information with community health staff, but only 44% with GPs, and just under one third (31%) with therapists. Community health staff were slightly less likely to have had experience of sharing information with social care staff (67%), although the likelihood of information sharing with therapists was similar in both groups (38%). Interestingly, GPs were far less likely to report any experience of sharing information across interfaces in scenario situations - only 41% with social care staff and 11% with therapists.

5.5.4c Preferred Means of Sharing Own Information in Scenario Situations

When asked to identify how information had been shared with other professionals in a scenario-type situation, social care staff were most likely to report that they had told colleagues formally, fed information into a multidisciplinary assessment, or told their manager; informal communication with colleagues was less likely to be used (see Figure 5.29). Community health staff (CH) exhibited a similar pattern to social care staff, but were less likely to share information with a manager and more likely to inform team members. In contrast, general practice staff (GPP) most frequently identified that they 'told colleagues informally', this was followed by 'told colleagues formally' or 'multidisciplinary assessment' as a means of sharing information. All three groups were very unlikely to use emails or memos.

Figure 5.29: Preferred means of sharing information in scenario situations



If the analysis is confined to professionals dealing almost exclusively with older people (>75% workload), responses show that they were most likely in a scenario situation to have told a colleague formally (67%), shared information as part of a multidisciplinary assessment (62%), or informed team members or a manager (54% each). They were unlikely to have told colleagues informally (35%) and very unlikely to have used email (3%).

In summary, the preferred mode of communication for professionals in such situations is verbal. Very few identified written memos or email, especially among community health staff. Verbal communication is likely to be in the context of joint- or team-work, especially for those dealing with complex cases relating to older people and their carers. Health and social care staff were very similar in their responses with social care staff adopting slightly more formal or managerial routes.

5.6 GENERAL VIEWS ON INFORMATION ACCESS & SHARING

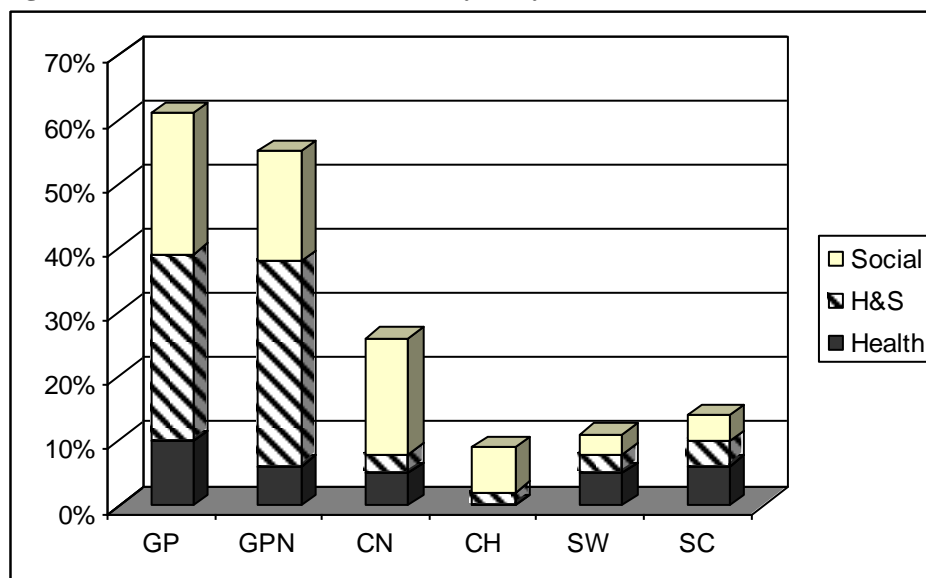
Having considered the scenario situations, professionals were finally questioned more generally questions about what type of information they would like to have available, and their experiences of sharing information on an inter-agency basis.

5.6.1 Key Areas of General Information Needs

Moving away from the scenarios, respondents were asked to consider a range of information that someone in their situation might need. A list was developed through interviews with professionals, voluntary groups and others involved with the care of older people [see Appendix 3, questionnaire]. For each item, individuals were asked whether they had information already or could find it if needed; required information but didn't know where to find it; or didn't require this type of information. The second category provided a measure of unmet need.

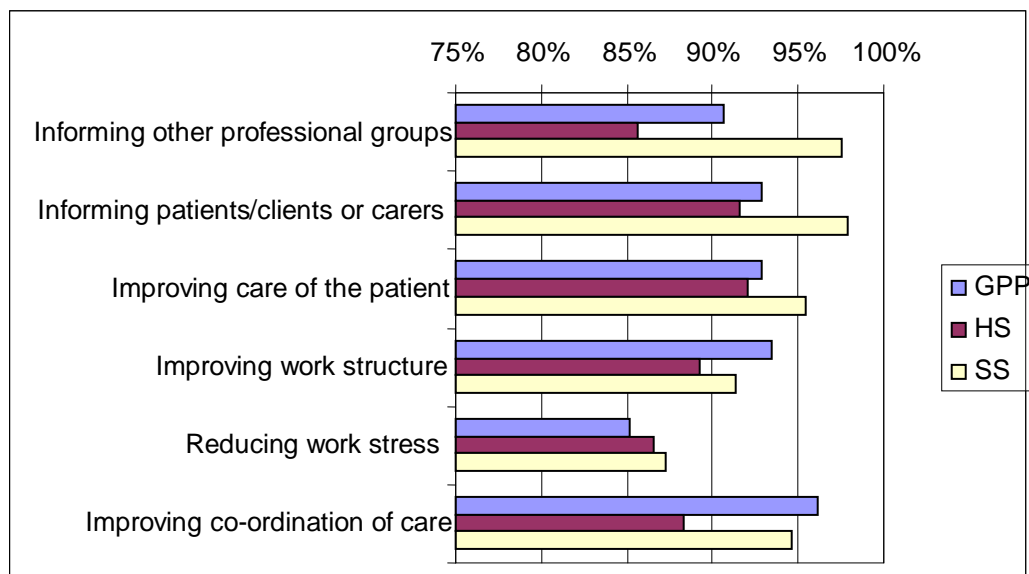
The level of unmet need for different staff groups is shown in Figure 5.30. The items mentioned by an individual was categorised as either 'All Social Care', 'All Health Care' or 'Both'. Clearly the staff groups reporting the greatest information needs are in primary care, with 60% of GPs and 53% of other practice staff reporting that they need information but don't know where to find it; the information needed is either all held by Social Care or both Health and Social Care staff. In contrast, just one in four community nurses reported information gaps, and these mainly related to information from the Social Care sector. Very few social care staff reported unmet information needs; fewer than 10% reported that they needed information from healthcare staff but couldn't access this. Thus, it would appear that there is a clear imbalance between the two sectors in terms of information needs, and that the gap is greatest in general practices.

Figure 5.30: Unmet information needs by likely source of information



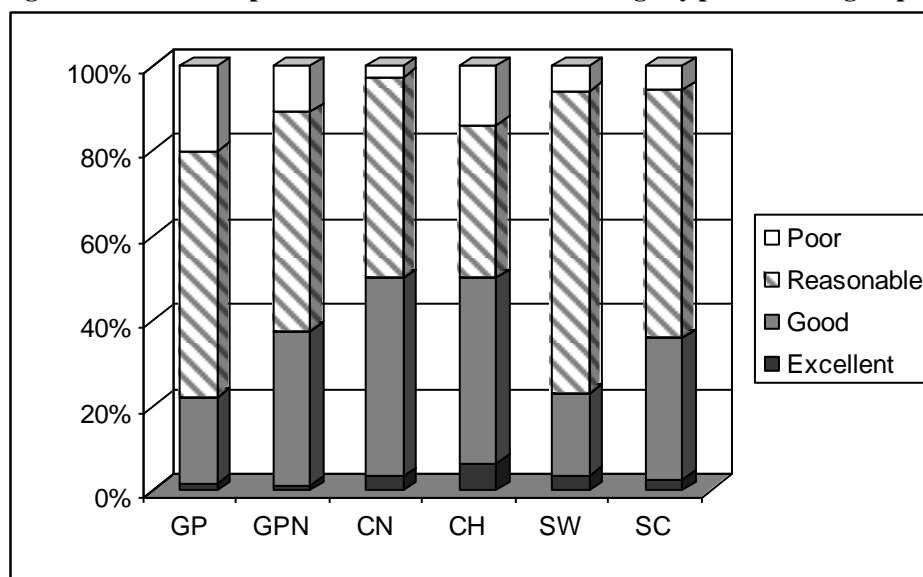
5.6.2 Key Areas for General Information Sharing by Professionals

Professionals were next asked their opinion on the main areas where they considered information could best be shared among professionals. This list was once again developed through interviews and items were clustered into six broad areas: 'informing other professional groups'; 'informing patients/clients or carers'; 'improving care for the patient'; 'improving work structure, better use of resources or time'; 'reducing work stress for self or colleagues'; and 'improving co-ordination of care'. The findings are displayed in Figure 5.31 for general practice staff (GPP), community health staff (HS), and social care staff (SS). Clearly, the perceived benefits of sharing information are high for all six areas, with little difference between staff groups, although social care staff emphasise informing other professional groups and patients/clients or carers more, whereas general practice staff are most likely to emphasise improving the co-ordination of care and work structure, and community NHS staff improving patient care and informing patients or carers.

Figure 5.31: Key areas for information sharing by professional group

5.6.3 Professionals' Overall Rating of Inter-Agency Communication

Professionals were asked to rate general inter-agency communication, in relation to different professional groups, based on their *own work experience*. The results are shown in Figure 5.32. Clearly GPs and social workers were least likely to rate existing communications as 'excellent' or 'good'. In general, community nurses and nursing auxiliaries/ health care assistants were most likely to report good communications (although still less than 50% of each group). Even though social workers did not rate existing communications as good, they largely rated them as 'reasonable' with few individuals reporting them as 'poor'. GPs were most likely to rate inter-agency communication as poor.

Figure 5.32: General professional communication ratings by professional group

The overall picture in terms of quality of inter-agency communication combined with unmet information needs (see Figure 5.30) indicates that practice staff report problems in accessing information and the quality of communication. Other groups such as social workers may give inter-agency communication a low rating but do not appear to have major unmet information needs (Figure 5.30).

5.6.4 Professionals' Reasons for Inter-Agency Communication Ratings

Respondents were asked to explain the rating they had given for inter-agency communication; 80% of the sample provided further information based on their own work experiences. Professionals gave a variety of reasons for their views. These comments were coded for content and categorised under two main headings:

(i) **Human communication related issues:** All the sample included comments related to this topic. These covered the following:

- Importance of networking and/ or knowledge of who to contact in the event of needing information. Importance of regular meetings between different professional groups
- Difficulties in contacting various professional groups – especially an issue with shift work and professionals working part-time hours / problems with delay of information reaching relevant professionals
- Time and persistence needed to communicate and gain access to information needed
- Some people could be 'protective' about sharing information / 'not my job'
- Communication hindered by conflicting priorities of professional groups
- Not knowing who is already involved/ duplication of working in practice
- Low morale
- Complexity of multi-disciplinary working in practice
- Records incorrect or people forgetting to complete forms
- Communication between primary care and secondary care (hospital) interface. Hospital discharge issues and concerns around discharge summary
- Communication systems and relationships with other professionals, both the negative and positive aspects of inter-agency work

(ii) **Technology related issues:** Only a small percentage of professionals (< 15%) provided comments related to technology:

- Too many different computer systems are in use and this is affecting communication across health and social care
- Computer system perceived as too complicated to help the professionals in their work
- Teams using different computer systems, even in the same professional group
- Other methods thought to be useful (e.g. greater possible use of fax) but professionals concerned about the problem of informed consent and confidentiality

Thus, the majority of issues impacting on inter-agency communication are human and organisational, rather than technology related.

5.7 IN-DEPTH INTERVIEWS

5.7.1 Introduction

In order to explore further some of the patterns emerging from the survey responses, a qualitative study was undertaken using in-depth interviews. It is acknowledged that, together, a mixture of quantitative and qualitative methods can play a valuable role in health services research [Barbour, 1999]. In the present study, by adopting this multiple methods approach, the research was able to use different methods to address divergent, complementary questions. In-depth interviews were utilised as a means of enhancing interpretability and to investigate more closely 'what is going on' [Robson, 1993]. These interviews examined professionals' views and lived-experiences of IT and of sharing information in inter-agency working across health and social care. In the large-scale surveys the focus had been an examining professionals' opinions about sharing information and the use of ICTs rather than discussing professionals' own experience.

The over-arching purpose of the in-depth interviews was to enable a further exploration of issues that could not be addressed by the use of survey methods alone but are considered to be of substantial practical importance. These issues were viewed from multiple perspectives rather than adopting a more rigid, and possibly more limited, approach [Murphy & Dingwall, 2001]. This is especially important in

complex areas of health services research such as studies exploring inter-agency working. The approach aided the development of greater understanding of this complexity and also helped identify where this research may 'fit' in current, and future organisation of service delivery for older adults and their carers [Banister et al., 1994; Monteagudo & Redondo, 2004].

Responses to the survey questionnaire and preliminary exploratory meetings conducted at the start of the project (Section 5.1) had provided evidence of both health and social care professionals facing challenges in their work in a rapidly changing arena. These impacted on attempts to work across the traditional professional 'boundaries' between health and social care, and influenced experiences of ICT use in the workplace. The in-depth interviews were conducted to provide further clarification of these issues, and other aspects such as the impact of service re-organisation taking place during the study, and the potential for more joined-up inter-professional working. Themes identified from the questionnaire responses were used to inform the in-depth interview schedule with the aim of enhancing and complementing the findings from the large-scale surveys [Gomm, Needham and Bullman, 2000].

The in-depth interviews also enabled a narrowing of focus and increasing depth of data analysis [Gantley et al, 1999; Huberman & Miles, 1998]. Furthermore, the 'mapping' of the survey findings with qualitative analysis of data from the in-depth interviews helped to ensure rigour in the research process [Henwood & Pidgeon, 1992] and could be considered to act as a credibility check [Elliott et al, 1999].

5.7.2 Interview Methods

A purposive sample [Robson, 1993] of professionals was selected and invited to participate in an in-depth interview. Individuals were sampled from across the data pool of professionals from two main sources:

- those identified from informal interviews with health and social care professionals in preliminary exploratory meetings for the study;
- those selected from the sample of survey respondents who had indicated in their completed questionnaire that they would be willing to help the researchers further.

The professionals selected were chosen in order to provide an even split between men and women (five men and five women) and across professionals working in health and social care. This also provided a cross-section of people involved in either direct or indirect care (or a combination of both roles) for older people (and other disadvantaged client/patient groups). The final sample therefore included:

- three professionals with a management/ indirect care role (executive officers either in the PCT or social care, including liaison with the PCT under the joint partnership initiative);
- four professionals whose work encompassed both direct and indirect care (e.g. general practitioners with PCT roles, care home manager with a 'hands-on' approach);
- three professionals with a direct care role: one working from a health perspective and two to provide the social care viewpoint.

A brief summary of the interview participants is set out in Appendix 5 (Table 1). All the interviewees gave fully informed consent. All professionals who were approached agreed to be interviewed, except for one person who withdrew due to serious family illness. This professional did still volunteer to help but the researcher considered it might be an intrusion on family circumstances and it was decided not to follow up. A professional from a similar category was then approached as a substitute to ensure a representative sampling frame.

An initial letter of invitation gave potential interviewees information about the topics that were considered likely to be discussed. The researcher followed up the initial letter by telephone to arrange an appointment date and time. This telephone call also served the purpose of offering the participant an opportunity to ask any further questions they might have. At interview, participants were assured that the usual conventions regarding anonymity would be observed. The interviews were audio-taped and participants were informed that they might have a copy of the audio-tape and also hard-copy of the interview transcript for their information after their interview. They were also offered the opportunity to comment on their transcript afterwards if they so wished. Two of the participants took up this offer but neither offered further comments nor wished to annotate their document.

The basic framework for the interview schedule is contained in Appendix 5 (Table 2). Themes identified as either problematic or needing further clarification were developed from the content analysis of respondents' comments in the questionnaire survey [Gillham, 2000]. These themes formed the basis for the interview schedule, although the discussions were not prescriptive and participants were free to talk about any issues they considered relevant to the study.

5.7.3 Analysis

Interview transcripts were analysed both for content and identified themes using an phenomenological methodology (Interpretative Phenomenological Analysis, IPA) [Willig, 2001]. Interview data were first categorised and shared themes identified from the texts. These themes were organised into clusters and the clusters further (re)-searched for patterns and connections. The transcripts were also examined for tensions, contradictions and inter-relationships between themes. Axial coding, a technique often associated with grounded theory [Strauss and Corbin, 1990] but also utilised in IPA analysis, was used to explore the relationship between the various conceptual groups. Thematic groupings were then organised into super-ordinate themes. The main themes to be identified from the data are set out in Box 1. Diagrammatic 'mapping' was employed to further facilitate the exploration of the relationships between thematic groupings.

Box 1: Super-ordinate themes identified from in-depth interviews

- ◆ **IT:** Using Information & Communication Technologies (ICTs) in health and social care. Sharing information.
- ◆ **Teams:** Inter-agency working. Team working.
- ◆ **Change:** Working in a rapidly changing environment.
- ◆ **Confidentiality:** Confidentiality in provision of care. Ethical considerations & practical applications.
- ◆ **Management:** Organisational issues.
- ◆ **Theory:** Putting theory into practice. Guidelines.

The elements incorporated into each of these super-ordinate themes are briefly summarised below. More detailed analysis and discussion of the interview data is provided in Section 5.8.

IT : The over-arching issue of the use of information and communication technologies in health and social care was incorporated with this theme. Interview content relating to *Sharing of Information* issues was also clustered with this theme. The theme also covered the challenges of IT use for joint inter-agency working.

Teams: This theme covered the professional and inter-personal aspects of inter-agency working across health and social care. It also incorporated issues involved with team working in the provision of care for older people more generally.

Change: This theme included both the challenges and the frustrations of working in the provision of care in a time of rapid change and re-structuring of services.

Confidentiality: All aspects of confidentiality were included in this category. It included the themes of ethics, stigma, provision of shared care, the potential advantages and (*dis*)advantages of the shared patient record, the electronic patient record and patient held records.

Management: This category contained such issues as 'strategy spotting' and best guessing where management would be leading next. It also included issues relating to new organisational structures and investment issues and funding.

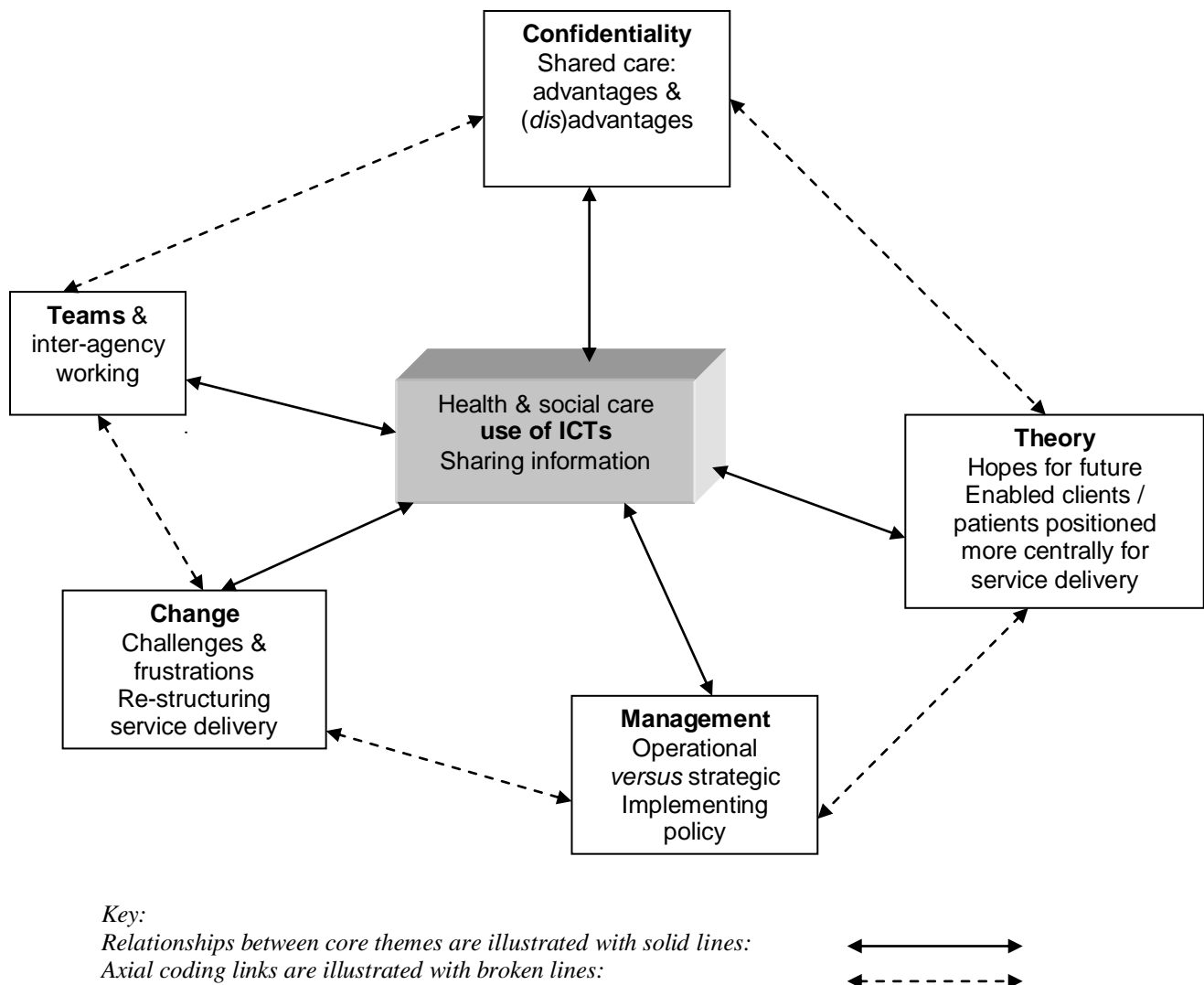
Theory: Hopes for the future with a more enabled client/patient group positioned more centrally for service delivery and local pilots, founded on evidence were included under this heading.

The categories and main themes identified by the thematic data analysis from the in-depth interviews are summarised in Appendix 5 (Table 3).

5.8 RESULTS: PROFESSIONALS' PERSPECTIVES ON INFORMATION SHARING IN THE COMMUNITY

The six super-ordinate themes described above had both positive and negative elements contained within them. Not all these super-ordinate themes were mutually exclusive, as there was some evidence of cross-fertilisation and shared linkages between themes, such that some themes might be considered to belong to more than one category. The themes and their inter-relationships, tensions and connections (identified from interview data analysis) are illustrated in the diagram below (Figure 5.33). *Confidentiality*, for instance, might be thought to link to issues relating to the development of the patient/client held health record but it was also an issue for the professionals interviewed with regard to the sharing of information, to enable better provision of care, via computer records.

Figure 5.33. Super-ordinate themes and their inter-relationships, tensions and connections



The issue of *Time* and/or the lack of time, professionals' usage of ICTs as taking them away from their patients/ clients, or their perceptions of too much to do and not enough time to do the work in, is another such example. *Uncertainty* is another theme identified from the interview data that showed evidence of cross-linkages. This could be thought to belong to both the theme of professionals' perceptions (or fears) of the *Use of ICTs / computers* in the work place and to *Confidentiality* issues relating to the sharing of information across and between health and social care professionals. With this proviso, as an aid to clarity, themes have been assigned to one main super-ordinate group. However, consideration of the inter-relatedness of identified themes and the fact that they are not mutually exclusive should be remembered.

The in-depth interviews yielded data that was both contextually rich and highly informative. It was noticeable that, for both groups of professionals, analysis of the themes demonstrated *more similarities than dissimilarities* between health and social care, although some difference of focus was identified over whether the professionals considered information sharing and the use of ICTs from an operational or strategic management perspective.

We next turn to a discussion on each of the main identified super-ordinate themes.

5.8.1 Information Technology (IT)

Contained within this theme were the categories of: Information needs; Sharing information with both the positive and negative aspects – the ‘Challenges’; the current usage of ICTs and future directions – the possibilities and professionals’ expectations; and the theme of ICTs as a potential enabler, rather than a driver.

Information sharing between professionals in health and social care was experienced as both a challenge and a frustration – both themes had also been identified from respondents’ comments in the questionnaire survey. Professionals reported having to struggle to manage information sharing in a rapidly changing environment, including their experiences of IT use. Both social care and health professionals reported an increase in computer technology being installed and / or upgraded with the professed aim of improving communication and providing better access to information. The professionals identified the need for improved information. This need included sharing data about clients / patients (e.g. patient files, case reports etc.), and accessing information or other resources that might be available electronically from intranet or Internet sites (e.g. general health information, protocols, information for patients and policy documents).

However, professionals also acknowledged that computer use was not without its problems. *Use of IT was especially problematic for those professionals based in the community*. Different reasons were uncovered such as:

- Access to the actual computer (e.g. for professionals working in the community who needed to travel back to their office to input their case notes; for those sharing computers).
- Access to IT training and being able to take time off to attend courses that fitted their working practice.
- Lack of understanding (whether due to the professionals’ understanding of what computers could do for them, or because of technical and management decisions which did not accord with the reality of professionals’ working practices).
- Perceived barriers between health and social care staff – although there was also evidence of innovative practice by some individuals who were committed to overcoming these cultural differences (this theme shows linkage with *Teams*).
- Time factors. IT rich and time poor. This related to professionals’ current workload and ‘traditional’ patterns of working that would need to become more flexible if computer use was to be more widespread and efficient. This theme is also connected to the theme of *Change*.

Some of these factors are illustrated by the following example from the data, where the professional, based in a PCT, acknowledges the challenge of supporting professionals so that they can work in a manner that both facilitates and maximises the perceived benefits of computerised working practices.

"Some of our practices (i.e. in primary care) have only recently i.e. within the last, sort of, six to twelve months been computerised. Now that doesn't mean they are *using* their computer – it means that they are 'computerised'. [...] It is very apparent that, although some of our (*location*) practices are computerised their notes are in a bit of a disarray. They are not exactly able to do the electronic audit at this particular point in time but need support to be developed to doing that." (*PCT professional*)

Contained in this extract are the themes of staff being provided with computers but, for whatever reason, not utilising them to optimum capacity. In this instance the reason identified relates to (paper) notes being in "disarray". This is a theme contained in much of the interview data since patient and client records had been collected in a variety of formats over the years. Professionals and managers were still in discussion as to what information they needed to enter into e-files and in what format any such e-information needed to be, prior to computer entry. In social care, the involvement of clerks in data entry was also contentious.

"Our recording is done on paper and scanned into the computer system by clerks so we can actually retrieve that on the system. That strikes me as being a very labour intensive system. So, a clinician will write all contact details down which are then passed onto somebody else who will scan it on to the system. Why we couldn't put it straight on to the system beggars belief. There's inevitably a time delay. [...]

They are proper forms but, again, they are scanned. So you fall into the same trap. Have you got all the information? Has it worked? Has the scanner done its job properly? Is it legible? - Because people's handwriting does vary. If there is a word there that isn't legible it is up to the clerk to make a 'best guess' attempt [...]

I think it's an interesting example of where IT is used, or attempts at using IT are being made. But it seems a bit of a cack-handed way really. It's not the most efficient way of using IT."

(*Social worker*)

This data excerpt also illustrates the theme of professionals' *Uncertainty* pertaining to issues relating to electronic records and the challenges and frustrations they experience in the re-structuring of service delivery (also evident in the theme of *Change*).

Issues arising from professionals' attempts to work across the traditional 'boundaries' between health and social care - what had been identified as the 'Berlin Wall' [Department of Health, 1998e], - were also seen as somewhat problematic by the professionals interviewed in this study. This theme has two components: discussion on developing an electronic patient record (EPR) and what might be included in the data set for an e-social care record (ESCR), or how a combined e-record for health and social care (EHSCR) might be considered (see, for example, Department of Health, 2001e). Apart from the technological challenges of developing any such e-record for the delivery of care, professionals identified issues *relating to the development of protocols for identifying data that is 'shareable'* between organisations as well as differences in terminology and professional philosophy.

"This is extremely complicated because the Social Services Department have just implemented a new computer system. However, the Mental Health team doesn't necessarily use it because we are, as a health team, we are driven more by the Health Service. Therefore, we are tending to use more Health systems than Social Services systems. Social Services system is driven more by financial requirements and records for statistical purposes that relate more to Child Protection and Child Care and Older People.[...]

So, a new system is being put in. We very rarely use it. We certainly don't use it for any of our reports or for any of our day to day work. The Health Service don't have any systems that would be appropriate to the work that we do. So, therefore, we don't use the information systems as we could do." (*Social worker*)

"In principle, particularly in relation to areas, groups like older people, where you want an integrated health and social care approach, of course there has to be a mechanism for sharing information and - this is something I have already mentioned to you - the NSF for Older People - we are expecting that to be taken forward. So the principles clearly are there. The mechanics of doing that are complex. Notwithstanding the fact that, where information is given for one purpose and to one particular set of providers, the use of it by another set of providers, or shared with others needs to be looked at very carefully (*PCT professional*)

Organisational use of computer technology for communication in the workplace is now well established and has much potential for further utilisation. However, the different groups of professionals reported varying patterns of computer use in addition to a workplace 'tradition' of limited communication with other professional groups.

"They don't get into our computers and we don't get into theirs"

(*Hospital social worker*)

Sessions are operated by separate organisations, you know, with health being in the NHS and the social care within the Local Authority. There are different systems, information collection, information storage - all the principles of Caldicott data protection apply to everybody - the way it is handled and managed is different. So, even at the practical end of sharing information, that's where there is going to be an issue about the technicalities of that. You get round the Caldicott issues and Data Protection issues, there's a, kind of, technology issue in terms of *how* the information can be shared." (*PCT professional*)

Elements identified on this theme centred on the conflicting interests and priorities of different professional groups, with their different education and training. Professionals, whether from the health care sector or social care, identified the *challenge of electronic working* and the need for improved skills and investment in staff training for successful deployment of electronic information sharing.

"Any system is devised by a person, and you have got to be on the same mind set as that person that devised the system. And I've spent many hours in the past looking for something but not going in the right direction - not looking for the right key words - and not finding anything. Whereas, if I had sort of thought a little bit more, or had been more in the direction of the way that the information was laid out, I would probably have found something a lot quicker." (*Social worker*)

Also identified here was the notion that ICTs could, paradoxically, demand more time, leading to the perception of there being less time available to the professional for the delivery of care for older people and other patient/client groups. It is interesting to note that the *professionals considered their experience of IT use as leading to a shortage of time*, rather than viewing the introduction of e-working as enabling or even time-saving. This theme was also contained in professionals' written comments from the questionnaire survey, thus providing further data triangulation from the large-scale survey to the in-depth qualitative analysis.

It was as if the introduction of computerisation was being seen as leading to time poverty rather than a time gain for professionals. This was a recurring theme contained in the data, whether viewed from the *resource angle* or from professionals' *perception of time* taken to use any newer technology e.g. in updating their records electronically. It would, therefore, be important to bear in mind that any investment in information technology needs to be introduced carefully since it may not always lead to an increase in productivity. This is recognised as the 'productivity paradox' [Macdonald, 2002].

"We're really into the electronic age - the age of the Internet and Intranet - that sort of thing, so I guess it is possible to disseminate information in that way. But that requires you to have time to be able to look, to fish around, and find what you are looking for and any system is only as good as the indexes it is probably working from. And if you don't know how to drive the system, so to speak, it could be very time consuming and you just give up in frustration." (*Social worker*)

The potential use of IT to inform professional practice and improve direct delivery of patient care was understood, but time pressures linked to administrative duties might prevent this and detract from care.

"It does actually take its toll in terms of the resources required to be able to fund (it). From the professionals' point of view there is an issue about professionals utilising the IT to their advantage both in terms of the delivery, the direct delivery of the service to patients, as well as keeping themselves well informed, as well as managing their own time. That is, sort of, the three strands to this because the professionals also, of course, have their own health." (*PCT professional*)

"I have noticed it's just paperwork, paperwork and, if you had to do every thing they wanted you to do, you would never get your head out of a piece of paper! That's not me - I would rather be hands on and make sure the people are looked after properly." (*Care home manager*)

Where health and social care staff *were* working together in teams (e.g. caring for older adults) the various professional groups had access to, and were using, the computer system in different ways. Methods and systems were not always compatible with other professionals involved in the team and were the source of some frustration, as was the question of access.

"I've said "Why can't the social worker who works for Rapid Access³, for example, intermediate care, why can't the social worker be employed by Social Services, so he or she is allowed to go into the Social Services computer system - have access to it. But because they are working, you know, for *health*, in a health team, they're allowed access to any health computer system in their office, or what have you." (*General practitioner*)

³ Rapid Access - a multi-disciplinary team offering rapid access to community care, managed by a nurse

"But then they're several years behind us with their [i.e. hospital] computer systems [...] They *do* put the patients on, who are on the ward, but they're not feeding the information in, in the same way we are. They're still writing in their medical notes and they're not putting it on the computer." (*Hospital social worker*)

"I think it is a longer time scale (sharing information) because, I mean, within the NHS we have had an Information Strategy - National Strategy for Information within the NHS - that has taken some time to be implemented within the NHS around information and information technology. So if we are looking at going across the health and social care boundaries then that is, I would imagine, an even bigger task." (*PCT professional*)

For health and social care, across both locations, computer use by professionals providing care for patients / clients was observed to be largely data-driven. Rather than looking to technology as a means of facilitating communication with other professionals and /or information sharing, the professionals saw computer use in terms of *feeding in information*. In locations where IT was used, professionals described computers as machines for data entry (e.g. inputting client information into a pre-designed, fixed response template), for audit and for monitoring by management.

There seemed little awareness, by staff, of how computers might facilitate improved working practice or optimise communication with their colleagues or with other groups of professionals. One participant summarised the professionals' situation from the primary care perspective.

"We've gone to computerised records. You can't get anywhere using the computer unless you're getting quality data onto it. There isn't time to put quality information on the computer as well as putting it down on paper. So the only way you can progress is to stop writing on paper and do it on the computer. There's only general practice that's got anywhere near doing that - nowhere else in the Health Service is getting anywhere near it. The labs, obviously the Path(ology) labs, but that's a small part of it. [...] and because there is no sign of the rest of the Health Service understanding how to use computers to change the way they carry out care [...] they've no motivation to get the data on because they can't get it back out again! They're only used to produce iffy data which they're clobbered with really. [...] So there's quite a level of frustration from people who would like the access to computers, but haven't the time or, if they're a nurse in a hospital unit, getting someone to cover so you can take the time to train. [...] You've got, you know, entire wards with one VDU computer screen, or computer, sitting in a corner, at the back of the office, gathering dust, while people are writing reams and reams of paper." (*General practitioner*)

The *computer was viewed as an additional 'task' to be fitted in with all their other work* by many professionals. This was especially an issue for those professionals who were working in the community. This was reported also by the survey respondents, many of whom made a plea for secretarial support for data entry. This next example from the interview data also shows linkage with the theme of working in multi-disciplinary *Teams*.

"Sadly over the years you don't get hardly any time now to talk to patients. You certainly don't do Social Work as I was trained to do Social Work and I'm just - I feel like I'm an automaton. I have to feed that computer so much! I would say that about 98% of my time is spent at my desk. I'm either on the telephone or I'm on the computer feeding information in. There's 2% of my time I go down onto the wards. I mean it's great working with the doctors and the nurses and, within a team it's - you know - it's a good feeling - and being with the patients, but it's only a very small part of my work now. I feel now it's like a conveyor belt. This is a hospital for elderly people in (*location*), mostly elderly people, and it's just a conveyor belt of one after another. And with limited resources you feel very frustrated about what you can and cannot do." (*Hospital social worker*).

For other professionals caring for disadvantaged people and older adults, the use of technology was not seen as a priority. Even if computers were physically present in their workplace, some of this group of professionals were unable to use them - representing a lost opportunity for accessing the information they needed at the time they needed it. This next excerpt from the in-depth data illustrates both these themes and is also an example of what might be termed '*e-information discrimination*'.

"It's (i.e. the computer in the office) all linked and connected to Social Services, but we're not linked up to any hospitals. [...] The system is what the Social Workers use, but we don't have access to that. [...] We can send them messages (i.e. to Social Workers) but we're not linked into the (social services package) information. We've got it on here - but we can't access it - only the Social Workers can.[...]"

I mean - if we need any information it should be written out in the Care Plan. We shouldn't have to be looking. We need a hardcopy because, um, it isn't just senior staff, but *care staff* who need to know about the person they're dealing with so it's best to be in hardcopy."
(*Care home manager*)

The data extract above illustrates how information is only available electronically to certain professional groups - in this instance the Social Worker team - not to the Care Home manager with the responsibility of care for her residents. It also highlights that access to hospital information is not easily available to the Care Home manager and her team, although they also need access to this data. This links into another theme contained in the data - that of issues surrounding the *Hospital Discharge* process - seen by several of those interviewed as the weakest link in the communication chain. Respondents in the postal survey also highlighted difficulties with communication and the sharing of information around hospital discharge.

The complex nature of issues around hospital discharge is a long-standing problem in the delivery of health and social care, especially for older adults [see, for example, Marks, 1994; Pathways Through Care Study Group, 1996]. Timely communication and sharing information around hospital discharge was identified as a concern in relation to the provision of nursing care in the community.

"Hospital discharge - that's poor. That's *not* good. That needs to be sharpened up - big time. It's a big problem - well, it's a poor problem nationally. And planning and post-hospital discharge - that's *not* good. It's not good.

What's poor about it? Can you expand on that?

Well, I don't get the discharges. Because I am just one of six (Community nurses for older people⁴) in this Trust now that does this job - I think they forget about me for one thing! District Nurses get, obviously, more discharges than I do. But, you know, all of a sudden, a fortnight later after discharge, I might have a 'phone call from a neighbour, a daughter, or anything. "Oh I am ringing on behalf of Mr. Or Mrs. So and So and they are at home".

"How long have they been at home?"

"Oh, ten days, a couple of weeks."

"What's the matter?"

"Well, they are struggling a bit now. They were all right the first week, but they are struggling." [...]

Once they are back in the community they are under GP care. [...] it's just that they haven't got it right - like the hips for example (i.e. after hip replacement surgery). They have a raised chair, they have a raised bed - if the bed isn't high enough - they have elbow crutches, or they have a walking frame or whatever they are starting to walk on. They probably *don't* have them - it's up to us then to get them.

So they come out (of hospital) and they are encouraged to be mobile and they can't be mobile because they haven't got the equipment?

Yeah. Yeah. It's bad.

(*Community nurse*)

In-depth interview data illustrated the frustrations and challenges of trying to access appropriate information in a timely manner. Professionals provided examples of trying to work flexibly across professional boundaries and described instances where they had needed to take action to resolve information and communication problems they had encountered in the delivery of care. It is noticeable that, in both the examples below, professionals were using *informal* mechanisms of communication with people they knew and trusted, to address potential difficulties and barriers they faced in the delivery of care

"There's an OT at (*location*) Hospital who is *lovely*. [...] So I got her to come out and she sorted everything for this lady. Which is great - *great!* [...]"

⁴ Community Nurses for Older People (CNOPs) had just been introduced into the community in this PCT

That is just the one I *know* about. But it happens all the time - hospital discharge - like Package of Care - the Social Services [...] There are a lot of beds blocked at (*location*) Hospital because the shifting is not as quick as it should be and we are out here. And we can accept them if they have got the Package of Care and if they got their finger out and did *something* a bit more often! I mean, individually, everybody you talk to is *very*, very nice. I think, really, what it boils down to, and I am, perhaps, probably old fashioned, but, as a nurse, you have a 'phone call, you think, "Yes, all right - I'll be there", or "I'll see you later today." Or you prioritise and you sort of think, "I'll see you tomorrow."

But, you know, three weeks - four weeks down the road when you have had a 'phone call about something is *not* good as far as I am concerned [...] Because they will be pushing up the daisies in three or four weeks time if we don't get there!

So what you are saying is that Social Services have different criteria?

Absolutely - different criteria, mm. Different model, call it what you want. But we have been trained to this I suppose - you *run* - don't you? Well you've *got* to go. People don't - yeah some people ring for nothing - the majority of people don't. They don't want to make a fuss about nothing. They are genuinely *worried* and you get there and you think "Oh God, what's all the fuss about?" But they are worried - in their little world they are worried."

(*Community nurse*)

This next example from the in-depth interview data, again discussing issues relating to hospital discharge (in this example discharge into a care home), illustrates how professionals once again utilised their own informal networks, and alternative methods to access the information they needed in order to provide suitable care.

"The Social Workers should supply one (Care Plan) before they come in (to the Home)

And does it ever go wrong?

It has done in the past. We have had occasions where we've had residents in and we've had no paper-work - really we shouldn't take people in without the paperwork, but we get them to fax it across because, once a resident has arrived on your doorstep, you can't say "Well, you can't come in because we haven't got the paperwork"! [...]

I mean, you can't account for human error. [...] They fax it. We'll phone up and say that we need it - like yesterday - and they'll fax it. Or, if it's the local Social Services office down the road, they'll bring it up."

(*Care home manager*)

The last excerpt exhibits both the strengths and weaknesses of current patterns of information sharing found in this study. It provides an example where the introduction of electronic information sharing had much potential for improving communication, thus potentially reducing the staff 'care-hours' currently spent chasing up relevant information, as well as their work-related levels of stress.

This extract is also an example of how professionals have formed and developed an informal network or 'team' in order to provide the care needed within a system that is currently, from their perceptions and experiences, not designed to enable staff to work productively.

However, while some teams *were* sharing information informally other professionals expressed concern around whether patients' relatives have access to such a record, linking to the theme of *Confidentiality*. Some of the dilemmas professionals faced in their practice are illustrated by the next example from the interview data about a community care team who were using a shared client / patient held record in the patient's home.

"The district nursing team leave their records at the patient's house, and we sometimes use that for passing information backwards and forwards. The downside to that is it's a wholly non-confidential set-up because the patient's family are all around. And there's another sort of dilemma that we're placed in. That, on the one side, we're supposed to keep patient's information confidential, on the other side we're supposed to keep relatives fully informed. And those are two mutually exclusive aspirations really."

(*General practitioner*)

This is, again, also related to the category of *Teams*, and information sharing in team working, which we discuss next.

5.8.2 Teams

Grouped under the super-ordinate theme of *Teams* were found a number of other themes. One was the category *Inter-agency working* where participants reported both negative and positive aspects as well as views and suggestions for the future. The challenges and benefits of liaison between health and social care professionals in the delivery of care were highlighted. Issues relating to working together such as *Differences in professional identities* and joint understandings in order to find a common language, relevant to both groups, were also identified as categories. Differences in philosophical ideology and training were also themes identified in the data.

In addition, the super-ordinate category of *Teams* covered the challenges different professional groups faced in trying to provide good quality care in the problematic contexts of assessments for health and social care, hospital discharge for older people and intermediate care. The *Single assessment process (SAP)* emerged as a theme contained in the data from the professionals' interviews. The attitudes of colleagues, lessons learned and barriers (both real or perceived) to joined up working were other themes in this category. These themes reflected and helped to clarify professionals' comments from the questionnaire survey. This example, from a Hospital Social Worker, emphasises the free flow of information to health care staff while also highlighting issues of *Confidentiality*, especially in relation to sharing financial information with other professional groups.

"Being the Hospital Worker, I'm doing assessments all day long. All the day I'm doing care plans. Dealing with my health colleagues, we share information all the time. There's absolutely no problem, there isn't any information that's held back from them to us. There's information that we have that we wouldn't give to them and that would be to do with finance. So I wouldn't pass on an assessment to any of my health colleagues without the patient's or the client's permission."

(Hospital social worker)

In contrast, care home staff perceived information sharing and joint working as still rather limited when working with health professionals. This next excerpt illustrates a view on communication from the care home perspective and the mechanism these professional groups use to share information relating to care home residents' health.

"The only dealings we have with the health side is the doctors and the district nurses. But we've got a good relationship going with them and when the nurses come to visit one of the residents we've got a 'Nurses Book' and they fill out who they've seen and what they've done for them so that it's all there - the information. But I mean, apart from that. We don't have any dealings with the health side - yet. I mean, we're *going* to, but not yet."

(Care home manager)

Of note here, is how the nurses are using a Nurses' Book in the care home rather than entering their notes on the computer system installed in the home. Presumably, these same nurses were keeping their own nursing notes where they were based, either in primary care or in the community, thus duplicating records.

From the general practice care perspective, team-working was also linked to the issues of *Confidentiality* and *who* shares *what* information and in *what* context that information might then be further divulged. This theme was related to *use of ICTs* as well as to issues surrounding different professional identities and perspectives arising from their professional philosophies. The following extract, by a general practitioner, illustrates professionals' concerns around issues relating to the sharing of information with regard to more vulnerable groups in our society, such as older people. The GP also highlights professionals' suspicions and concerns about the working practices of other professional groups - in this instance social workers.

"The problem is it does boil down to where does that information go then? There are *some* social workers that I wouldn't share some information with because I've known them react *bizarrely* - and one learns from that. But that's down to individuals and with the vast majority of social workers I've had an *excellent* working relationship and work very well with them. The problem comes then, well, where else does that information then go within their organisation? Just as patients might have concerns about our receptionists seeing their medical records, it does spill over in terms of the home care assistant, who's going in to get the patient up in the morning, the (sheltered housing) warden."

(General practitioner)

Examples were also found in the data where professionals had identified disadvantaged patient groups who were most likely to benefit from a team-working approach to care delivery. This was especially the case in general practice. One such example from the data from a rural practice illustrates how professionals in the primary care team had been pro-active in forming a team, linked in with Social Services, with responsibility for care of older people, especially in relation to hospital discharge.

"I'm very much part of a primary care team and, in terms of the main client group that we are dealing with, in this practice it's older people. Obviously, we have got all age groups but the one where we interact with Social Services is, particularly, old people, mental illness and, occasionally, teenagers. So, if you are talking about interaction with Social Services, in terms of the large majority of my care, we see ourselves as working as team members with a strong team of Practice Nurses in the practice, and then Community Nurses, Health Visitors, Midwives, CPNs, as part of that team [...] then OT and Physio and a Day Unit - all there."

(General practitioner)

However, due to changes in policy and the establishment of the PCT, the rural-based community team was being disbanded with some of the team members relocated to different areas. Older adults in their care were then being referred further afield for care in a district hospital, situated in a town, rather than receiving care more locally, in an environment with which they were more familiar.

As discussed above, the *Assessment process* could be an area of considerable complexity even when good working relationships were reported. Communication was thought by professionals to depend on opportunities to meet and discuss their cases as well as being willing to share information to facilitate patient / client care. This had also been reported in the qualitative responses to the survey, where factors such as sharing office buildings or meeting regularly led to better sharing of information. Examples of good practice also involved an understanding of, and a willingness to engage in, seeing the situation from the other professionals' perspective.

"You know who communicates well because we're a small team."

"Each needs to understand the philosophy and procedures of other groups."

(Comments from survey respondents)

Evidence for the need to understand the viewpoint of other professional groups was also found in the in-depth interview data. For example, within the primary care team relationships were perceived to be good whereas working with other professional groups was seen as rather more problematic. Primary care staff, in some respects, did appear to be rather isolated, something which was evident from the large-scale surveys also. The interview data did, however, also identify groups of health and social care professionals who were actively working on developing good working practices as teams. Where interview data focused on attempts to work across traditional boundaries between health and social care, professionals viewed information exchange in this environment as being both a challenge and a frustration, with team working as an integral component of this challenge. Successful team working was identified as being down to individuals' personalities and *having the opportunity to meet face to face and get to know the relevant staff members*.

"Usually one is working with small pools - in general practice you're relating to Social Services Mental Health Teams. I mean, I deal with Adult Psychiatry Social Worker, Elderly Psychiatry Social Worker, occasional Child Protection Social Worker - but very rarely. And you know I see them so rarely that I probably would be dealing with a different one each time. And actually in our practice we have very little dealings with any other Social Workers as such. Trying to get a Social Worker interested in care of the elderly in the community I find incredibly difficult. I've had patients with problems, and I've done referral letters saying "Please will you do a Care in the Community Assessment for this patient?" And they've rung the patient up and spoken to them on the 'phone. The patient has told them "Oh no, everything's all right." And they've left it at that! When you know the patient is bent double - level with their knees - and you know they've just left it!

I can tell other similar horror stories about general practice where I used to work in (previous location). [...] But that worked better [...] we spoke the same language - we saw each other face-to-face quite regularly." *(General practitioner)*

Some barriers to good team working and communication may be due to a fundamental lack of understanding of how other professional groups work and acquire information, while other topics uncovered in the interviews centred on information being patchy and provision a question of 'too little and too late', especially in areas such as hospital discharge. Again, this may be related to a combination of differences in professionals' philosophy and recognised problems with working across boundaries [Davies, 1998].

"There is never mention of Physio, OT or Social Worker involvement. There may only be a statement the person's gone into a residential home - or a nursing home - or back to their own home. But that's all you get. You never get any assessment and that's one of the, in certain aspects, one of the glaring gaps you know? [...] and if I refer them to Social Services, as a GP, Social Services may not tell me exactly what they've done [...] I wouldn't necessarily get anything at all, unless they organised a case conference. [...] So, yes, mm, it's very hit and miss." (*General practitioner*)

Improving team working and increased sharing of information were acknowledged by professionals (both those working in the 'field' and those with a management role) as areas in need of further development in the future. The next example from the interview data identifies the need for professionals to trust both the system (i.e. computer system) and each other, in inter-agency working. The extract also illustrates professionals' acknowledgement of both *the challenges and benefits of change*, two strong themes contained in the data.

"It's just interagency stuff, inter-professional within organisations frankly, if you want my view. So, I mean I think there are, there's a number of issues aren't there? There's a number of levels at which you need to approach the problems. If you really *did* move to patient-centred care, with the patient at the centre, with multi-professional teams around them providing the care, then you'd have a modernised service and the professional barriers would have been overcome. And that's where we all want to be, but we all know that's a very long journey from where we started, which is separately trained professionals who work in different teams, who work in organisations, but have had barriers between them. So I think we're approaching it on a number of levels through modernisation, and there's a specific modernisation module in (*location*) about IT and how we use IT better. How we use it better between general practice and the hospitals. How we use it better between community nurses and general practice. And then, ultimately, how we use it better in health and social care. So, through modernisation, through professional development, and then, sort of, structurally through things like joint posts, [...] I think it's got to be multi-level really." (*PCT professional*)

5.8.3 Change

Due to the timeframe in which the project was conducted, and the introduction of various new health and social care policies such as the *Single Assessment Process*, the concept of *Change* naturally emerged as a strong theme in the data from the professionals interviewed. Again, the interview data illuminated the complex processes of change precisely during the creation of new organisations and the re-organisation of service delivery in the move towards joined-up working for the provision of care. This concept included the theme of *Uncertainty* about the direction any changes might take and the problematic nature of coping with change during the modernisation process. Another theme found in this category was acknowledgement of work that still needed to be done. This was in order to reach the targets for changes in services during the modernisation process. The perception of *lack of time*, with the feeling that the time-scales 'imposed' on them were too short, was another strong theme identified by professionals. Other themes contained in the category of *Change* were professionals' views that they were sometimes faced with new technology problems they were not prepared or trained to deal with, and the related issue of how under such circumstances they could use it to try to improve the delivery of care.

"Next step is for us to actually support the staff to be able to use their computer and change their way of working such that they begin to actually keep computer records. That then helps with a number of audits that we are trying to get the practices to participate in." (*PCT professional*)

Related to the theme of change was the *re-structuring of service delivery*, which professionals viewed as being both challenging and frustrating as they struggled to incorporate changes necessary for

integrated services. The *uncertainty* generated by the introduction of management and policy changes led to some feelings of disquiet. This was particularly an issue with the timescales proposed for the introduction of targets (e.g. SAP) where professionals considered the time frames to be unworkable. This theme, that of the introduction of *theory into practice*, is connected to the themes of *Theory* and *Management* with the focus on the *implementation of policy*.

"I suppose the ambition is, for one thing, an integrated service which gets very hard at the moment with barriers of information sharing. I think it is about an improved service for older people and, you know, some of the seams are ironed out and that, from their perception, because they are not overly concerned generally with who's providing the service or which agency it is. They are just concerned with the *result*. So I think it is a means to achieving that. [...] it centres around Single Assessment and person centred care. I think I would like to get to the point where, electronically, it's possible to share selected information easily and quickly. [...]"

I don't think we are going to be able to fully meet the milestones that are laid down. We've just had to do a position statement that we've had to send in. [...] It was, April this year (2002) was the original timescale which is completely unrealistic. [...] They've reset it now to - it's slightly unclear - April 2004? I *think* is the ideal and, at a minimum, agreeing an overview assessment process and the absolute *latest* April 2005? But it depends what you mean by implementation really. I think full implementation of single assessment across every sector you won't achieve in that timescale. The issues, complexities are just too great for that. Where are we? Um - we're struggling to be honest."

(Social services manager)

Professionals' views around uncertainty also centred on their concerns about the delivery of care in practice and what it would mean to the staff under their management. This theme is related to the theme of *Management*. One such example from the data is from the manager of a care home who knew that changes were proposed but felt she did not have sufficient information to guide and inform her - she needed knowledge that she could utilise in practice.

"We don't even know what we'll be this time next year (i.e. whether the care home will be caring for more older people with dementia). [...]"

If we knew, we could work towards that, but it's the *not knowing*. [...]"

I just want to *know* - I just don't like the unknown. I can work with what I know - I can't work with the unknown. [...]"

We're not getting the information, because all we're told is "This is what's been proposed", but, I know deep down, that what they've said - it can't happen. [...]"

They're (i.e. staff in care home) asking me and I feel like I've a duty to tell them and I have to say "Look, I'm not hiding anything from you". [...] and that makes me feel awful because I'm one for if you know something you share it and it all helps out. You can't share what you don't know."

(Care home manager)

Data from this professional's interview highlights the problem of communication and of needing information that is timely and appropriate, and in the right format. This was especially an issue for operational aspects of care management - which, of course, is the type of management that most health and social care professionals engage in, since delivery of care is about relating to, and meeting the needs of, client and patient groups. This theme is also linked to the theme of *communication* with other professionals and the *sharing of information* across and between health and social care. It is an example of part of the wider context in which professionals working across boundaries encounter difficulties in language and culture [Davies, 1998]. This can, in turn, contribute to communication difficulties and barriers to the sharing of information - reinforcing a 'them and us' attitude. This has become known as 'professional tribalism' [Peckham & Exworthy, 2003; Beattie, 1995] and it was evident in this study, where professionals reported misunderstandings arising from use of different language and different care perspectives.

"I've been to a couple (of meetings around proposed changes) but they talk - well - it's just a load of *gobbledegook*! You come out and you think "Well, what was all *that* about? You're still none the wiser! [...] I ask when I'm there - never mind *after*. But they fob you off with their answers. [...]"

It's information you *don't* need. The information you *do* need you don't get! [...] I mean all I will say is *we* live in the real world and they live in 'Paper World'. You know, the residents to them are a sheet of paperwork - or a case note. It isn't to us - they are *people*."
(Care home manager)

The *Complexities* surrounding the provision of care for older people in today's health and social care systems create enormous professional diversity while, as in the Care Home manager's situation, professionals are at the same time being encouraged to deliver care across these organisational and professional frontiers. Maintaining and crossing these boundaries, especially in a period of sustained organisational *change*, entails dealing with this complexity [Holt, 2002]. This theme was linked to the theme of *Management* and, because of the proposed move towards increasing use of technological mechanisms for information sharing, to the theme of *Confidentiality*.

5.8.4 Confidentiality

Data analysis around the super-ordinate theme of *Confidentiality* cannot be considered in isolation, since there are links and cross-fertilisation with other themes in the data such as *information sharing*, *ICT use*, *communication* and *team working*. Other aspects related to *Confidentiality* included the challenge of *change* (the introduction of e-communication methods and the proposed move toward a computerised patient/client e-record), and *management* issues relating to getting the *theory* (or policy) into practice.

Confidentiality was a topic where participants' discussion most obviously reflected their professional viewpoints and backgrounds. Participants' debate about confidentiality centred on information sharing both within and between health and social care teams. Who could view what data, and in what situation it would be appropriate were topics that occurred frequently. This was a particular concern with primary care in relation to the move towards the introduction of electronic medical records, and is linked to the themes of *information and communication technologies*, and, as the next example shows, the theme of *stigma*.

"The ability to share information is one that I worry about when we go electric - there will be evidence and things in peoples' notes, in the Lloyd George folder, that any of my partners can see, my practice nursing staff can see and so on. But there may well be bits of evidence buried there that even the patient has forgotten about - things that happened to them in childhood [...] sexual abuse [...] may be sexually transmitted disease. [...] Without any restrictions on access, I worry about it, even among my colleagues."
(General practitioner)

From a management perspective, the idea of a shared electronic record was perceived as a way forward by people engaged in management and/or policy implementation. However, professionals seemed more uncertain (or 'exhibited less clarity') about *how* this was to be implemented in practice and, indeed, about the concerns and needs of their clients and patient groups.

"I suppose in an ideal world then there would be a patient-owned record, to which the patient had access, which was available to people directly involved in that patient's care. Which, I guess, is what the Electronic Health Record - whatever it's being called now - the Integrated Care Record System? - is actually aiming for [...]
In terms of *getting* there, I mean, I think the national IT strategy is looking at how they can deliver the right kind of technical solutions to achieving that vision, but I think that really does need to be [...] very influenced by consumer views, what the patient wants. Do the patients want an electronic record that they can just log into? It's like an Internet bank account, isn't it? Log in here - "Oh this is what they said about you today. This is your state of health, as opposed to your financial health or ill health". And who else can look at that record? And what's appropriate? So I think it's a *huge* agenda.
Would you care to put a time scale on it?
No!" (gives small laugh)
(PCT professional)

From a management perspective *confidentiality* was often considered in relation to the introduction of the Single Assessment Process. At the time of these interviews, however, the debate was still ongoing as to *which* assessment tool it would be appropriate to use *if* professionals were to have access to a shared record. This debate was also linked to the themes of inter-agency working and information

sharing across professional boundaries. The next example, from the data, is from the perspective of a social services manager, who deliberated on these issues.

"I think it's become clearer and clearer that one of the main obstacles to the implementation of Single Assessment is information sharing, and, in particular, the use of information technology to facilitate the sharing of information. And we've done some pilots on Single Assessment which have made it very clear that without information technology it's going to be extremely difficult and cumbersome to have an effective flow of information around Single Assessment" [...]

What about confidentiality - I wondered what your views are?

Well, I suppose my *personal* view is that we ought to be able to deal with that! Now, not *everybody* thinks that and it is often raised as a barrier. We've recently produced an Information Sharing Protocol which is for (*location*) and has been signed up to by all the Health Trusts and Social Services and County Councils and District Councils you know, all the main public bodies have signed up to that. I had a hand in developing it actually. It's a fairly basic document. [...] I probably have an over simplistic view of this, but the key element seems to be getting the person involved (to give) informed consent to sharing that information. If you do that you are OK it seems to me. I think sometimes people are putting up more obstacles than they need to be. I know it's a complicated area and a contentious area. So I think it's 'doable' but not everybody is persuaded yet. [...]

I mean it is not appropriate for *every* bit of information to be shared across the board with other agencies and I think that has been one of the big stumbling blocks. [...]

It's not just a case of joining two plugs together between two systems so that, for example, we would have access to the health records in their entirety and *vice versa*. I mean we have got a lot of *very* confidential information. [...] I mean it's going to be a change in practice about working with people and helping them to be clear and understand where this information might be shared and so on and so forth."

(Social services manager)

This excerpt illustrates how professionals see disadvantages, as well as benefits to e-sharing. They view electronic sharing of health and social care information as having the potential to breach client/patient confidentiality, although they do also perceive clear advantages to sharing information. These themes show connections to the theme of *inter-agency working*, discussed under the theme of *Teams*.

Professionals' concerns about confidentiality also focused on the theme of the more *vulnerable groups* of clients / patients, such as people with mental health problems, older people and other disadvantaged and marginalised groups in society (e.g. HIV carriers). Increased levels of stigma and isolation and the threat to privacy were related identified issues under the theme of *Confidentiality*. Linked to the issue of assessments and confidentiality was the theme of *privacy* and information sharing with the patient or client.

"You're almost like ward entertainment, especially if the elderly person's deaf. Because you sometimes repeat what you're saying a bit louder and the patient in the next bed can hear the answer or somebody from across the way. It's not always about finance obviously. It's about, you know, "How's your walking?" and that person (from across the ward will reply) "Oh, she's walked today, she's done better than yesterday". And so you don't have any privacy and there are hardly any rooms available. [...] but you might use Sister's office occasionally - if it's free. And then of course, you've got to then get the patient into the office - it's often at the end of a corridor. [...]

There are no problems in gaining access to the medical notes and I take the information from the medical notes. I've asked time and time again is this right - because it's third party - and we're not supposed to take notes and transfer it onto ours - but we *do*. We've had no guidance from our Social Services about whether this is right.

And it's *bothered* me because, as I say, I give the assessment to the client. They may read something there that they didn't know. They didn't know they've got this illness and they may not know that they've got illnesses that I have to report on, you know, that they've had previously. So it's a very *difficult* business. [...] And the information that you're passing on sometimes is things like senile dementia - cancer."

(Hospital social worker)

Issues of *stigma* and selected provision of information are illustrated by this next extract from the interview data. For this professional, concerns centred around problems relating to what patients /

clients understood about issues relating to the release of information and how this might impinge on the potential for information sharing across different professional groups, as well as adversely affecting the type of information patients might divulge to their doctor or social worker.

"One of the key issues that came out around HIV care was the *huge* concerns which the risk groups and HIV infected groups had about confidentiality. To such an extent that [...] people who were HIV positive weren't sharing their information with GPs either. And, when one sees general practice from their perspective, you come to realise that the same anxieties are shared by lots of other client groups as well. One of the key things is that patients can't complain about a breach of confidentiality without making themselves more yet *more vulnerable*. Because they have to share that confidential information with the body that they might complain to, and that can actually increase their vulnerability. [...]

(Then there is) the release of information between professionals. And the standard sort of assumption has been "I'm a professional - he's a professional, therefore I can share information with him in professional confidence." This concept of professional confidence builds up. Which actually has no basis at all in law. It's just another concept that's evolved, which has no substance to it. [...] The problem comes when the professional assumes that information release is OK, when that view might *not* be shared by the patient. [...]

Very often a patient will tell a Social Worker something that they wouldn't want their GP to know about and *vice versa*. Conversely I will see patients who have postnatal depression, are worried they are not coping, if it was automatic that a Social Worker had access to their medical records they would be very worried about divulging their mental state to me. I've had that (happen) several times - postnatal depression - bringing it to the surface - "Oh my God! Are you going to take the kids off me?" [...]

But it will result in patients not sharing information with *any of us* - rather than it being shared by *more of us*."

(General practitioner)

Professionals repeatedly maintained that their patients and clients may wish to confide in one member of staff while, at the *same time*, being unwilling for another member of the care team to know about their worries or concerns. Participants respected this, while also seeing it as a potential barrier to sharing information between professional groups.

"And also she told me lots of little problems about something *personal* she had got that, perhaps, she wouldn't discuss with a GP. Nothing against GPs - it's a '*nursey*' job and they'll talk to a nurse perhaps. [...] It's all sorts of things we pick up. There are all sorts of things that they walk around with that they don't know - urine infections mainly, and little problems that they probably wouldn't discuss if we hadn't (made contact)."

(Community nurse)

"How *are* we going to resolve this difficulty of confidentiality where patients may be perfectly happy at present to divulge things that are written in their notes? But, if they know that that's going to be available to 46 practitioners in (*name of town*), because they may see somebody out of hours, are they going to worry that that data is going to be *more* widely available - even outside those 46 (GP) principals or practitioners? And, certainly, *I'd* be worried if we integrated our medical notes with Social Services, because (Social Services) colleagues have said that, if they come across [...] some other thing in somebody's record, or relative, they feel honour-bound to refer it to their seniors, or their manager who has to make a decision. And that would be a real conflict for me, as a GP, because over the 30 years I've been a GP, I've had, not *many*, but several times I've had information that [...]

I've had to keep it confidential [...] And that's a *real* concern - a real concern about this idea of opening up electronic records to everybody. [...]

I worry about this confidentiality issue."

(General practitioner)

At the same time, some professionals also expressed concern about the patient accessing their own electronic health record and the influence on the patient-doctor relationship.

I am sure there will be instances where it actually may be harmful for the individual. But there would be, if you like, a small minority [i.e. electronic patient record] of patients that would be in that position. I think even the sort of people who are seriously mentally ill [...] (*pause*)

There are times in the patient's journey where they *shouldn't* have records - it's not helpful - it might even be harmful at that particular point in time. [...]

I think also it might have a knock-on effect of health care practitioners recognising that, actually, they are there to give all the appropriate information and advice but, at the end of the day, if the patient has made the decision and direct the care that they want [...] (it's about) the doctor - patient partnership. [...] (*PCT professional*)

Thus, professionals' views around confidentiality often centred on the ethical considerations involved in sharing information, especially information of a more sensitive nature. Professionals considered information sharing from the perspective of their patient / client, as illustrated in the extracts from the data below. While they acknowledged the need for good communication they were cautious about sharing information because of issues of confidentiality and their clients' understanding of *consent*. They tended to try to put themselves in the 'other person's shoes' when discussing the ethical complexities and challenges of information sharing.

"You get into the difficulties of - is the patient already *aware* that information is shared between people, and, if so, to *what extent* it's shared? [...] are *my* views of what's reasonable shared by what the *patient's* views are of what is reasonable? [...] the patients and public have a sort of dichotomous thinking, in the sense that they're *outraged* that a doctor is aware that somebody's got such-and-such a problem. Then they get *very* frustrated at having to tell the district nurse the same information. [...] if I was to share my records with the district nurse there is often information in there that they (patient) wouldn't want the nurse to know about. [...]

We're probably making it worse because the government is pushing more towards the policy of this Single Electronic Patient Record, which will be held in this nebulous central database. And anybody involved in care is supposed to be able to access this information and pull it out [...] I think it's a fundamentally flawed model for that reason. (*General Practitioner*).

"I always think - whatever I do - I always put myself *in their position* and think how *I'd* feel." (*Care home manager*)

In summary, professionals considered the theme of *Confidentiality* as being an area of enormous complexity with no easy solutions. Participants also highlighted this theme as being one of their main areas of concern with regard to any future implementation of inter-agency working information sharing.

"Confidentiality is an interesting one - yeah, mm. Because it's all on paper it's dangerous. I think you could also say that if it was on a laptop. That could be equally destructive if that were to get lost or stolen - all the information is on there. So - that's a thorny problem I think." (*Social worker*)

How professionals viewed the tensions identified in the data between confidentiality and information sharing in inter-agency working and how these themes might be related with management are considered in the next section, under the category of *Management*.

5.8.5 Management

Contained in this super-ordinate theme were the themes of *finance*, continued investment and other budgeting issues. The financial theme focused on the changes in purchasing structures and procedures with the formation of PCTs. Other issues centred on professionals' concerns about job cuts and changes to funding. These concerns, while focused on financial issues were also interwoven with the theme of *uncertainty* (see *Change* above). In the period when this research was conducted there was particular evidence of this uncertainty around issues relating to funding of innovative practice. The future of local projects, designed in consultation with professionals and introduced to meet local care needs, was also seen as dependent on national *policy* as well as the continuation of funding. Staff expressed doubts as to whether, with the organisational changes, local pilot projects would be able to continue.

"It's a complete nonsense what we are doing at the moment. [...] we actually had a project where we looked at the assessments we were doing. [...] you see (there is) a different model of nursing, OT, Physio., have got health assessments - so do Social Services - and we worked very hard to get a shared patient record that was then agreed to be used for that purpose. The

pilot on the wards and in the day hospital was quite successful. *Then* the government said we must have a *new* model - and we were overtaken. I don't think they were very happy with the new model either."

(General practitioner)

"Really this started off as seeing them once a year but, because I am on my own now, doing this (community care and visiting older people)

There were two of you to start with weren't there?

Oh yes, but the Trust froze the hours last April. There's 52 hours frozen in this area."

(Community nurse)

The rhetoric of management, and identified targets, such as those contained in the NSFs, was another identified category for this thematic grouping. Wrestling with the complexity of organisational change and its associated frustrations (e.g. with funding issues) was also identified as a theme. This next example from the interview data illustrates a general practitioner's concerns about financing IT improvements within his practice. He is discussing decision taken by his partners for the practice to 'wait and see' what transpires around central funding for IT development in primary care.

"I think we're waiting, [...] when you're told that heads will roll unless you balance your books....[...]

We're slow in our development of it (local IT policy) because of the fact that primary care has only had allocations of reimbursement money towards the cost of IT. [...] But *that* meant that practices had to find the other 50% themselves out of their income. When you try and upgrade the IT, as Social Services have done [...] that gets more and more costly. And, unlike business - where you generate income that helps you pay for your investment in IT, the Health Service *doesn't*. If you spend more money on IT, and you see more patients, and you treat more people, it *costs* more, and the funding doesn't follow that. [...]"

(General practitioner)

For those professionals involved with negotiations at the PCT level, management issues focused on the challenges and difficulties they faced in reconciling their managerial role with their professional care role.

"I know, both as a GP and a PCT (role) that it's tax payers' money - we shouldn't be wasteful. But I know, more and more, that my colleagues find it very, very *frustrating* and yeah, get pessimistic. [...] These are the tick boxes - these are the hoops you have to jump through [...] there's this tension."

(General practitioner)

Strategy and spotting the likely direction of *future strategies* were other related categories contained under *Management*. Professionals saw these issues both from the perspective of attempting to carry out their work providing care in a changing environment, and as being due to the formation of new organisations with the attendant organisational uncertainty and need for a clear vision.

"You've got all these different organisations [...] this is one of the problems, because I see this in other areas - the boundaries between the organisations. I see this both as a GP, but also sometimes as a Primary Care Trust Officer, as it were. And it's one of the problems we have - this communication between Trusts."

(General practitioner)

"The PCTs are distinctly anti - no, not anti, but (they) haven't been in the business of developing primary care teams and team working. They (management in PCT) still see themselves as a Trust of these independent contractors, you know, organisational stuff. *Madness*. [...] had a very confrontational meeting about ten days ago when they did their Development Plan and it wasn't primary care development. You know - don't you imagine these changes in the hospital are going to affect primary care? Where is the vision? You know - do you have a *vision* for primary care?"

(General practitioner)

From the perspective of *management*, professionals saw their role in introducing change as a long term challenge that sometimes left them feeling frustrated since not all their colleagues felt the same way. These issues are also related to the themes of *theory*, *inter-agency working* and *change*.

"Well, it *will* improve things, but it's going to take 10 to 20 years to improve things. The other frustration I have is that there's a mindset amongst *some* people in the Health Service. [...] They could be managers, it can be health professionals, where they say "We've only done it this way and we're not going to do it any other way." And that's the modernisation challenge - you know, the agenda of the government - which is right. [...] So that's a frustration."
(*General practitioner*)

5.8.5 Theory

It is the super-ordinate theme of health and social care policy and its implementation that we discuss finally - the concept of getting the *Theory into practice*. Theory is used here in the sense of defining and relating to, the implementation of evidence-based guidelines, such as the introduction of the *NSFs* and other policy measures, in the drive for improving practice [Gray, 2001]. The over-arching theme of *Theory* encompassed the categories of applying theory and introducing it into health and social care delivery [Lawler et al, 1985].

Professionals often identified that, in relation to the introduction of any new model of care, differences in organisational culture needed to be acknowledged to ensure the success of any new way of working.

"But I don't think that's easily achieved - not just technically - that might be the *least* of it, but certainly *culturally* it requires a lot of change."
(*PCT professional*)

While some professionals were attempting to implement policy changes and introduce a more joined-up approach to service delivery for older people and other disadvantaged groups, they were coming up against certain practical problems. These included the realities of professional practice in an organisational climate of uncertainty (linked to the theme of *Change*) and the uncertainty, or lack of awareness of, new targets for change by certain more *isolated professionals*.

Have you heard of, or seen, the National Service Framework for Older People?
"Mm, I *have* (sounding doubtful), but I'm more involved with residential care [...]
I've *heard* about it.
You seen a copy?
I *probably* have, but I don't know.
The cover's green.
Green, green, green, mm, you see most of this information the (other) manager would have had and if she'd have showed it me, I'd perhaps have looked at it. [...]
Well, I probably wouldn't have *read* it. [...] I don't remember seeing anything green. [...]
As I say, I've *heard* of it."
(*Care home manager*)

Interview data on the theme of *theory* also included information on local 'pilot' schemes, where professional groups had formed teams to incorporate policy changes into their work. Professionals gave examples where collaborative working had tackled an identified problem for that locality. This theme links to the identified category of *Teams*.

Professionals' *Hopes for the future* with the development and implementation of a truly patient/ client centred model of care was another theme identified from the data and classified in this category. Participants did, however, acknowledge the *complexity* of introducing a more integrated approach with inter-agency working. In turn, this was linked to issues relating to sharing records, challenges to technology, and the theme of *Confidentiality*, as discussed in this excerpt from a professional, based in a PCT. While the professional recognises the need to incorporate the policies of *NSF for Older People*, she also debates the challenges professionals face in working towards an integrated care approach and the complexities of introducing a shared record.

"Groups like older people where you want an integrated health and social care approach, *of course* there has to be a mechanism for sharing information and this is something I think I mentioned to you - the *NSF for Older People* - and we are expecting that to be taken forward. So the principles clearly are there. The mechanics of doing that are complex. Notwithstanding the fact that, where information is given for one purpose and to one particular set of providers,

the use of it by other sets of providers or shared with others needs to be looked at *very* carefully. So it is getting that understood, by the users of services.
(PCT professional)

Similarly, the perceived optimism of policy makers was viewed with scepticism by some professionals.

"They talk about, you know, grandiose ideas about the way it's going to work, and this Single Patient Record. But it's just not going to happen from what I can see of the way things are being implemented. When you ask about the pilot, you know, the places that are supposed to be further down the road [...] they're still asking the questions - no *solutions*."
(General practitioner)

In reality, professionals considered the introduction of new policies to be a challenge. This was especially an issue in relation to providing care for older people, where in many instances this was constrained by provision of adequate funding. This is illustrated by the next excerpt from the data, from a Hospital Social Worker who discussed Care Packages for older people to allow them to remain independent in their own homes.

"I read their *National Services Framework* before, last week, before you came. [...] I'm dealing with this problem, the 14 hours that (*location*) County Council allows per week to give elderly people, those over the age of 65, a Care Package. I mean, well, it's *impossible*, to get carers to go in (to clients' homes) four times a day just for half-an-hour. And, if they need two people to go in, they're given half-an-hour in the morning and half-an-hour at bedtime. And that's supposed to keep people in the community? It's *very* frustrating, but it's worse when you know that, in April last, they should have looked at and started a non-discrimination policy against the elderly. They're still giving those of the age of 65 and under, 36 hours care per week, but they're giving the old people *14 hours*. [...]
I asked only last week "When are we going to hear that we can spend more money?" They said "We still don't know, but we can't take from the younger people to give to the older people and we haven't got the money for the older people."
(Hospital social worker)

This example from the interviews highlights the theme of professionals' concerns that decisions about care delivery were being based, as in this instance, on the availability of resources (adequate funding). However, professionals stressed that it was also important to provide care that considered available evidence (theory) and did not discriminate against people needing care (values).

Finally, professionals did not only discuss the proposals for a shared record in relation to inter-agency working, and the negative and positive aspects of record sharing in connection with their technological concerns and the proposals for a client / patient held record. They also considered the place of the patient / client and their carer as central to this debate.

"I guess if we are moving towards, if we can actually implement the Patient Health Record, why can't we do that with *all* our clients and to carers? If *they* hold the records then what we need is a sort of end system that allows these records to be read. [...]
In the home, wherever. I mean, I can't believe the technology isn't there for us to do that. I think we need to become much more sophisticated about putting the patient in the centre and then looking at the information needs and information sharing around that. [...]
We have got different systems that don't necessarily match very easily in terms of, you know, sharing information, let alone the other sort of Caldicott type stuff or whatever. [...]
I think it empowers people to know what information is held on them so that they have their own information with them. [...]
It was very patronising twenty years ago where the professional tells you what is wrong with you and tells you what needs to be done and you just accept that passively. Now we are looking at a partnership but actually we probably need to be moving to a consumerism model where all the information is there [...]
(It's like) going into a supermarket. You have all the information and then you decide what product you want to buy. So, increasingly, we need to move to the partnership model and then slightly more to the consumerist model - where the patient becomes really the lead decision-maker, much more empowered. And Patient-Held Records is one of the ways of empowering the individual around that - not the only way - but one of the ways."
(PCT professional)

5.9 CONCLUSIONS: PROFESSIONAL PERSPECTIVE

The professional perspective was explored through large scale surveys and in-depth interviews. The 686 professionals replying to the survey represented a cross section of staff providing care for older people in the community spread across six staff groups: general practitioners; practice nurses and practice managers; community nurses and other community health staff; community nursing auxiliaries/ assistants; social workers; and other community social care staff (Table 5.1). Community nurses (n=157), general practitioners (n=123) and social workers (n=90) represented the three largest professional groups. Virtually all respondents (99%) had regular contact with patients, and over two thirds stated that more than half their workload was associated with older people. Staff provided care in several locations, with community nursing staff and social workers reporting the widest range of settings (Figure 5.5).

All staff, apart from some auxiliaries, had face-to-face contact with other professionals in the course of their work. GPs, other practice staff and nursing auxiliaries were much less likely to report contact across the professional 'divide' i.e. with social care staff (Figure 5.6). Virtually all staff used some form of non face-to-face contact for communication (Figure 5.7). Telephone, letter and fax were universally used (to a lesser extent by auxiliaries, especially written communication). Day books/ message books were also used for information sharing by the majority of professionals (88%). Email was far less likely to be used, especially by community nursing staff and social workers (15%) and, as would be expected, by auxiliaries (<5%). Email use was most widespread among GPs (40%).

Most staff (85%) had access to a computer at work, whether for personal use or shared, except for ca 12% of community nursing staff and 60% of auxiliaries who had no access. Almost all GPs had access to their own computer and over half of social workers, but only 10% of community nursing staff had a computer for personal use (Figure 5.11). The intensity of computer use reported varied significantly (Figure 5.13). GPs were the most intensive users with only ca 10% spending fewer than 2 hours per day using a computer. This figure was slightly higher (20%) for social workers, whereas ca 90% of community nursing staff reported low intensity use. The sub-set of professional whose workload consisted almost solely (+75%) of older people did not differ in their patterns of use (Figure 5.14). There was a clear tendency for those who used the computer longest to have access to their own terminal, as might be expected. But over 40% of those who used a computer for only 1-2 hours per day also had their own, as did nearly 70% who used it for 2-4 hours (Figure 5.16). This confirms the presence of significant 'notional' spare capacity in the system, although because of the reasons outlined in section 4.5 this may be of limited use to other professionals. Access to the Internet at work was variable (see Figure 5.12). Access was highest for practice staff (80% of GPs). Levels were lower for community nursing staff (ca 50%) and lowest for social workers (<10%). Health care staff were much more likely to report using a computer at home for work purposes (67% of GPs, 47% of community nursing staff) than were social care staff (33% of social workers).

When asked about their IT skills, approximately half of the various professional groups rated themselves as 'competent', except for community nurses and nursing auxiliaries where the figures were much lower at ca 15% and 5% respectively (Figure 5.8). Only 6 professionals (<1%) considered themselves to be 'expert' users. In terms of IT training, very few general practice staff who used a computer reported having received any formal training; ca 15% of GPs and 30% other staff (Figure 5.10). In contrast, half of community nursing staff and 70% of social care staff had received training. Interestingly, 20% of nursing auxiliaries had also received training. Training was mainly in service packages, word processing or database management, and nearly half of these professionals (45%) reported they had received their training 'over three years ago'. The likelihood of an individual being trained was not related to intensity of use (Figure 5.18). Staff using a computer for 6 plus hours per day were less likely to report any formal training (20-30%) than were those whose use was less intensive (50-60% trained); in fact, levels of training were similar to those reported by staff who made no use of a computer. For the most intensive users (>8 hours per day), ca 80% had either received no training or were self taught.

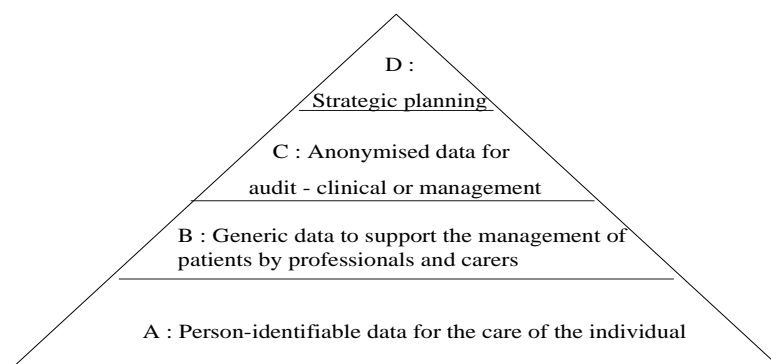
The ways in which professionals communicate with each other were further explored in the survey. Survey participants were presented with stylised scenarios and asked questions about information sharing:

- in dealing professionally in these scenarios;
- whether other professionals might have information which they did not typically have access to, but which would be useful when dealing with such scenarios;
- whether they personally had information that could be usefully shared in cases like the scenarios described.

Only a minority of healthcare staff reported that they had access to any guidelines for the scenario situation described, 20% of GPs and 45% of community nurses. The figure was higher for social workers (65%). The majority of professionals had asked other professionals for information in the scenario situation; 88% of GPs, 75% community nursing staff and 93% of social workers (Table 5.5). A wide range of information had been requested (Figure 5.23), with information across the ‘divide’ being required by all staff groups. Information was most likely to be accessed by telephone, followed by face-to-face (particularly for community health and social care staff) or via reports, especially social care staff (Figure 5.24). This differed from the means used to access guidelines, where computer use was more likely (see Table 5.4). In total, professionals reported 17 different means of accessing information from other professionals in a scenario situation.

Professionals were similarly asked to identify what information they themselves held that would be of value to other professionals in scenario situations. A similarly wide range of items was identified (Figure 5.26), mirroring those requested by professionals (Figure 5.23). The vast majority of staff (91%) said that they would be able to share this information with other professionals in the scenario situation. Only 8% said they would be unable to share information. Very few professionals (< 10%) said that information access was easy, although most thought it was acceptable (Figure 5.25). GPs and other practice staff were most likely to report that it was difficult (59% and 45% respectively). The extent to which professionals had experience of information sharing across the ‘divide’ in scenario situations differed (Figure 5.28). GPs were the most isolated in this respect. Nearly two thirds (60%) reported they only shared information with other health professionals, although community nursing staff were less isolated (20% did not share information with social services). Only 10% of social services staff had not shared information in a scenario situation with health care staff. The main reasons for being unable to share information were confidentiality issues or lack of responsibility. Even for those who could share information, consent issues were important. For professionals, a hierarchy could be conceptualised, following the principle of not requiring at a ‘higher’ level (equating to a strategic level further away from the patient/client themselves) data that was not required nearer to the patient. This is shown in Figure 5.34.

Figure 5.34: Hierarchy of Information



Potentially useful data identified by respondents which they did not currently have direct access to was mainly at levels B and A. Privacy and confidentiality was thus only a partial issue in this study, because respondents focused in the first instance on ‘generic’ information (level B), rather than on person-identifiable data (level A). A large number of shared responsibilities were noted with their associated non-person-identifiable information requirements. These included guidelines; resource availability; other services e.g. sheltered housing; availability of aids and adaptations; service

specifications etc. Even so, few of the level B requirements identified appeared to have been provided at field level.

The preferred means of sharing information in scenario situations were verbal; very few professionals (<5%) would use email (Figure 5.29). General practice staff were more likely to report that they told colleagues informally. Whereas more formal means such as team meetings and multidisciplinary assessment were used by community nursing and social care staff. When asked whether their information needs were generally being met, professionals reported varying degrees of unmet needs (Figure 5.30). GPs were most likely to report a need for further information (60%), predominantly involving information from social services. Other practice staff also reported a high level of unmet need. Community nurses (25%) and social workers (10%) were far less likely to identify an unmet need for information from the other sector. In terms of sharing of communication between the two sectors, although not excellent, the majority rated this as 'good' or 'reasonable' (Figure 5.32). Professionals were also generally positive about the benefits that information sharing could provide (Figure 5.31). Individuals gave a variety of reasons for their views on the state of communication between groups; most issues centred on human communication, with technology related issues presenting far less frequently. Both health and social care professionals acknowledged that sharing information did not always happen and that there was "room for improvement here". It was described as being of "variable quality" and relevant information did not always reach professionals when needed. Communication sometimes conflicted with interests and priorities of different professionals, where "each needs to understand the philosophy and procedures of other groups". Thus, the facilitation of any data sharing in this complex socio-technical environment needs to take account of the multiple stakeholders in each sectoral environment.

Analysis of qualitative data from in-depth interviews with a sample of participants identified a number of themes:

- ICT: Using information technologies in health and social care. Sharing information
- Teams: Inter-agency working. Team working
- Change: Working in a rapidly changing environment
- Confidentiality: Confidentiality in care provision. Ethical considerations & practical issues
- Management: Organisational issues
- Theory: Putting theory into practice. Guidelines.

Many professionals felt that communication in multi-disciplinary teams worked best when people knew each other. Factors such as sharing office buildings or meeting regularly led to better sharing of information ("You know who communicates well because we're a small team"). Professionals also considered that communication was rather variable outside their 'own' multi-disciplinary team. They cited poor co-ordination between different agencies. Problems with poor records and people forgetting to complete forms were also mentioned as were difficulties in contacting various professional groups. This was especially an issue in the context of shift work and part-time work where information might be slow to reach the relevant professionals.

Important factors associated with effectiveness of solutions for meeting professionals' information needs included:

- whether the information is given at a time when it can be acted on, or later;
- how to present questions to different professional groups in a common language or at least to avoid misinterpretation;
- whether the system delivers the information to the user or the user must take an action to view it;
- whether it is necessary to make any changes/ compromises in content in order to communicate consistent messages to receivers of different types;
- whether complex systems for generating information (e.g. an expert system for care pathways) would be more effective than simple information/ patient data;
- consideration of preferences for navigation forms related to any information delivery.

The potential for collaboration was identified as multi-dimensional - across the health and social care divide, inter and intra-organisationally, and cross-professionally. The research identified areas where data sharing was a catalyst to multi-professional working. However, there were opportunities that had not been realised, especially at the level of 'generic' information, where informatics-related steps should be taken as a priority.

6. USER/ CARER PERSPECTIVE

6.1 INTRODUCTION

As well as examining the use of existing ICTs from the informatics perspective and the perspective of professionals who work with older people in the community, the research team also wished to consider the service user/ carer perspective. Carers, and the older people for whom they care, are potentially a key group in terms of improved information and communication. They may need to draw on a wide range of services from health and social care agencies, as well as the voluntary sector, and therefore require information on these services as well as other aspects of caring.

Questionnaire development involved the same iterative process used to develop the professional surveys. A number of key bodies were approached for information, including Age Concern, The Princess Royal Trust for Carers, The Carers National Association, and Carers Online. Following this, practitioners and fellow academics were contacted to examine potential routes of access to service users. Since most older people receiving formal NHS or social care will also have an informal carer, the best strategy for accessing the service user perspective was considered to be via their carers.

It also became evident that there were a number of difficulties in identifying and accessing carers. These included: the absence of a register of carers, leading to major problems in identifying carers through service routes; differences in carers' own perceptions and classifications of their role, reinforced by a reluctance to seek help in their caring role; and ethical issues in seeking input from an already burdened group of people, combined with the possible sensitivity of material to be explored. For these reasons it was decided to undertake some initial work locally prior to any survey.

6.2 SURVEY METHOD

Preliminary discussions took place with a range of individuals in health, social work, local government and voluntary agencies, in order to identify the optimum local route of access to carers of older people for a postal questionnaire survey.

South Warwickshire Carers' Support Services (SWCSS) was approached as an organisation in contact with and trusted by carers, along with other local organisations. This approach was used rather than attempting to ask local general practice staff to identify a representative sample because it was clear that many carers were not known to their general practitioner. It was also considered that the carer organisation's endorsement of any survey would help to improve response rates. A sample of carers was selected to include predominantly carers in contact with SWCSS, but also carers in contact with another support group (the local Parkinson's Disease support group), as well as carers identified from one surgery where the staff did use a flagging system to identify carers' medical records.

The survey instrument (postal questionnaire) was developed in close consultation with SWCSS. It was designed to explore: (i) carers' information needs and relevant aspects of the care giving experience and (ii) for those who were in contact with SWCSS, patterns of use of the carers' support services and any preferences in terms of future service developments. Information was also gathered on the demographics of carers and the people for whom they are providing care. The survey of carers, like the professional surveys, was targeted at those caring for older people. Where possible, scaled data were collected in order to enable quantitative analysis. To maximise response rate, we limited the amount of information collected in the questionnaire, assured complete anonymity, and indicated that findings from (ii) would be used to improve services for carers. The questionnaire was piloted before use. A copy of the final survey questionnaire is shown in Appendix 6.

6.3 CARER SURVEY RESULTS

6.3.1 Description of survey respondents

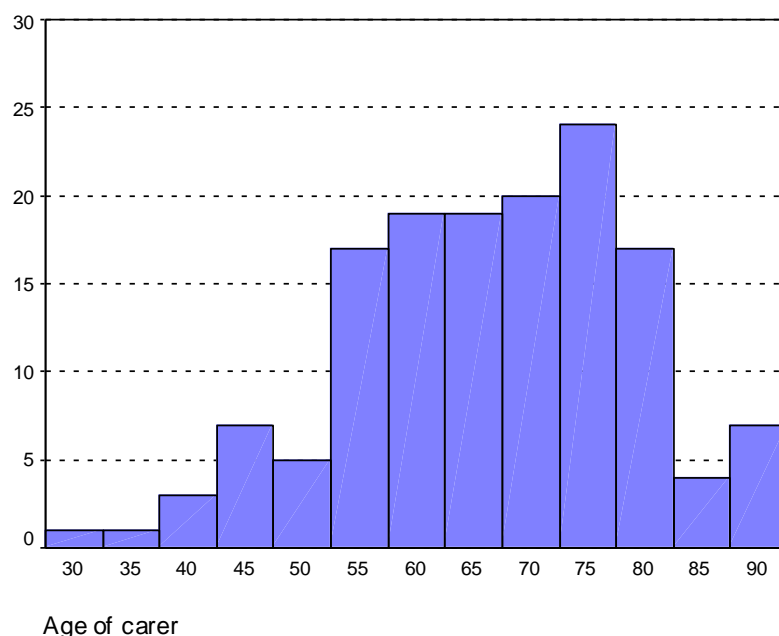
6.3.1a Carers' age and gender

A total of 150 informal carers completed a detailed questionnaire. Figure 6.1 shows that respondents had ages ranging from 30 to 92 years old. As a group they were relatively old with a mean (average)

age of 67 years; 54% were over 65 (this is high compared with nationally quoted figures e.g. Princess Royal Trust for Carers, 2002).

The majority of carers (71%) were female, but nearly one third (29%) were male. The mean age for male carers was higher (72 years, range 43-92 years) than for females (mean age 64 years, range 30-88 years). This difference is statistically significant ($p=0.002$).

Figure 6.1: Age of carers



Almost all carers (97%) described themselves as British/European White, 3 as Indian, and 2 as 'Other'. The survey, therefore, contained very few carers from minority ethnic groups. Most carers were from urban areas (61%), one third (34%) from rural areas, and 5% did not complete this question. There were no differences in the age and gender breakdown of urban and rural carers.

6.3.1b Carers' time spent caring

As has been demonstrated in other studies, carers reported that they devote a considerable amount of time to caring. Three out of four carers reported caring for 15 plus hours a day (including caring during the night as well as day). In fact, nearly two thirds of all carers (64%) reported that their carer role covered 24 hours a day. Only a small minority in the sample indicated that they cared for 4 hours or less a day (e.g. just a morning or afternoon); or up to 8 hours (e.g. during working hours). There was once again little difference between urban and rural carers in these statistics as is shown in Table 6.1 below.

Table 6.1: Time spent in carer role

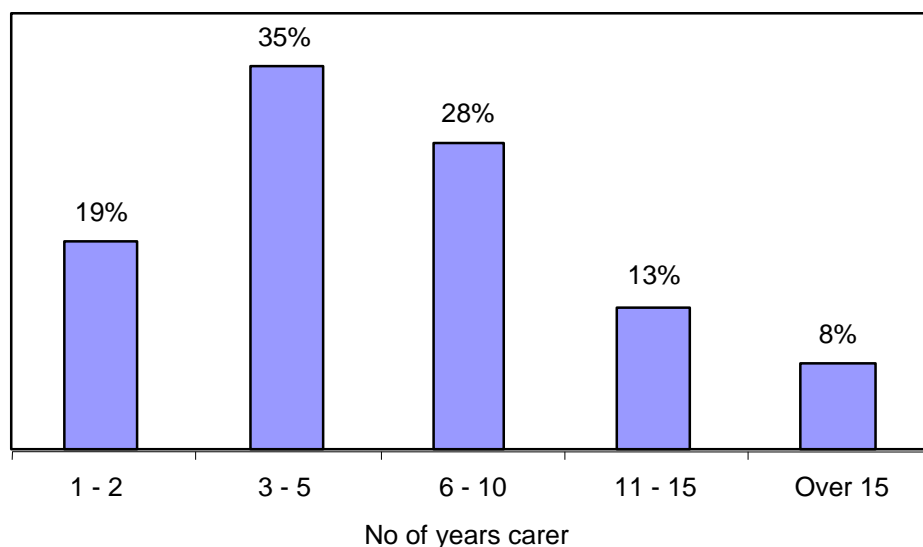
Location	Percentage spending this time on average caring per day			
	Up to 4 hours	4 – 8 hours	8 – 14 hours	15 + hours
All carers (urban and rural)	7%	6%	10%	77%
Urban (town/ city/ urban area) carers	5%	7%	13%	75%
Rural (village & isolated rural) carers	12%	4%	6%	78%

As might be imagined, most carers are not in employment. Over two thirds (69%) described themselves as retired. This figure was higher among males (80%) than among females (65%). Very few were working: 5% full-time and 9% part-time. One in ten (11%) were seeking work i.e. unemployed. A small number (3%) reported that they were doing voluntary work as well as caring. All but two carers gave details in response to this question.

6.3.1c Carers' experience levels

The carers who completed the questionnaire were in general highly experienced in terms of the number of years they had spent caring. Those who provided this information (n=140) had spent, on average, 8 years acting as a carer. The range was from 1 to 62 years, and Figure 6.2 shows that half had spent six or more years in this role. Responses were comparable with national figures of one in four carers having been in that role for 10 years or more.

Figure 6.2: Number of year spent providing care

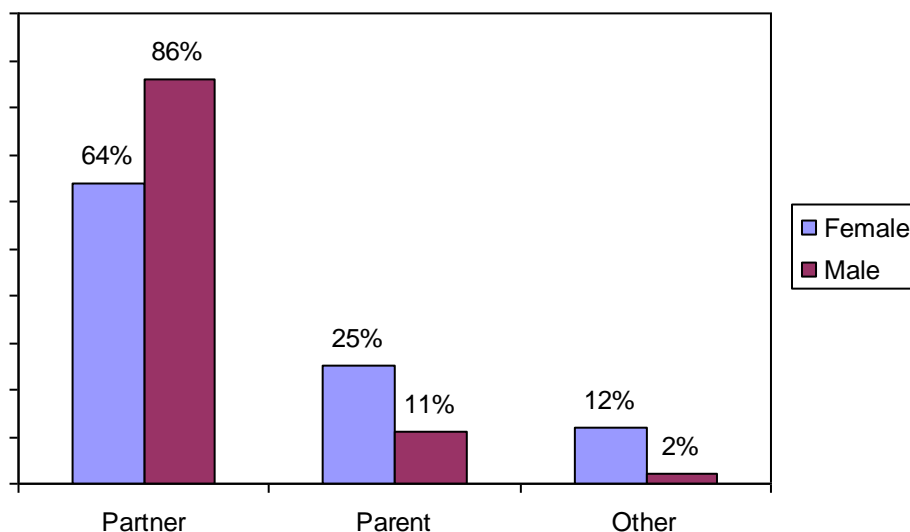


In terms of their own perceptions, the largest group of carers (42%) described themselves as 'experienced carers'. However, about 1 in 3 (30%) stated that they had only 'recently realised I am a formal carer'. One in ten (9%) stated that they were 'just beginning informal caring'. A similar number (12%) had 'recently finished caring'.

6.3.1d Carers' roles

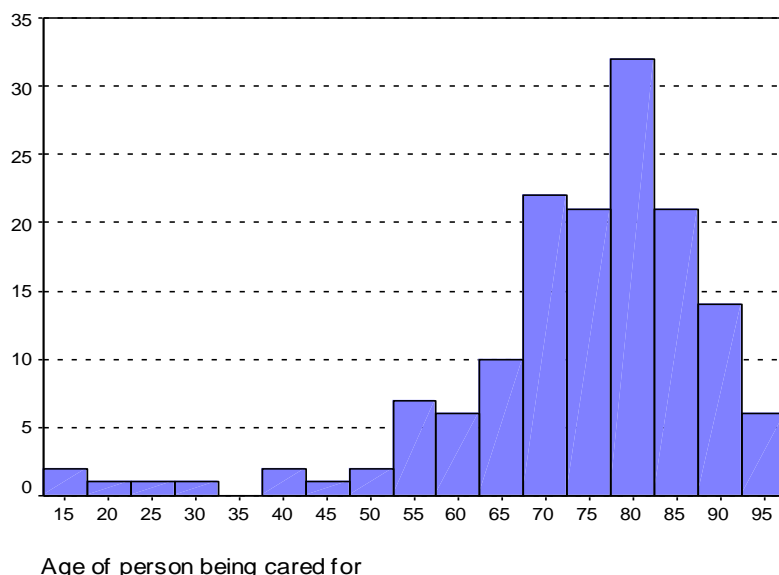
The vast majority of those who responded (90%) were caring for one person only. In most cases (70%) the person being cared for was a partner, more likely if the carer was male (see Figure 6.3). Women were more likely to be caring for parents or another member of the family.

Figure 6.3: The relationship to the person cared-for



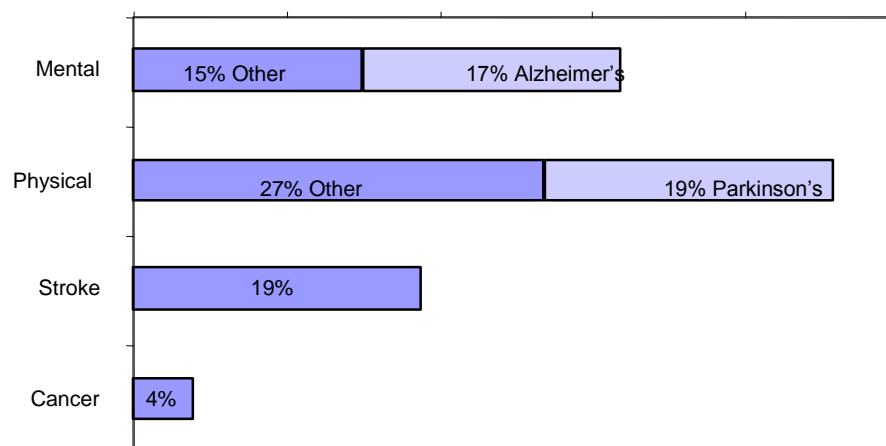
In general, the vast majority of those being cared for were 55 years or older. Figure 6.4 shows that the age range of those being cared for was 13 years to 96 years old (mean age 74 years), with a significant number of very old people (80+). This fits with national data that shows half of carers look after someone over 75 years old.

Figure 6.4: Age of cared-for person



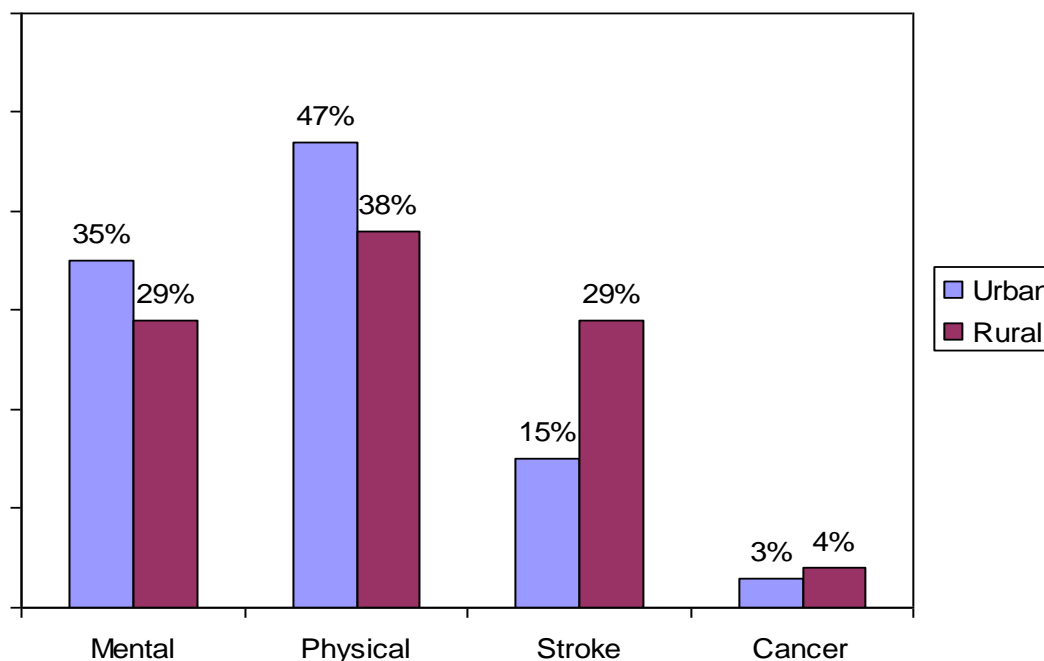
The condition that the person being cared for suffered from had varied. Approximately half had a physical condition, as shown in Figure 6.5. Parkinson's disease (19%) was the most common condition; a further 19% of those being cared for had had a stroke; and 4% of carers were providing care for cancer patients. Other physical conditions represented the remaining 27% of cases. Only one third of those being cared for were people with compromised mental health (32%); over half of these (17%) had Alzheimer's disease. The carers who responded were therefore principally providing care for older people with long-term conditions.

Figure 6.5: Types of conditions



These conditions did not vary significantly between urban and rural locations. As shown in Figure 6.6, slightly more rural carers in the sample were caring for stroke patients, but this difference was not statistically significant. There were no differences in the pattern of conditions cared for by male and female carers.

Figure 6.6: Types of condition by carer's location



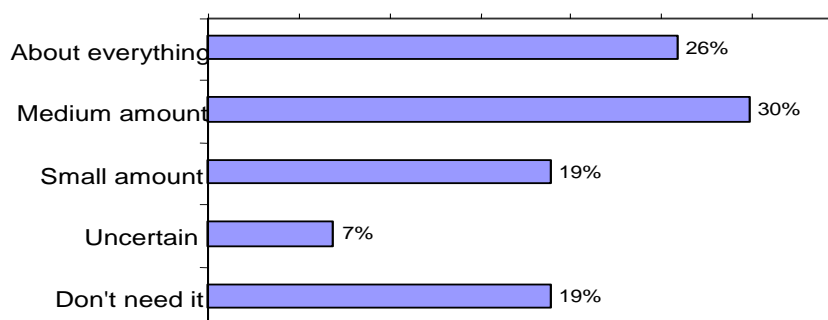
6.3.2 Views on general information needs and accessing information

The 150 carers who responded can be viewed as representative of carers nationally who look after older people. Their requirement for, and use of, information should therefore similarly be representative of carers more generally.

6.3.2a Key areas of general information needs

Carers were asked to quantify and describe their current information needs. Figure 6.7 shows that, even though the group is relatively experienced, of those who responded (n=139) three quarters considered that they were in need of information (albeit at different levels).

Figure 6.7: Carers' current information needs



Only 19% of carers reported that they didn't need further information at all. One in four carers (26%) identified a need for information 'about everything'. There was no significant difference between the pattern of female and male responses.

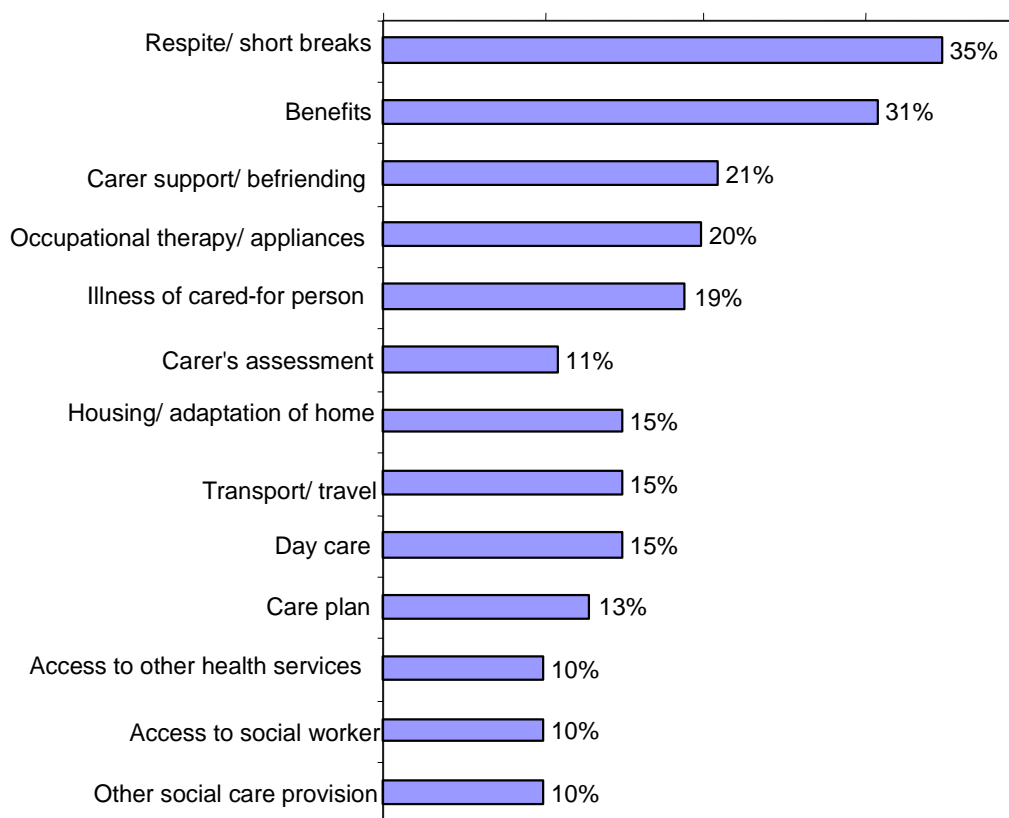
The types of information required by carers are shown in Figure 6.8. This demonstrates the need for a broad spectrum of information.

One in five (19%) of carers wanted more information on the illness of the person they are caring for; one in eight wanted information on the person's care plan (13%); and just over one in ten wanted information on the carer's assessment (11%).

The most important (identified by over one third of carers) was information on access to respite care or short breaks, closely followed by information on benefits. Following this, there was a need for information on access to various other services, most importantly carer support and befriending services (21% of respondents). Other types of information need included (in rank order) occupational therapy, housing, transport, day care, access to social worker, and other health and social care services.

Once again, there was no difference in male and female carers in terms of their main information needs.

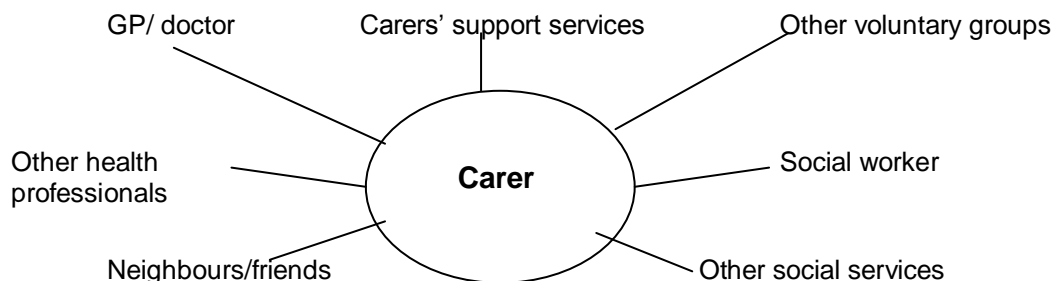
Figure 6.8: Main types of information needed



6.3.2b Carers' current sources of information

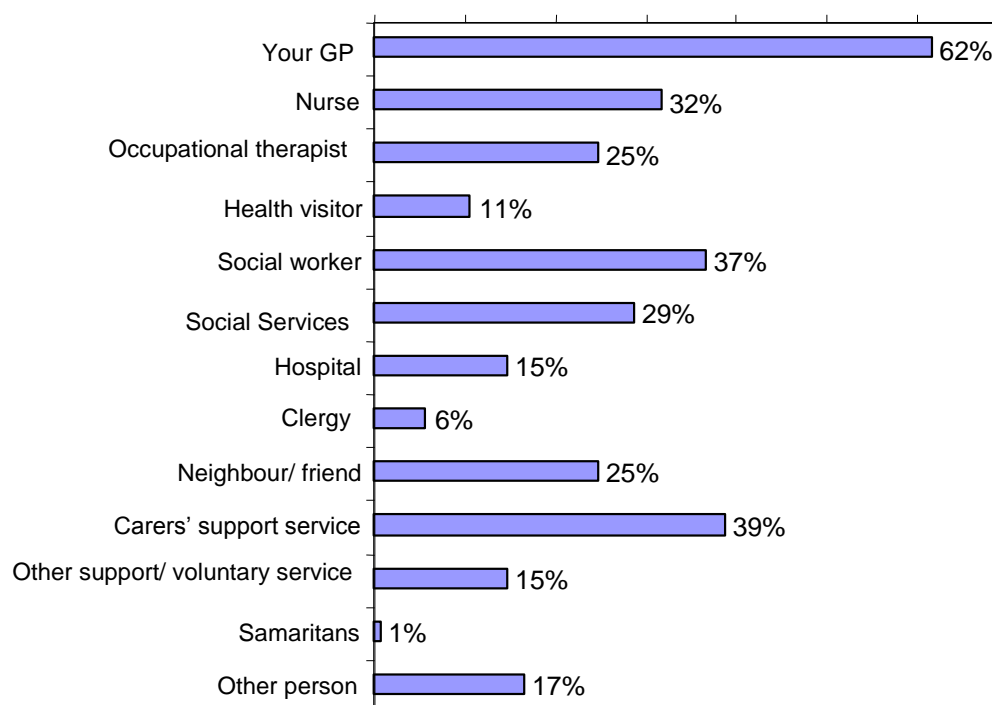
Initial interviews identified that carers may turn to a number of sources for the information they need, as the Figure below shows.

Figure 6.9: Potential sources for carers' information



Carers in the sample were asked who they would mainly approach for information and advice. Figure 6.10 below shows that carers will make use of a broad range of sources, but the most important one is GPs (62% of carers). Social workers (37% of carers) or nurses (32% of respondents) were the next most important, after a carers' support group (39% of respondents). There were no differences in the pattern of responses for male and female carers.

Figure 6.10: Main sources of information currently used



6.3.2c Carers' views on their information needs and current information provision

Figure 6.11 provides a profile of carers' views on current information provision as expressed through their agreement (strongly agree or agree) with specific statements about information and communication.

Clearly, carers consider information as crucial to their carer role, with 84% rating it as important in their role as a carer. A high percentage (74%) had found the information provided useful to their

caring role. However, only half (58%) of this relatively experienced group of carers considered that their needs for information were generally met, and two thirds (64%) reported that they had not known who to ask for information when they needed it. Only just over half (53%) reported that the information they received from professionals was of good quality. Nearly three quarters (71%) reported that information from carers' services was helpful (88% of those who had made contact with a carers' support service), and 68% had received useful advice by chatting to friends.

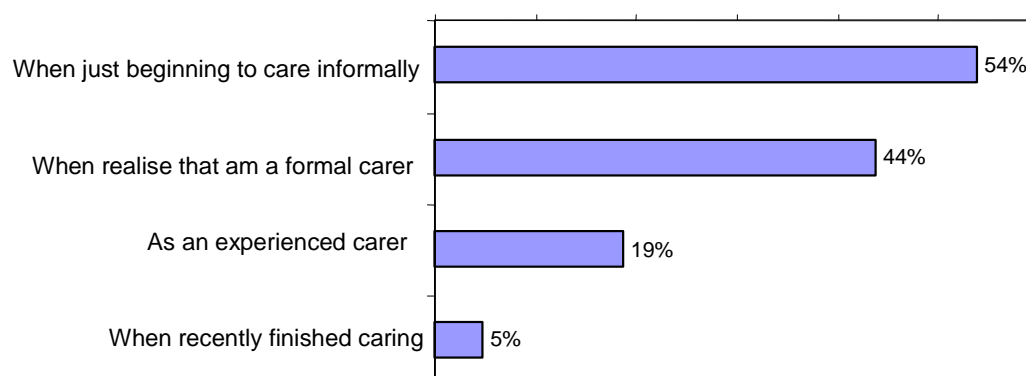
Over half the carers had found it difficult to get information at the time they need it (57%); a similar proportion had received useful information too late (58%). Interestingly, nearly half of these experienced carers (48%) were able to identify instances where they were unaware that they needed information, suggesting that leaving the onus on individual carers to ask for advice and information is not sufficient. One in four of the group (26%) reported that, as a carer, it was difficult to ask for information, reinforcing this conclusion. Only one in five (21%) felt they were over burdened with information, or had been given information that was inappropriate (21%). Only half the group agreed that 'when I have a problem there is someone there I trust to talk to'.

There were no significant differences between male and female carers in response to all these questions.

Figure 6.11: Carers' agreement with the following statements about information provision



Carers were also asked, based on their own experience and knowledge, to identify at which stages they consider that carers most need information to help them in their role; respondents could, if they wished, identify more than one stage. Figure 6.12 shows that, overall, carers identified the point at which someone is just beginning informal caring (before they realised they are actually a carer) as the key point for relevant information to be communicated to the carer. Almost as important is the point at which an individual realises they are now a 'carer'. Although fewer identified experienced carers as most needing information, the percentage reporting this was still sizeable (19%). Relatively few selected 'when finished caring' (5%); 12% of the sample had recently finished caring.

Figure 6.12: Stages in the carer's lifecycle at which information is most needed**6.3.2d Carers' preferred means of accessing information**

Information can be provided to, or accessed by, carers in a number of ways. These are listed in Table 6.2, together with the percentage of carers who expressed a preference for a particular mode of communication (strongly prefer, prefer) or against it (would *not* use this method). The Table shows that the three most strongly preferred modes for accessing information are via the GP surgery, carers' brochures or information leaflets and carer support services. Closely behind these, the next three preferred modes are via the telephone, face-to-face (e.g. at an advice bureau), or via a carers' support group (rather than a service).

There was less widespread preference for other modes of accessing information. Only one in ten carers would prefer to use their own computer, a similar number would prefer the radio or (slightly more) the television as a source of information. Very few (<1%) expressed a preference for accessing information via someone else's computer (e.g. a relative's, friend's or in the library) or touch screen kiosks.

Table 6.2: Preferred means of accessing information.

Method of accessing information	<i>Preferred (%)</i>	Would not use (%)	No view expressed (%)
<i>Via GP surgery/ health centre</i>	55	1	31
<i>Brochures/ information leaflets</i>	53	3	29
<i>Carers' support services</i>	53	2	30
<i>By telephone</i>	48	2	31
<i>Face-to-face e.g. advice bureau</i>	45	5	35
<i>Carers' support group</i>	39	7	34
<i>Via television</i>	14	19	38
<i>Via radio</i>	11	22	39
<i>Using own computer</i>	11	38	38
<i>Via digital TV</i>	5	47	41
<i>By fax</i>	5	53	41
<i>Touch screen kiosk</i>	<1	48	42
<i>Using other computer (e.g. library, relative)</i>	<1	48	43

These preferences were examined by age of carer, gender and location (urban or rural). Table 6.3 presents an overview of these findings. If a particular sub-group expressed a stronger preference (sometimes only slightly) than other groups this is indicated; where there was no evidence of an age, gender or location preference a dash (-) is entered in the Table. Modes of communication are presented in this Table in rank order for the whole group's preferences, as in Table 6.2.

For the three preferred modes of accessing information there is no evidence of differences apart from a slight preference by the over 75's and by males for accessing information via a GP's surgery, compared with younger carers and female ones. Rural carers also expressed a slightly greater preference for carers' support services than urban carers. There is no difference in the age and gender breakdown of urban and rural carers, as explained in section 6.3.1a.

As might be expected, contact by telephone was preferred by the over 75's and by rural carers, and younger carers and males (slightly) expressed a preference for face-to-face advice bureau contact. Carers' support groups was preferred by those under 75 years of age and (slightly) by urban carers, presumably because access may be easier for both these groups. Women expressed a slightly higher preference for accessing information via computer and radio, although this may be linked to the fact that female carers were slightly younger (see section 6.3.1a). Generally, those who stated a preference for using a computer, either their own or someone else's, or digital TV were younger carers. Finally, people over 75 and urban carers (slightly) expressed a preference for touch screen kiosks, but the number of responses was so low that it is not possible to draw any conclusions.

Overall, the preferred means of accessing information make intuitive sense, with the preferences of older carers (more than 75 years old) being for access via telephone or the GP's surgery. Rural carers prefer telephone or carers' support services. Evidently, other modes of communication (e.g. computer) are preferred by the younger group of carers (less than 65 years old), by women and by urban carers (both slightly). However, the number of respondents selecting these modes of accessing information was low, as shown in Table 6.2.

Table 6.3: Preferred means of accessing information by age, gender, location

Method of accessing information	Preferred (Total %)	Preference by age group	Preference by gender	Preference by location
<i>Via GP surgery/ health centre</i>	55	>75 (slightly)	m (slightly)	-
<i>Brochures/ information leaflets</i>	53	-	-	-
<i>Carers' support services</i>	53	-	-	rural
<i>By telephone</i>	48	>75 higher	-	rural
<i>Face-to-face e.g. advice bureau</i>	45	<65 higher	m (slightly)	-
<i>Carers' support group</i>	39	<75 higher	-	urban (slightly)
<i>Via television</i>	14	-	-	urban
<i>Via radio</i>	11	<75 higher	f (slightly)	urban
<i>Using own computer</i>	11	<65 higher	f (slightly)	urban (slightly)
<i>Via digital TV</i>	5	<65 higher	-	-
<i>By fax</i>	5	-	-	rural (slightly)
<i>Touch screen kiosk</i>	<1	>75 higher	-	urban (slightly)
<i>Using other computer (e.g. library, relative)</i>	<1	<65 higher	-	-

6.3.2e Preferred means of accessing carers' support

As well as coming into contact with health and social services staff in their carer role, individuals also had direct contact with the voluntary sector. Approximately two out of three respondents (63%) were carers with experience of accessing a voluntary carers' support group. On average, carers reported that they had had contact with the carers' support group four times in the previous year. The frequency of contact ranged from one contact in the previous year to 52 contacts (i.e. once a week), with one quarter having been in contact over 10 times or more.

Figure 6.13 shows the ways in which these 95 individuals contacted the carers' group. Over two thirds (68%) had made contact via the telephone, and half (50%) had received a home visit. Just over one in four (28%) had been able to attend a group, and a similar proportion (25%) had attended a social event. Approximately one in five (21%) had been in contact by letter. A few (8%) had made use of the befriending service (a new service set up by the voluntary group). Male carers tended to report more frequent use of the telephone than female carers (86% of males versus 60% of females, $p=0.01$).

Figure 6.14 illustrates the most valued types of support that carers' had received from the support group.

Figure 6.13: Type of contact that carers have with voluntary support group

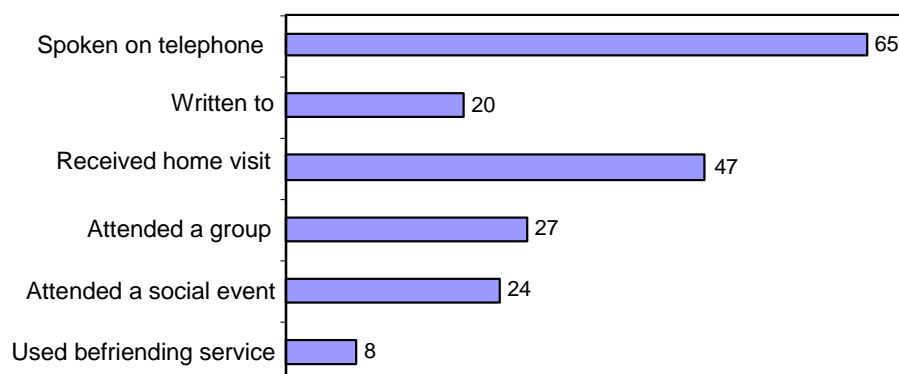


Figure 6.14: Types of support carers report as being most helpful

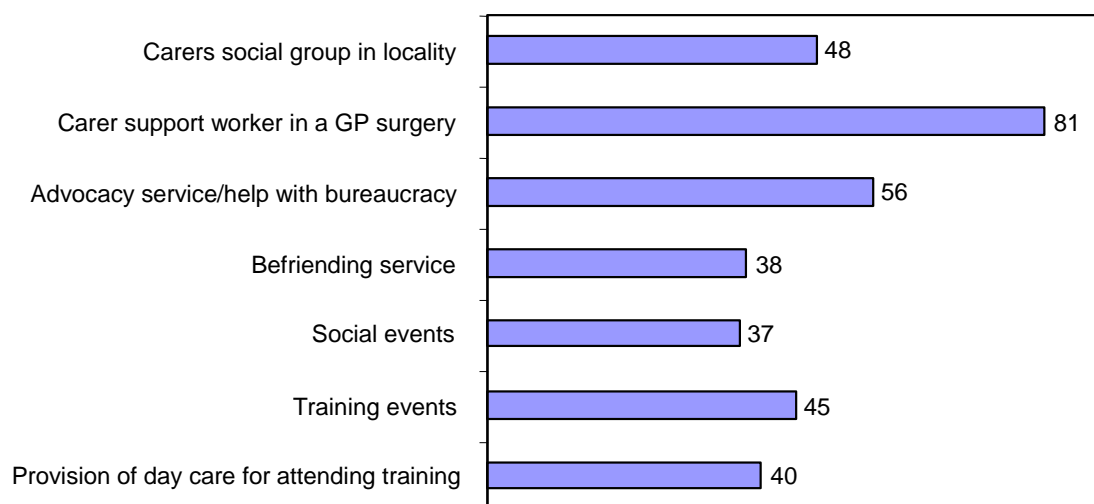


From Figure 6.14 it is clear that the most important service provided is ‘someone who listens’. Associated with this are ‘links to other carers’, ‘befriending service’ and ‘counselling’. However, the voluntary sector organisation also appears important in addressing many of the information needs shown in Figure 6.8. These include information on benefits, respite care, day care, short breaks, aids / adaptations and transport. Help with sign-posting to other organisations for help was also highly valued. Concrete help in filling in forms, for aids and adaptations and housing advice were also identified as useful services by carers. When carers were asked about training, one in four were interested to receive training in computer skills and to learn how to use the Internet.

6.3.2f Carers' suggestions for future development of carers' support

When asked what services the voluntary sector should develop in the future, the most important service identified by carers was access to a support worker in their GP surgery (see Figure 6.15). This was followed by a request for advocacy services, in other words not just provision of information but also active help with making use of the information provided e.g. in accessing support, filling in forms etc.

Figure 6.15: Future support service developments wanted by carers



Carers would also value the provision of a carers' social group in their locality. A similar number wanted training events, with most requesting provision of day care facilities to enable them to attend such events. Development of a befriending service and provision of general social events were also identified as important. In terms of all these responses, there were no significant differences between male and female carers.

However, there were important differences depending on where a carer lived. Urban carers were significantly more interested than those in rural areas in developing a ‘carer support worker in a GP surgery’ (69% v 47%, $p=0.05$). It may be that rural carers would prefer to access information via telephone (see Table 6.3) rather than travelling to the GP surgery. This may be associated with transport difficulties, since it does not appear that rural carers are tied for longer hours to the person for whom they are caring (see Table 6.1).

6.4 CONCLUSIONS: USER/CARER PERSPECTIVE

The carers who responded to our survey had an average 8 years experience, longer than the median number of years reported by all professional groups except practice staff (see Table 5.2). Even so, they still reported the need for a broad spectrum of information. Most of this related to the services they and the person they care for need, including respite care, benefits, carer support, OT/adaptations, housing, transport, day care, social worker, and other health and social care services. In addition, one in five carers wanted more information on the illness of the person for whom they are caring. Carers look to

various professionals for information and advice; the most important ones being GPs, followed by social workers and nurses/health visitors. Carers' support groups are also important.

Overall, well over half the carers surveyed had found it difficult to get information at the time they needed it or had received information too late. A significant number of carers could identify instances where they were unaware that they needed information, and similarly reported that it was difficult as a carer to ask for information. This suggests that services that leave the onus on individual carers to ask for advice and to identify their own information needs must be replaced by a more *proactive* approach. The most important stage at which carers considered information has to be provided is when someone is just beginning informal caring. Once again, this argues for the need for professionals to proactively identify individuals who are starting to care and to provide them with information judged to be of most importance by their more experienced peers.

In terms of the preferred means of accessing information and advice, the three most strongly preferred modes were via the GP surgery or health centre, via brochures / information leaflets or through a carers' support service. Only one in ten would prefer to use their own computer, and even fewer (<1%) another computer (e.g. a relative's, friend's or in the library). Therefore, communication (via a trusted provider GP, carers' service) and in written form is preferable. There were slight differences based on age or location. Overall, the preference of older carers (over 75 years) was for access via the GP's surgery or by telephone contact, whereas rural carers expressed a preference for access via the carers' support services or telephone. Computers were mostly preferred by the younger group of carers (less than 65 years old), by women and by urban carers. One in four carers expressed an interest in training in computer skills and learning how to use the Internet.

Voluntary carers' groups were an important source of valuable information and support, by providing 'someone who listens' and links with other carers. They also acted as a source of valuable information on benefits, respite care etc. plus supplying concrete administrative help (e.g. in filling in forms) and help with aids and adaptations. From the perspective of carers, information services could best be improved by providing access to a support worker based in GP surgeries.

7. DISCUSSION

7.1 A Challenging Context

Since community-based staff are peripatetic, many NHS and Social Services professionals working in the community are isolated from other professionals and information sources in their day to day activities. Improved use of existing ICTs could potentially provide a means of making information available at the point of need, and also making such 'lone' professionals feel supported and part of a wider team. However, effective provision of ICT support for these professionals presents a range of challenges as well as potentially providing benefits. Although various authors have studied ICTs in healthcare in Europe [Constantelou & Zambarloukos 2003] and in America [Warschauer 2003], no large-scale UK study has, to our knowledge, looked at these issues. We have examined health, social care and voluntary sector (carer and support group) views on improved ICT use based on data provided by 686 professionals and 150 carers.

In order to study the actuality of, and possibilities for, improved use of ICTs by professionals in the community, the study team elected to focus on one section of service users. Since the needs for information to support integration of care delivery for all isolated patient/ client groups could not be addressed in a single study, older people were selected as the focus for our research. The project therefore principally explored the needs of the various professional groups who support this circumscribed but important cohort of the population.

Older people are a rising proportion of the population in Europe - 20% of England's population are currently over 60 years of age, and the number of individuals aged 85 years and over is set to triple over the coming 30 years, with long-term care spending predicted to quadruple in real terms by 2031 [Pickard et al 2000]. While not wishing to reinforce a negative model of ageing (the 'poor dear' syndrome) [Hochschild 2000; Bernard 2000] this does mean that increasing numbers of people are likely to spend a greater proportion of their later life at risk of complex and chronic age-related disability. Whilst older people do not reflect the whole spectrum of populations served by health and social care staff, it was considered that an examination of existing ICT use and information needs of professionals who support such a group should result in generalisable findings for a number of other populations. A study focused on older people and their informal carers could also highlight any commonality of information requirements for service users, and contribute to an assessment of the feasibility of extending information services to a wider population.

The findings of the project highlight many of the challenges associated with improving the use of existing ICTs by health and social care professionals in the community. The research was undertaken during a period of major change (1999-2003) within a complex and fluid context that resulted from various policy changes in areas such as: improved partnership working between health and social care; enhanced informatics; and an increased focus on service users and their carers. Each of these areas is now briefly considered in turn.

7.1.1 Health and Social Care Integration

It is recognised that harmonisation of health and social care services should improve management of capacity across the interface, enhance service delivery, and encourage provision of information to service users and their informal carers. Fragmentation of health and social services is recognised to result in service duplication, abreaction between professionals, ineffective use of scarce resources, and overall threats to patient/client wellbeing [Department of Health 1998g]. The concomitant fragmentation of information and duplication of informatics services between organisations is similarly accepted to be inefficient and to present a major barrier to the availability of patient-centred information to professionals and informal carers. Thus, any move towards an integrated or partnership approach to health and social care will require harmonisation of ICTs between these two distinct sectors, both of which have already invested large amounts of money and organisational effort in their IT and information processes [Department of Health 1998b, 1998e & 1998g; Department of Health 2002b; Wanless 2002].

The agenda for integrated or partnership working between the NHS and Social Services proved to be an important policy driver during the study. The Audit Commission defines partnership as a joint working arrangement where partners are independent bodies who co-operate by the creation of a new organisation structure or process to plan and implement a joint programme through the *sharing of*

relevant information, risks and rewards in order to achieve the same goal [Audit Commission 1998]. Prior to the project start, the Government had issued a wide range of strategic guidance to encourage partnership between health and social care agencies in order to promote the health and well being of local populations, and enhance quality and performance [DoH 1997a; DoH 1997b; DoH 1998a; DoH 1998b; Department of Environment, Transport and the Regions 1998]. Improved joint working between health and social care is a long standing Government issue [Means *et al* 2003]. The 1999 Health Act moved the agenda forward by enabling health and local authorities to pool budgets for specific clusters of services and also to delegate overlapping commissioning responsibilities. The ostensible rationale for improved inter-agency working in community services was two fold: i) to place the *service user and carer at the centre of care* by ensuring equality of access to services, and multidisciplinary input to meet user needs, and ii) to *reduce pressure* upon, and inappropriate (re)admissions to, the secondary acute sector [e.g. Foresight Ageing Population Panel, 2000; DoH 1997c, Audit Commission 2000a; Audit Commission 2000b; DoH 2000a]. The NHS Plan [DoH 2000b] set out a new organisational structure for achieving this i.e. Care Trusts. These were established as 'single, multi purpose legal bodies to commission and be responsible for all health and social care' by the Health and Social Care Act (2001).

Inter-agency working was also encouraged through the publication of two National Service Frameworks (NSFs). First, one for adults with mental health problems [DoH 1999a] and then one for older people [DoH 2001a]. The NSF for adults with mental health problems stressed that its implementation would 'require new patterns of local partnership', with mental health a cross cutting priority for all NHS and social care staff and their partners [DoH, 1999a]. Similarly, the NSF for older people stressed new options for inter-agency working, confirming the introduction of a single assessment process across health and social care [DoH, 2001d], and highlighting a £900 million investment in intermediate care to reduce so called 'bed blocking' and support early discharge [DoH, 2001c]. The White Paper, *Valuing People* [DoH, 2001b], established an objective of promoting holistic services 'through effective partnership working between all relevant local agencies in the commissioning and delivery of services'.

All of these initiatives underline the importance placed by Government upon improved interworking for health and social care within the overall modernisation agenda during the course of the study. These inter-agency activities were expected to develop through *enhanced use of information and communication technologies* [Department of Health 2001e & 2001h].

At the same time, over this period there were a number of broader organisational changes which indirectly impacted on the ability to move forward with this informatics development. Probably the most important on the health side was the introduction of Primary Care Trusts, since this necessitated focusing considerable effort on other activities rather than joint informatics development plans. At the same time, *Shifting the Balance of Power* [Department of Health 1998e] also introduced Strategic Health Authorities —organisations which would negotiate informatics service provision contracts on behalf of their constituent organisations with Local Implementation Strategies (LIS) in Health and Local Information Plans (LIP) in Social Care cross-referencing each other.

In the first study site, the realignment of the Community Trust to the South Warwick PCT meant that resources for informatics development were not being made available as rapidly as first envisaged. The hospital sector in general 'suffered' from supposed (hypothecated) allocation of funds for informatics being diverted to more pressing priorities such as waiting list reduction. Staff time was also directed to single sector initiatives. In Leicester, major organisational change not only included the formation of the PCTs, but the hospital trusts were also merged to deliver unified working across the three acute hospitals in Leicester city. Furthermore, in the Leicester study area, Social Services plans were focussing on the roll-out and support of a new version of their own management system (CareFirst) rather than on the interface between health and social welfare working. In Warwickshire, the transition of responsibility, accountability and workload to the PCT from the Community Care Trust was taking the major part of staff time. Although a joint sector Mental Health initiative was just starting in Warwickshire, and proposals were being developed to integrate the provision of mental health services across the health and social care community in Leicester, the pilot development of SAP was the major project involving both sectors. The National Service Framework for Older People had collaborative target elements for health and social care. As the NSFs were performance monitored very closely, both localities anticipated that the technology necessary to the delivery of these would have to be prioritised.

7.1.2 Informatics

The agenda for informatics was also changing significantly during the period of the study. *Information for Health* had acknowledged that the track record of the NHS in benefits realisation from investment in IT was relatively poor. There were a number of strategic documents emanating from this document. Included among these was *Information for Social Care* which contained similar social care objectives [Department of Health 2001e]. As a result, initially the convergence of informatics for health and social welfare across England seemed quite clear cut with *Information for Social Care* mirroring *Information for Health* but with later target dates. Elements in the former which required significant field worker informatics enablement included the single assessment process (SAP) for older people (target date April 2002), and direct access for front line staff to technology including email and Internet (target date October 2002).

Subsequent to *Information for Health*, the *Building the Information Core* (BIC) update qualified the original targets for informatics to support health [Department of Health 2001f]. This was followed in mid-2002 by the *Delivering 21st Century IT Support to the NHS* document [www.doh.gov.uk] indicating that the targets for the NHS were so onerous that Social Care Informatics targets from *Information for Social Care* were being suspended for the time being. Thus, complexities in the NHS programme required slippage to the published targets for Social Care, although the principles recommended would be applicable once convergence was re-prioritised. Not only was this slippage a challenge for Health, it was also felt to be delaying Social Services strategic use of information [Information for Social Care and the Directors of Social Services (ADSS) [website www.adss-img.org.uk].

In healthcare, much discussion was focused on developing an Electronic Patient Record (EPR) for health to be in use by 2005. For Social Services, there was a similar expectation i.e. that “all records will be held and maintained in electronic form”, with the date set for the e-social care record (ESCR) being October 2004 [Department of Health 2001e]. Where services were combined, communities were considering developing a combined e-record for health and social care (EHSCR). E-sharing was integral to the vision of a “seamless” service across “whole systems” and supported by ongoing governmental funding to finance (re)investment in modernising systems [Office of the e-Envoy, Cabinet Office. 2001]. It remained unclear however, how such a combined approach could be applied in practice, and our study revealed that professionals in both locations were debating how best to proceed in order to tackle these issues.

The introduction of e-government also represented a major challenge for health and social care staff at this time. E-government encompassed the many initiatives that were ongoing to interconnect government departments effectively, and to position them to be able to respond to the general public electronically by 2005, from all departments. The e-government agenda was centred on the Government’s commitment to provide an improved and informed ‘customer-focused’ access to government online resources [www.iagchampions.gov.uk]. All public services organisations were subject to the e-government agenda which required them to communicate between like organisations by 2003 and with lay persons by 2005 for all transactions. In addition, the House of Commons Public Accounts Committee, in its report *Improving Public Services through e-Government* (September 2002), expressly charged providers to do more to encourage people to use e-services, *particularly older persons* and the less well off.

Finally, in 2002 the Wanless Report was published which stated its aim ‘to universalise the best’ and ‘to identify the key drivers of health need and cost over the next two decades’. One of the *main drivers indicated was informatics* into which the report suggested major investment be made; this was ratified by the Treasury in the Budget 2002 Spending Round. Welcome for the principles was almost universal but there was some concern about the detail of what would constitute effective investment in informatics; for example, whether it included funding wider elements such as additional skilling of clinical professionals, investment in breaking down the boundary between health and social care, and questioning ‘how future *elderly people’s* demands for healthcare are likely to differ ... changing expectations related to health service use’ [Wanless 2001].

Thus, health and social care staff were both facing challenging ICT and organisational agendas during the course of this study. Both organisations had already made, and were planning to make further investment in ICT infrastructure, and it was felt that this further investment should reflect the particular priorities, expectations and starting point of the individual organisations concerned. On the service provider side, the immediate challenge for ICTs was *how to extract the maximum from existing*

infrastructure in order to facilitate joint health and social welfare working, and to carefully introduce new technology where most appropriate. This was set against a backdrop of shifting targets and target dates. On the service user side, there was also increasing pressure for professionals to improve use of ICTs for provision of resources for the public.

Inevitably, both the integration and informatics agendas had an effect on the views of professionals over the period of the project. Our research findings in terms of the professional perspective should therefore be viewed within a background of changing organisational and ICT agendas, and also the changing context for older clients/ patients and their carers.

7.1.3 Older People and their Carers

An important group of patients/ clients for whom an integrated approach to health and social welfare services is required are the elderly. An 'ageing society' calls for increasing levels of inter-agency support since older people are often the main users of health and social care services. For many, the nature of this support, and the individual level of sustenance needed, is complex and multi-faceted.

Unfortunately, service and system failings can lead to provision of care for older people that is far from ideal. This results in increased rates of inappropriate hospital admissions and premature admissions to care homes. The NSF and other government documents (e.g. the White Paper *Modernising health and Social Services*, [Department of Health 1998b]) all called for improved, integrated approaches to service provision for the older citizen, emphasising the need for partnership between the NHS, social care, councils and other agencies to provide the most appropriate care. Before implementing SAP, both health and social services were expected to review the *information they provided for older people's services*, and the formats in which this information was available. The NSF requirements in relation to the NHS were mirrored by the Best Value programme for Social Services. This required that each separate County Council produce a plan annually that addressed services across all its areas, monitoring service quality improvements and the Care Standards Act (2000) that had set national minimum standards for care delivered outside the NHS for older people e.g. in care homes [www.carestandards.org.uk].

For many older patients/ clients in the community, informal carers clearly make a major contribution to care provision. It has been estimated that in the UK such carers annually provide long term care that would cost £34-44 billion if it were provided formally; this compares with estimates of £7 billion for institutional care and £3.1 billion for professional home care [Nuttall 2001]. Equally significant, however, is the associated relationship between older people and caring: being elderly and being a carer and being elderly and being cared for, most often by an elderly carer. One half of all carers in the UK look after someone aged over 75 and over a quarter of all carers (27%) are themselves over 65 years. In addition, Government's Actuary Department projections indicate that many more elderly people are likely to receive informal care in the next thirty years than had been previously projected. One reason is that the number of widows is set to fall and this will give rise to more elderly women with partners. This implies that spouse carers are likely to become increasingly important. It also raises concerns about the need for support and improved information for informal carers, since spouse carers themselves tend to be elderly and often in poor health.

During the study period, the National Strategy for Carers was published [HM Government 1999]. This acknowledged that technology could have an important role to play in developing support for carers, especially by providing up to date and easily accessible information. A large amount of data for carers could be made available through the Internet, including relevant details of health and social care (collated on Government sites) and details of services for carers and benefits (provided by carer related sites e.g. Princess Royal Trust for Carers, Carers UK, Crossroads, Age Concern etc). The case for increased use of the Internet to provide information for isolated carers was made by carers' organisations themselves. For example, at the launch of the Royal Trust for Carers website:

'we have always said that information technology was what we really needed to develop around the network of Carer Centres because by definition a 'Centre' is not an obvious place for a carer to go because on the whole they don't get out very much...and we will always try to develop a method of reaching those carers who cannot get to a centre....but still need the services and still need the information.... still need the support' [May 16th 2002 HRH The Princess Royal address].

However, the actual access that carers had to the Internet was only scantily documented. This was at least partly due to difficulties in identifying carers in the population [The Princess Royal Trust for

Carers 1999]. Enthusiastic earlier predictions for IT use in this group [e.g. Sixsmith 1994] did not appear to have been met, although such findings were by no means universal. Other work appeared to dispel the belief that elderly people and modern technology are incompatible. For example, the Net Value Survey 2000 found that Internet use by people aged 55 and over in the UK had increased by 90% between March 2001 and February 2002; it also noted that within Europe, the UK has the highest percentage of 'Silver Surfers' [Net Value 2002].

7.2 Critical Issues Underpinning Study Findings

Within this context of changes in partnership working, a revolution in informatics, and a heightened emphasis on the role of carers, the research identified a number of critical issues that underpinned our study findings.

7.2.1 Spare ICT Capacity & Access

One objective of the study was to examine the intensity of use of existing IT infrastructure in order to identify spare capacity. Surveys of community locations and professional groups and related interviews were used to determine how much time was currently spent by different professionals using a computer and whether there was spare capacity available in systems that could be utilised to address potentially shareable information and improve communication.

Surveys of different locations identified a large variation in the apparent intensity of use of terminals. Low values in many sites reinforced the idea that existing equipment was not fully utilised, and that there could be improved use made of existing infrastructure. However, more detailed examination showed that this notional spare capacity might not in reality be useable for a number of reasons. For example, certain physical locations were off limits to other staff (e.g. GP consulting rooms) or not accessible at certain times (e.g. when clinics held in a room). Also, premises might be manned for a limited number of sessions during the week and therefore any notional spare capacity could not be accessed e.g. branch surgeries. Even if accessible, terminals may be designated for certain functions and unavailable for other purposes (e.g. terminals at a reception desk). Most importantly, the working practices of field-based staff in both sectors meant that they were only occasionally 'in the office', rendering much of the spare capacity identified of little use. Responses to the large scale postal surveys of professional groups produced a picture of low levels of usage by many staff, especially community nurses, at least partly linked to their work patterns.

Rationalising access to systems across the two sectors was also constrained by other factors related to differences in established usage. In some locations use involved shared server facilities with other local authority departments. Furthermore, the inter-working of Social Services with other public organisations like the police increased the reluctance to share intranet access where sensitive data could be thought to be in jeopardy. NHS staff similarly were sometimes not prepared to share information with regard to more vulnerable groups, such as older people, because of concerns about the working practices of other professional groups: *"The problem is it does boil down to where does that information go then? There are some social workers that I wouldn't share some information with because I've known them react bizarrely - and one learns from that."* (Interview general practitioner). All staff in both sectors had their data protection responsibilities spelled out in either their job specifications or separate documents.

A constant issue in both the health and social care domain was reported to be access to the Internet. During the course of the study Internet use had increased exponentially in both public use and the number of health-related sites. It had therefore become a viable medium for cross-sectoral data sharing, subject to privacy regulations, the strength of the protective firewall around sensitive procedures and data, the robustness of the 'service', and the commitment to broad band (fast) access in the near future. However, returns from our surveys and interviews showed that many existing end-user access points and potential users were not Internet-enabled. This was for a number of reasons:

- dumb terminals were still prevalent in many GP systems;
- selected end-user access points were restricted in the functionality one could use (library/ reference terminals and senior staff had the main Internet access);

- access was limited by the permission vector for particular users, which limited what an individual staff member could access. This might be through an organisational decision about levels of empowerment or the fact that the individual had not yet undergone requisite training.

Thus, local policy on who was allowed to use terminals for what purposes (governed by password permissions) could significantly limit general utilisation of any notional spare capacity. As a result, some staff did not have access to equipment enabled to support specific applications or functions which they required and were competent to use. To turn notional into *useable* spare capacity, there would need to be re-designation of permissions, training of staff, re-siting of equipment, and/or re-organising of work patterns.

7.2.2 ICT Environment

The changing technological environment opened up the option to recommend the placement of shareable data in one location, on the Internet. Initially, it was envisaged that the integrity of the NHS intranet would be paramount in any shared information strategy. The situation at the start of the study therefore required duplicate 'mirror' data outside the firewall to facilitate sharing and to support the other (non-NHS) professional groups who were within the focus of our project. During the course of the research this ceased to be the case. There was increased acceptability nationally of the Internet as a vehicle for carrying shareable information. The NHS Code of Connection and improved firewall protection facilitated connection to the Internet. In addition, many more of the NHS dumb terminals observed in our survey that would not allow Internet access at all had been withdrawn during the study. For example, GP application suppliers Torex and InVision reported a considerable migration of the ratio of dumb terminals to PC workstations. Torex went from 45%:55% in 1999 to 27%:73% in 2002; InVision went from a similar start point to 10%:90% in 2002. In addition, the national strategies for informatics in support of health and social care and the overarching e-government framework had also legitimised the utilisation of the web, through their use of Internet technologies themselves.

There were major changes in NHS suppliers in both localities over the period of the study, plus a newer version of the prime application in Social Services. More volatile through the period of study than in the recent past was the number of acquisitions and mergers amongst NHS suppliers, following which efforts were focussed commercially on rationalising portfolios and re-positioning the collective brand offerings. Many of the GP practices in the Warwick area had changed their systems (either just the version or in a significant proportion the supplier too). The volatility in the application vendor market was national, and although Leicester Health seemed to have almost reached a homeostasis viz GP systems, there had been considerable change to achieve this state. For various reasons, including the pace of technological change, the reducing cost and rapid obsolescence of equipment, the emerging ubiquity of technology outside the working environment and the greater articulation of demands for technological competence by all professions, the goal posts of the research moved significantly during the course of the study.

Thus, even if shared data were to be available, for example via the Internet, harmonising the disparate technological infrastructures, ways of working and informatics architectures of the combining bodies, or at least making them interwork effectively whilst legacy systems continued to be used, was considered to be a challenge. As more PCs were introduced as desk tops, and as more professionals were empowered to work 'smart', from home or on the road, technology could selectively be opened up to access the Internet in a number of ways. These ways could either be dependent on individual password definitions or the physical location and status of the equipment, as was demonstrated by the policies of the Warwick and Leicester agencies. Both sectors would need their staff to undergo training and awareness, and would have to cover the costs of enablement/ licensing Internet use.

The main issues raised from the informatics perspective included:

- a considerable shortfall in training, in how to use the available applications, in effective use of information, and in creating protected time in which to train
- a willingness to extend the ad hoc sharing of information between friends to a more formal arrangement
- difficulty in utilising any spare capacity in existing configurations because of various factors.

If health and social care content and applications could be accessed through generic Internet procedures, then a wider professional audience would be able to view, comment, use and validate the material thereby achieving confirmation of shareability and content at a speedier rate. Delivering

information on a just in time basis to wherever it is required could contribute to the aim of providing professionals working in the community with access to information resources to support their work. As the location of any care, treatment or support may vary over time for a variety of reasons, the use of point to point connections is limiting and may not be cost-effective in this type of situation. Instead, a more flexible vehicle for delivery is needed.

However, as observed in other studies, the main challenges for improved use of ICTs appeared to be cultural rather than technical [Coleman and Glendinning 2001; Callaghan *et al.* 2000; Myles *et al.* 1998]. These included differences in professional perspectives, in particular professional tensions between health and social services cultures, with a GP/medical perspective seen as being too dominant by some from social services, and NHS staff observing that social service staff adopted a slow and bureaucratic approach to care: *So what you are saying is that Social Services have different criteria? "Absolutely - different criteria, mm. Different model, call it what you want. But we have been trained to this I suppose - you run - don't you?" (Interview community nurse).*

Those interviewed also identified differences in corporate attitudes, for example, to use of the Internet and ways of opening up the Internet to their users.

Other issues that emerged in Warwickshire during ICT interviews related to the pressures of meeting current strategic targets, maintaining data quality over professional boundaries, the rapidly emerging place of the web in informatics to support health and welfare, and the funding of ICT-related activity in general. These concerns were repeated in the Leicester area. Additionally during the period of the study, the Wanless report recommendations [Wanless 2002] and the subsequent Budget review plans required time and effort to put into place, resulting in a blight on developments being reported in the research sites. In a review by the King's Fund [Banks 2002] of joint working between the NHS and local government, although positive signs of progress were reported, similar challenges were also identified, including the question of local sustainability in face of high national political pressure, the effects of continuing reorganisation, and an integration limited to health and social services with the exclusion of a wider range of local government services and other sectors. These all emerged as important issues in our interviews with professionals.

7.2.3 Professional Perspective

It was generally accepted in both sites that the use of existing ICTs in the community setting was intermittent and that additional service support material might, in principle, be made available through current configurations at a minimal marginal cost with considerable potential benefits for service improvement. Identifying and also facilitating a shared managerial vision was essential to realising this benefit. But the development of a shared inter-organisational vision was not enough. The positive views of senior management were not necessarily apparent in survey responses or interviews with front line staff. As research by Peck *et al* [2002] on inter-agency work between health and social care has indicated, there is often a gap between the enthusiasm of senior managers and the level of real improvement in the services provided. One explanation for this is the considerable disruption and uncertainty produced by most inter-agency arrangements [Alter & Hage 1993]. Also important is the evidence that any such effect will be magnified in times of rapidly changing policy [Hoggett 2001]. This was clearly the situation during the study period.

Rhetoric abounds on the subject of technology for health and social care in the context of rapid change to improve care [Appleby & Coote 2002]. Senior managers may spend too much time analysing policy statements and second guessing estimating the next initiative [Spurgeon 1999]. Preoccupation with policy change can distract attention from operational aspects of care delivery. Yet it is the operational aspects of care that engage most health and social care staff. Some of this operational versus strategic dichotomy was evident in our findings. The research took place in a continually changing environment and a seemingly steady stream of policy documents, many relating to care of older adults. Executive and senior management meetings and interview data have a different 'flavour' (strategic) to events reported by staff working at the (operational) level of care delivery. However, the findings also highlight much good will with genuine attempts by all groups of professionals to improve information sharing and to communicate effectively to deliver appropriate and good quality health and social care.

It was accepted that electronic information systems could play a significant role in improving communication and access to information. However, there was much debate on how best to integrate information to achieve a "whole" system that focused on individuals. In practice, this appeared to be difficult to achieve due to differences in culture and values, and associated issues of confidentiality and

training, rather than due to the technology itself, as has been reported by other researchers [Kluge 2001, Mitchell & Sullivan 2001]. Inhibitors to cultural change may operate across all levels of the organisation, and include underdeveloped support systems, staff shortages, inadequate training for staff, and different professional perspectives which impede relationships [Banks 2002]. From our findings there was clearly a need to break down barriers between health and social care professionals who had traditionally operated in parallel, especially general practice staff. There was also a need to position the participants for convergence, and to indicate to other potential users how best to position for future joint health and social welfare information working. Such changes were difficult to achieve against a fluid technological and organisational background.

Although there was clearly the potential for improved utilisation of existing ICTs, organisational use of computers for communication in the workplace was already well established. The various groups of professionals demonstrated different patterns of computer use. This was in addition to the differences in systems. There was also a lack of integration between health and social care e-records for information sharing. An important issue, therefore, is the development of protocols for identifying data that is 'shareable' between organisations. Health and social welfare sectors might not agree on either terminology or professional philosophy. This is part of a wider context in which professionals working across boundaries encounter differences in language and culture [Davies 1998] that may contribute to 'professional tribalism' [Peckham & Lee 2001, Beattie 1995]. This was illustrated by research findings such as: *"They don't get into our computers and we don't get into theirs"* ((Interview Social worker).

Barriers to good communication may be due to a fundamental lack of understanding of how other professionals work and the type of information they might need, with information being viewed as 'hit and miss' or too little and too late. This was especially an issue in relation to hospital discharge letters: *"There is never mention of physio, OT or social worker involvement [...] and if I refer them to Social Services, as a GP, Social Services may not tell me exactly what they've done. [...] I wouldn't necessarily get anything at all, unless they organised a case conference. [...] So yes, mm, it's very hit and miss."* (Interview general practitioner).

Professionals were aware that various reports had highlighted the need to invest in technology to improve the UK's information technology for health [Wanless 2002] and stressed the importance of technology for sharing information in inter-agency working [Department of Health 2001e, 2002b]. They also acknowledged that information sharing in inter-agency work was not always as good as it might be [Bainbridge 2002]. Fewer than half of respondents rated communication as being good or excellent and many identified a 'need for improvement', underlining the importance of intersystem communication connectivity and training. Although e-communication would seem ideally placed to strengthen and build on professional relationships to enhance good practice, inter-agency teams were felt to work best when people knew each other (*"you know who communicates well"*) and had opportunities for informal meetings (*"we meet regularly as we share the same building"*). Thus, human factors rather than the technology itself once again emerged as a key issue for sharing of information.

Use of electronic means of communication (e-mail) was very low. Given the data on Internet access points, professionals' responses on Internet use would appear to be low, even allowing for some professionals who experienced restricted net-rights. When asked if they used e-mail to facilitate communication in similar situations to those given in the scenarios, fewer than 5% of professionals said they shared information this way (slightly more likely for GPs and social care staff). Data from the in-depth interviews confirmed low levels of e-mail and Internet use. Professionals reported that they used computers more for audit purposes, data input into e-records/forms and generating 'activity reports' rather than for communicating with one another or extracting information: *"I feel like I'm an automaton. I have to feed that computer so much! I would say that about 98% of my time is spent at my desk. I'm either on the telephone or I'm on the computer feeding information in."* (Interview hospital social worker).

Information sharing was reported to be problematic by some professionals in relation to inter-agency work because of differences in IT systems. In the social care group, where nearly one in three (30%) reported using an internal system to communicate with colleagues, individuals were unable to communicate with other professional groups due to incompatibility of systems.

"This is extremely complicated - because the Social Services Department has just implemented a new computer system. However the Mental Health Team doesn't necessarily use it [...] as a health team we are driven more by the health service, therefore we are tending to use more health systems. [...] a new

system is being put in. We rarely use it. [...] We don't have any systems that would be appropriate for the work i.e.[would] do. So therefore we don't really use the information systems as we could do.
“(Social worker).”

Nearly all professionals in this study used message books for information sharing. Electronic record keeping was reported to be difficult in practice when caring for their clients/ patients, and some staff thought technology might even be a barrier in care delivery [Mitchell & Sullivan 2001]. In a busy community setting, the most widespread means of communication for both health and social care staff were established technologies such as the telephone and fax (93% of professionals). Only 85% reported even having access to a computer in the workplace. Very few (<5% of overall sample) reported using other ‘new’ technologies such as hand held devices (e.g. Palm top or similar); with mainly health care professionals saying they used these in their work. Information kiosks were also being used by very few staff (<5%).

Interview data acknowledged that management faced challenges in trying to increase professionals’ use of IT. *“Some of our practices (i.e. in primary care) have only recently i.e. within the last, sort of, six to twelve months been computerised. Now that doesn't mean they are using their computer - it means that they are 'computerised'” (PCT professional).*

Survey responses also revealed that many staff did not have computer training, being either self-taught or learning on the job. Thus, one of the barriers to improved ICT use found in this study was the lack of training, especially in health where only a minority had received training. There are a number of issues to be addressed here. One is the establishment of a culture of ICT usage and e-communication [Whitfield 2003]. Another issue seems more intractable, namely the discomfort people feel at opting for training where hard-pressed colleagues are not easily able to provide cover for them.

Furthermore, the training given to professionals appeared to be very limited and did not follow a pattern that could be extrapolated:

- training was limited to the functionality of the application used in day to day work, rather than in general informatics awareness or information issues;
- training was only provided at the time of initial system implementation; subsequent refresher training, training in enhanced functionality and the induction of new staff was ad hoc and delivered by existing more proficient users;
- self-development in the use of the Internet, office tools and other software was external and personally-driven.

Many professionals surveyed identified the need for proper and in-depth training as a priority. The LIS targets required all professionals to be competent to use core systems and to be aware of major (health) informatics concepts. Interviews with Social Services staff in both study areas indicated that Internet training and access were being rolled out quite slowly due to cost and the need for wide scale upskilling to get the best from such technologies.

Much of the non-application-specific training was acquired on the job from peer guidance or by self-initiated study. In such cases, some staff requested official recognition for their competencies, for example the ECDL qualification. The ability to handle information technologies, an understanding of data quality, and an ability to work with shared data in multi-professional or even multi-sectoral teams, were not universally identifiable. There was a need for wide-ranging additional training based around these competencies. This was substantiated by other competency matrices [NHS Information Authority 2002] and in the capacity and capability theme in the RADICAL STEPS initiative [British Computer Society 2002].

There are no complete solutions as yet for many key issues raised by professionals in this study. In terms of actions in support of improved use of existing ICTs that could be delivered quickly or on a longer term basis, and that should be addressed to get the most benefit out of the huge investment in informatics, typical observations included the need for:

- a code of ethics for all workers (inside and outside the health service) who access health information ;
- establishment of protocols to facilitate consent being passed between organisations, retaining identification of the responsible person;

- seamless data across sectors and between departments. Ways of achieving this should be explored with the potential players;
- ruthless standardisation to be put in place for cross-sectoral linkages and shared systems use – defining what clinical and technological areas are to be included / excluded;
- a clear picture of how Social Services, Housing, and private healthcare (e.g. care homes) are envisaged as interacting with the NHS;
- systems (or service) specifications that include a flexibility requirement to accommodate changing working practices/ shifting boundaries/ increasing multi-disciplinary team working.

This study tells us about the current state of information sharing and ICT use in health and social care. In an area of such complexity the results indicate that there is no one clear message. Much of the current debate is about computer-related issues for information sharing and about identifying drivers for change. However our research highlights a more fundamental topic, which is the need for agreed shared information, also identified from other studies (e.g. Canada) [Leonard et al 2000]. Much current information sharing is fragmentary and sporadic, and different groups hold separate pieces of the puzzle. The prior need is to determine who should view what information and in what context before focusing on computer use and e-sharing. The study identified the need for feedback and increased interaction between users and information systems personnel. Increased ICT use has enormous potential to contribute to a seamless approach in care. However, it must be emphasised that this will be conditional upon consultation with, and continuous reference to, users in the workplace for any such information-sharing system to be successful. Hagerdoorn *et al* [2000] also argue that it is crucial for policy authorities who aim to support such arrangements to be aware of the varied reasons for participation among, for example, private, public and voluntary organizations.

While much goodwill was evident, and many professionals expended considerable effort to share information, frustrations abounded and e-communication was viewed as a bewildering challenge. Writing about accessing information in current care Richard Horton states, “we are in a phase of uncertain transition. Information is all around us but it is hopelessly disorganized. There are huge gaps in the information available” [Horton 2003]. It would also be as well to remember that investment in information technology for care may not result in increased productivity. This has become known as the ‘productivity paradox’ [Macdonald 2002]. A great deal of other work has to be done if electronic systems are to help provide a fully integrated care approach.

7.2.4 Older people and public access

Although the carers we surveyed were experienced (average 8 years as a carer), they still reported a wide range of information needs. These included items relating to social services and to health care e.g. details of welfare rights, carer organisations, advocacy groups, social workers, therapists, equipment sourcing etc. Also, information in support of ‘everyday living information’ ranging from straightforward questions on where to access aids, to wider social and environmental services, including for example transport etc.

It is evident that systems could be developed that further organise and collate such information for carers. Much potentially shareable data is not person-specific, for example items, like information leaflets, facilities’ opening hours, and health and specialist services - which could readily be shared with carers. Other items, like those describing familial relationships and socio-economic conditions, will require sensitive privacy issues to be faced before wider use can be realised in practice. A central repository for information storage would help meet the information needs of carers [Chambers 1997]

The method by which carers of the elderly and older users prefer to source information is also important. Such information could be made accessible to carers via GP surgeries, libraries or other locations. Emery et al (2002b) noted in their research on elderly carers that it was not only the information which was important but the way that information was provided. They observed that: “*the method of information delivery for older people should always be the method that the individual finds most useful. This can include word of mouth, use of telephones, paper-based media, television, radio or use of the Internet*”. Our findings indicate that carers would prefer verbal information delivered via a trusted source such as the GP surgery or through a carers’ support service, or information in written format (brochures / information leaflets). The majority of carers in our sample had found it difficult to get information at the time they needed it, had received information too late, or were unaware that they needed information. These findings have been replicated in other studies such as CarePlus, where

elderly people were critical about current methods of dissemination or targeting information [Emery et al 2002a].

Only one in ten of carers would prefer to access information through the Internet. This is despite considerable developments in technology, and the availability of electronic information. In order to help maximise further usage of IT, it is important to understand the reasons behind this reluctance. There is some evidence to suggest that the internet focuses on affluent users and ignores those who are carers, women tied to the home, or without formal employment [Fabian Society 2001]. Given the experience level of the carer group in this study, one solution to this problem could be to let such users choose and compile information of most use to their communities. The 'Careplus Programme' in Sheffield adopted such an approach to provide older people with access to high quality, local, customised health and social care information. Despite this the majority of users still preferred to use other media for information delivery, including word of mouth and paper. Acceptance of an IT-based solution appeared to depend on: being able to afford to buy and run a computer at home or having transport to a computer access point, and receiving training, support and facilitation. There are also indications that carers will access systems if they have a specific information requirement. Web statistics confirm that among older users there are low levels of searching and browsing usage behaviour [Emery et al 2002a].

A crucial point to note, however, is the importance of the quality of the information being accessed; how relevant it is to the client; how it is grouped/collated and managed. Previous work has suggested different approaches to improving and integrating information for elderly people in an effort to provide an appropriate acceptable vehicle of communication. Findings from *Better Government for Older People* include creative, innovative and tailored outreach activities; the integration of information (and delivery) between agencies; and active involvement of older people [Hayden & Benington 2000].

There is complex interrelationship between IT use for information access and a number of other factors. For example, information improvements may be achieved by transport improvements. Also, where financial barriers prevent people getting their own computer but dedicated silver surfing time at local libraries can counteract this.

Our results indicate that carer help in GP surgeries would be route to follow if there is unwillingness by the elderly to use IT, and a preference by older people to have someone facilitate computer use. Slow acceptance would also indicate the need for further research on acceptability of information mediums for carers and patients.

7. Conclusions

From our analysis, we can make a strong case for the added value of cross-sectoral sharing of non-person-specific data. In addition, there is evident demand for sharing of person-identifiable data, subject to further privacy issues being resolved. Notional spare capacity is present in current configurations, but cannot always be realised due to a number of factors. Internet-enablement of end-user access points and the training of potential users in effective Internet use will help facilitate data sharing without jeopardising sensitive data and in-house procedures. Benefits will be realised by informing current computer users of the wider value of their data, in addition to meeting their expressed needs for further joint access to existing data in a controlled cross-sectoral way. There is a demonstrable demand, articulated in this study, for increased access to technologies in the workplace by both sectors, and the demand for establishing a technologically robust environment, conducive to collaborative working, is increasing. There are, however, residual concerns about current configurations, not only professional data sharing but also citizens' and voluntary agencies' demands for more information. The project identified much information that, once shared between professionals, could also be usefully made public. This will not be possible if the chosen solution for sharing requires access to an intranet where other, non-public, data resides. The increased use of joint patient care plans could be expedited by putting outlines on the web, to inform patients, their carers, and the professionals, involved about the general direction of care. Further work will be needed if specific individual client plans are required. Data input from multiple locations presents challenges in update management, change tracking, data security, authentication, audit, and multiple use.

However, many professionals still operate paper-based systems. Even where the users indicated the availability of computer systems, they did not feel secure enough to terminate their paper-based message books. Work is still needed to demonstrate that informatics is safe not threatening.

Facilitating joint working may be the trigger necessary to remove many doubts. There were many interesting ideas from the study about what data could usefully be shared - including syntheses of bulky official reports, generic protocols and guidelines, templates for joint care programmes - which could form the basis of later developments.

The facilitation of any data sharing in this complex socio-technical environment should be carried out sympathetically taking account of the multiple stakeholders in each sectoral environment separately. Pressures from citizens for like data are emerging rapidly so these demands should be addressed sequentially, rather than as separate disjoint exercises. The competency gap amongst professional end-users should urgently be addressed through work-based or recognised initiatives in order to achieve equity and consistency, currently being challenged by sporadic official learning activities, home-based computer access, and self-learning. Our study indicates that the Internet will allow an efficient transition from inter-professional data sharing to a scenario where patients/ clients can have robust access to the same data.

BIBLIOGRAPHY

- ACRE. (1998). *Rural Life: Facts and Figures*. Cirencester: ACRE.
- Ala, A.B. (1997). The desk-top computer as a magic box: patterns of behavior connected with the desk-top computer; GPs' and patients' perceptions. *Family Practice*, 14(1): 17-23.
- Alter C and Hage J (1993). *Organisations Working Together*. Newbury Park, CA: Sage.
- Aneshensel, C.S., Pearlin, L.I., Mullan, J.T., Zarit, S. H., Whitlatch, C.J. (1995). *Profiles in Caregiving: The Unexpected Career*. San Diego & London: Academic Press Ltd.
- Appleby, J. & Coote, A. (Eds.). (2002). *Five Year Health Check: A review of Government health policy 1997-2002*. London: King's Fund.
- Arksey, H., Hepworth, D. & Qureshi, H. (2000). *Carers' Needs and the Carers Act: An Evaluation of the Process and Outcomes of Assessment*. York: University of York, Social Policy Research Unit. DH 1743 6.00 HA/DH/HQ
- Audit Commission. (1992). *Lying in Wait: The Use of Medical Beds in Acute Hospitals*. London: HMSO. Dd 297924 12/94 C8
- Audit Commission. (1995). *Setting the Records Straight: A Study of Hospital Medical Records*. London: HMSO.
- Audit Commission (1998). *A Fruitful Partnership. Effective partnership working*. London, Audit Commission Publications.
- Audit Commission (2000a). *Services for older people*. London, Audit Commission Publications.
- Audit Commission (2000b). *Forget me not. Mental health services for older people*. London. Audit Commission Publications.
- Audit Commission (2000c). *A Step in the Right Direction: Lessons from Best Value Performance Plans*. London, Audit Commission Publications.
- Audit Commission. (2000d). *The Way to Go Home*. London: Audit Commission.
- Audit Commission. (2001). *Going Places: taking people to and from education, social services and healthcare*. London: Audit Commission.
- Aydin, C.E., Rice, R.E. (1991). Social worlds, individual differences, and implementation: Predicting attitudes toward a medical information system. *Information & Management*, 21: 119-136.
- Bainbridge, M. (2002). 'There's information in them there systems!' *Informatics in Primary Care*, 10:71.
- Banister, P., Burman, E., Parker, I., Taylor, M., Tindall, C. (1994). *Qualitative Methods in Psychology: a Research Guide*. Buckingham: Open University Press.
- Banks, P. (1999). *Carer Support: Time for a change of direction?* London: King's Fund.
- Banks P. (2002) *Partnerships under pressure. A commentary on progress in partnership-working between the NHS and local government*. Health and Social Care Policy and Development Department. London., The King's Fund.
- Barbour, R. S. (1999). The case for combining qualitative and quantitative approaches in health services research. *Journal of Health Services Research and Policy*, 4(1): 39-43.

- Bates, J. (2003). An evaluation of the use of information technology in child care services and its implications for the education and training of social workers. In J. Reynolds, J. Henderson, J. Seden, J. Charlesworth & A. Bullman (Eds.) *The Managing Care Reader*. London: Routledge.
- Baum, F. (1995). Researching public health: beyond the qualitative-quantitative methodological debate. *Social Science and Medicine*, 40(4): 459-468.
- Beales, D., Denham, M. & Tulloch, A. (Eds.). (1998). *Community Care of Older People*. Oxford: Radcliffe Medical Press.
- Beattie, A. (1995). War and peace among the health tribes. In K. Soothill, L. MacKay & C. Webb (Eds.). *Interprofessional Relations in Health Care*. London: Edward Arnold.
- Bernard, M. (2000). *Promoting health in old age: Critical issues in self health care*. Buckingham: Open University Press.
- Berwick, D.M. (2001). Quality Comes Home. In T. Heller, R. Muston, M. Sidell & C. Lloyd (Eds.) *Working for Health*. London: Sage Publications. In association with the Open University. (first pub in *Annals of Internal Medicine*, 125(10): 839-43. 15 Nov 1996)
- Blackler, F., Kennedy, A. & Reed, M. (1999). Organising for Incompatible Priorities. In A.L. Mark & S. Dopson (Eds.) *Organisational Behaviour in Health Care: The Research Agenda*. Basingstoke: Palgrave.
- Bond, J. & Buck, D. with assistance of Clarke, W. & Marsden, T. (1999). *Comparative Study of Social Protection for Dependency in Old Age in the United Kingdom*. University of Newcastle Upon Tyne, Centre for Health Services Research Report No. 82.
- Bond, J. (1990). NHS nursing homes. *Nursing Times*, 86(10): 54.
- Bond, J.(1991). National Health Service Nursing Homes Again: Commentary. *Age and Ageing*, 20: 313-315.
- Bond, J., Atkinson, A., Gregson, B.A., Newell, D.J. (1989). Pragmatic and Explanatory Trials in the Evaluation of the Experimental National Health Service Nursing Homes. *Age and Ageing*, 18: 89-95.
- Bond, J., Bond, S., Gregson, B. (1990). Care of the elderly: nursing homes and continuing care. *Nursing Standard*, 4(36): 38-40.
- Bond, J., Bond, S., Gregson, B. (1990). Care of the elderly: nursing homes and continuing care. Part III. *Nursing Standard*, 4(38): 35-37.
- Bond, J., Bond, S., Gregson, B. Donaldson, C., Atkinson, A. (1990). Care of the elderly: nursing homes and continuing care: Part II. *Nursing Standard*, 4(37): 21-23.
- Bond, J., Cartlidge, A.M., Gregson, B.A. et al. (1987). Interprofessional collaboration in primary health care. *Journal of Royal College of General Practitioners*, 37: 158-161. Bond, J., Farrow, G., Gregson, B.A., Bamford, C., Buck, D., McNamee, P. & Wright, K. (1999). Informal caregiving for frail older people at home and in long-term care institutions: who are the key supporters? *Health and Social Care in the Community*, 7(6): 434-444.
- Bond, J., Gregson, B., Smith, M., Lecouturier, J., Rousseau, N., Rodgers, H. (2000). Predicting place of discharge from hospital for patients with a stroke or hip fracture on admission. *Journal of Health Services Research & Policy*, 5(3), 133-139.
- Bond, J., Gregson, B., Smith, M., Rousseau, N., LeCouturier, J. & Rodgers, H. (1998). Outcomes following acute hospital care for stroke or hip fracture: How useful is an assessment of anxiety or depression for older people? *International Journal of Geriatric Psychiatry*, 13: 601-610.

- Bond, J., Gregson, B.A. & Atkinson, A. (1989). Measurement of Outcomes within a Multicentred Randomized Controlled Trial in the Evaluation of the Experimental NHS Nursing Homes. *Age and Ageing*, 18: 292-302.
- Bond, J., Gregson, B.A., Atkinson, A., Newell, D.J. (1989). The Implementation of a Multicentred Randomized Controlled Trial in the Evaluation of the Experimental National Health Service Nursing Homes. *Age and Ageing*, 18: 96-102.
- Bond, S., Bond, J. (1990). Outcomes of Care within a Multiple-case Study in the Evaluation of the Experimental National Health Service Nursing Homes. *Age and Ageing*, 19: 11-18.
- Bowers H. (2001). Developing inclusive mental health services for older people. *The Mental Health Review*, 6: 6-13.
- Bowers, B.J. (1987). Intergenerational caregiving: adult caregivers and their aging parents. *Advances in Nursing Science*, 9(2)20-31.
- Bowers, H. & Preece, D. (2000). Change and changing: risk management in the NHS. *International Journal of Healthcare Technology and Management*, 2, Nos. 5/6: 498-511.
- Bowling, A.(1997). *Research Methods in Health*. Buckingham: Open University Press.
- Bowling, A., Farquhar, M. & Browne, P. (1991). Use of services on old age: Data from three surveys of elderly people. *Social Science and Medicine*, 33(6): 689-700.
- Bradley, G., Penhale, B. & Manthorpe, J. (2003). Messages for managers: the dilemmas of means testing. In J. Reynolds, J. Henderson, J. Seden, J. Charlesworth & A. Bullman (Eds.) *The Managing Care Reader*. London: Routledge.
- Bridges, J., Cotter, A., Meyer, J. & Salvage, A. V. (2000). The progress of older people placed during the first year of the 1996 continuing care guidance. *Health and Social Care in the Community*, 8(2):147-150.
- British Computer Society Health Informatics Committee. Radical Steps Final Report (available at www.bcshic.org, accessed October 2002).
- Brodaty H. (1992). Carers: training informal carers. In T. Arie (Ed.): *Recent Advances in Psychogeriatrics*. Churchill Livingstone, London .
- Brown, J., Nolan, M. & Davies, S. (2001). Who's the expert? Redefining lay and professional relationships. In M. Nolan, S. Davies, G. Grant (Eds.) *Working with older people and their families: Key issues on policy and practice*. Buckingham: Open University Press.
- Brown, S.H., Coney, R.D. (1994). Changes in Physicians' Computer Anxiety and Attitudes Related to Clinical Information System Use. *Journal of the American Medical Informatics Association*, 1(5): 381-394.
- Bruce E. (1995). Support through human contact for family carers. In T. Kitwood and S. Benson (Eds.): *The New Culture of Dementia Care*. Bradford: Bradford Dementia Group.
- Buck, D., Gregson, B.A., Bamford, C.H., McNamee, P., Farrow, G.N., Bond, J. & Wright, K. (1997). Psychological distress among informal supporters of frail older people at home and in institutions. *International Journal of Geriatric Psychiatry*, 12: 737-744.
- Bull, M.J. & Roberts, J. (2001). Components of a proper hospital discharge for elders. *Journal of Advanced Nursing*, 35(4); 571-581.
- Burns A, Howard R, Pettit W. (1995). *Alzheimer's Disease A Medical Companion*. London: Blackwell Science Ltd.

Cabinet Office. (2001). *e-Government: Benchmarking Electronic Service Delivery: A report by the Office of the e-Envoy*. London: Cabinet Office. (Authors: Atkinson, M., Honeywood, A., Pomlett, F., Whittaker, A.

Callaghan G, Exworthy M, Hudson B and Peckham S, (2000). Prospects for collaboration in primary care: relationships between social services and the new PCGs. *Journal of Interprofessional Care*, 14 (1), 19-26.

Cartlidge, A.M. & Bond, J. (1986). *Collaboration among Professionals in the Delivery of Primary Health Care. Report No. 30*. University of Newcastle upon Tyne, Health Care Research Unit.

Cartlidge, A.M. (1987). *Collaboration: A study among Primary Health Care Professionals in Four London and Sixteen Non-London Health Authorities. Report No.32*. University of Newcastle upon Tyne, Health Care Research Unit.

Chambers MJ (1997). Using telematic interventions to meet older people's needs *Psychiatry Ment Health Nurs* 1997 Dec; 4(6):435

Chang, B.L., Brecht, M-L., Carter, P.A. (2001). Predictors of Social Support and Caregiver Outcomes. In A.I.Meleis (Ed.) *Women's Work, Health and Quality of Life*. London: The Haworth Medical Press.

Chau, R. C. M. & Yu, S. W. K. (2000). Chinese Older People in Britain. In A. M. Warnes, L. Warren & M. Nolan (Eds.) *Care Services for Later Life: Transformations and Critiques*. London: Jessica Kingsley Ltd., British Society of Gerontology.

Chin, H.L., McLure, P., Permanente, K. (1995). Evaluating a Comprehensive Outpatient Information System: A Case Study and Model for System Evaluation. *Proceedings of Annual Symposium for Computer Applications in Medical Care*, 717-21.

Clark, H. & Spafford, J. (2001). *Piloting choice and control for older people*. York: Joseph Rowntree Foundation.

Clarke- Carter, D. (1997). *Doing Quantitative Psychological Research: From Design to Report*. Hove: Psychology Press.

Clarke, C.M. (2001). Rationing scarce life-sustaining resources on the basis of age. *Journal of Advanced Nursing*, 35(5): 799-804.

Coleman A and Glendinning C. (2001). Partnerships. In: D Wilkin, S Gillam, A Coleman (eds). *The national tracker survey of primary care groups and trusts 2000/2001: Modernising the NHS?* Manchester, NPCRDC and London, the Kings Fund..

Constantelou, A. & Zambarloukos, S. (2003). Health-Care in the Information Society: Drivers and Barriers. *IPTS Report, Joint Research Centre, European Commission*, 76: 4-10.

Cordingley, L., Hughes, J. & Challis, D. (2001). *Unmet need and older people: Towards a synthesis of user and provider views*. York: Joseph Rowntree Foundation.

Cork, R.D., Detmer, W.M., Friedman, C.P. (1998). Development and Initial Validation of an Instrument to Measure Physicians' Use of, Knowledge about, and Attitudes Towards Computers. *Journal of the American Medical Informatics Association*, 5(2): 164-176.

Cox, J. & Mungall (Eds.). (1999). *Rural Healthcare*. Oxford: Radcliffe Medical Press.

Cox, J. (1999). Rural poverty, deprivation and health. In J. Cox & I. Mungall (Eds.) *Rural Healthcare*. Oxford: Radcliffe Medical Press.

Cozzi-Burr, H.A. (1992). Telephone Reassurance: A Social Support Intervention. In P. Winstead-Fry, J. C. Tiffany, R.V. Shippee-Rice (Eds.). *Rural Health Nursing: Stories of Creativity, Commitment, and Connectedness*. New York: National League for Nursing Press.

Crabtree H, Warner L. (1999). *Too much to take on*. The Princess Royal Trust for Carers.

Cropper, S. (1999). Value Critical Analysis and Actor Network Theory: two perspectives on collaboration in the name of health. In A.L. Mark & S. Dopson (Eds.) *Organisational Behaviour in Health Care: The Research Agenda*. Basingstoke: Palgrave.

Curry, R.G. (2001). *The use of information and communication technology (ICT) in assistive technology for older and disabled people: an overview of current UK activity*. Personal communication author, editor, UK National Database of Telemedicine.

Dalley, G. (2000). Defining Difference: Health and Social Care for Older People. In A. M. Warnes, L. Warren & M. Nolan (Eds.) *Care Services for Later Life: Transformations and Critiques*. London: Jessica Kingsley Ltd., British Society of Gerontology.

Davies, C. (1998). The Cloak of Professionalism. In M. Allott & M. Robb (Eds.) *Understanding Health and Social Care*. Buckingham: Open University Press.

Dawson, S. (1999). Managing, Organising and Performing in Health Care: what do we know and how can we learn? In A.L. Mark & S. Dopson (Eds.) *Organisational Behaviour in Health Care: The Research Agenda*. Basingstoke: Palgrave.

Dean, K. (1989). Conceptual, theoretical and methodological issues in self-care research. *Social Science and Medicine*, 29(2): 117-123.

Delamothe, T. (2002). Three new initiatives involving bmj.com. *British Medical Journal*, 324: 559-560.

Dening, T. & Lawton, C. (1998). The role of carers in evaluating mental health services for older people. *International Journal of Geriatric Psychiatry*, 13: 863-870.

Department of the Environment, Transport and the Regions. (1998) *Modern Local Government – In Touch with the People*, The Stationery Office, London. July (Cm 4014)

Department of Health. (1989). *Working for Patients*. London: HMSO.

Department of Health. (1992a). *The Health of Elderly People: An Epidemiological Overview*. Central Health Monitoring Unit: Epidemiological Overview Series. Volume 1. London: HMSO. Dd295170 C15 9/92 531/3 12521

Department of Health. (1992b). *The Health of Elderly People: An Epidemiological Overview: Companion Papers*. Health Care Division with Central Health Monitoring Unit: Epidemiological Overview Series. Companion Papers to Volume 1. London: HMSO. Dd295172 C15 8/92 531/3 12521

Department of Health. (1997a). *The new NHS: modern, dependable*. London: The Stationery Office. Cm 3807.

Department of Health. (1997b). *Better services for vulnerable people*. London, Department of Health

Department of Health. (1998a). *Partnership in Action*. NHS Executive. London, Department of Health

Department of Health. (1998b). *Modernising Health and Social Services: National Priorities Guidance*. London, Department of Health.

Department of Health. (1998c). *A First Class Service. Quality in the new NHS*. London: The Stationery Office.

Department of Health. (1998d). *Independent Inquiry into Inequalities in Health Report*. ('Acheson Report'). London: The Stationery Office.

Department of Health. (1998e). *Modernising Social Services: Promoting Independence. Improving Protection. Raising Standards*. London: The Stationery Office. Cm 4169.

Department of Health. (1998f). *Our Healthier Nation*. London: The Stationery Office.

Department of Health (1998g). *Information for Health*. London: Department of Health, 1998

Department of Health. (1998h). *Informal Carers: results of an independent study carried out of the behalf of the Department of Health as part of the 1995 General Household Survey*. London: The Stationery Office.

Department of Health. (1999a). *National Service Framework for Adult Mental Health*. London, Department of Health

Department of Health. (1999b). *Promoting Independence: Preventative Strategies and Support for Adults*. London: Department of Health Local Authority Circular. LAC(99)14

Department of Health. (1999c). *Saving Lives: Our Healthier Nation*. London: The Stationery Office. Cm 4386

Department of Health. (1999d). *Working in Partnership. Joint working between Health and Social Services in Primary Care Groups (PCGs)*. London: The Stationery Office.

Department of Health. (2000a). *The National Beds Inquiry: Care closer to home, answers for an ageing population*. London, Department of Health.

Department of Health. (2000b). *The NHS Plan: A plan for investment. A plan for reform*. London, Department of Health.

Department of Health. (2000c). *National Service Framework for Coronary Heart Disease*. London: Department of Health Publications.

Department of Health. (2001a). *National Service Framework for Older People*. London: The Stationery Office.

Department of Health (2001b). *Valuing People*. London, Department of Health.

Department of Health.(2001c). *Intermediate Care*. Health Service Circular/Local Authority Circular HSC 2001/01, January.

Department of Health (2001d). *The Single Assessment Process. Consultation Papers and Process*. London, Department of Health

Department of Health. (2001e). *Information for Social Care: A framework for improving quality in social care through better use of information and information technology*. London: Department of Health.

Department of Health. (2001f). *Building the Information Core – implementing the NHS Plan*. London: Department of Health.

Department of Health. (2001g). *Building the Information Core: Protecting and Using Confidential Patient Information. A Strategy for the NHS*. London: Department of Health, Information Policy Unit. <http://www.nhs.uk/def/home.asp>

Department of Health. (2001h). *Guidance on Integrated Services* London: HMSO.

Department of Health. (2001i). *Health Inequalities*. London: The Stationery Office.

Department of Health. (2001j). *The Expert Patient: A New Approach to Chronic Disease Management in the 21st Century*. London: Department of Health.

Department of Health (2002a). *Care Trusts: Demonstrator sites*. November, <http://www.doh.gov.uk/cartrusts/infodemosites.hmt>.

Department of Health. (2002b). *Delivering 21st century IT support for the NHS: national strategic programme*. London: Department of Health.

Department of Health (2003). Press Release 2003/0040 Health minister Lord Hunt announces next steps for new independent health and social care inspectorates. <http://info.doh.gov.uk/doh/intpress.nsf/page/2003-0040?OpenDocument>.

Doll, W.J., Torkzadeh, G. (1991). The Measurement of End-User Computing Satisfaction: Theoretical and Methodological Issues. *Mississippi Quarterly*, 15:5-10.

Donaldson, C., Bond, J. (1991). Cost of Continuing – care Facilities in the Evaluation of Experimental National Health Service Nursing Homes. *Age and Ageing*, 20: 160-168.

Donaldson, L. & Johnson, M. (1993). The health of older Asians. In J. Johnson & R. Slater (Eds.) *Ageing and later life*. London: Sage Publications.

Edwards, P., Roberts, I., Clarke, M., DiGuseppi, C., Prata, S., Wentz, R., Kwan, I. (2002). Increasing response rates to postal questionnaires: systematic review. *British Medical Journal*, 324: 1183-1185.

Elford, D.R. (1997). Telemedicine in northern Norway. *Journal of Telemedicine and Telecare*, 3:1-22.

Elliott, R., Fischer, C. T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38: 215 - 229.
Emery et al (2002a) *Care Plus*. Final Report. June 2002. The University of Sheffield, School of Nursing and Midwifery.

Emery et al (2002b). Telecare delivery of health and social care information, *Health Informatics Journal* 2002; 8; 29-33

European Directorate (2000). The Emerging European Health Telematics Industry: Market Analysis, European Directorate Commission-Directorate General Information Society Ref C13.25533, February 2000

Evans, G.J., Bond, J. (1997). The challenges of age research. *Age and Ageing*, 26-S4: 43-46.

Eysenbach, G., Köhler, C. (2002). How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *British Medical Journal*, 324: 573-577.

Eysenbach, G., Sa, E.R. & Diepgen, T.I. (2001). Towards the Millennium of Cybermedicine. In T. Heller, R. Muston, M. Sidell & C. Lloyd (Eds.) *Working for Health*. London: Sage Publications. In association with the Open University.

Fabian Society (2001). *Beyond Access: ICT and social exclusion*. Fabian Society, London

Farmer, J.C., Baird, A.G. & Iversen, L. (2001). Rural deprivation: reflecting reality. *British Journal of General Practice*, 51: 486-491.

Farrell, C., Robinson, J. & Fletcher, P. (1999). *A New Era for Community Care? What people want from health, housing and social care services*. London: King's Fund.

Faulkner, M. (2001). A measure of patient empowerment in hospital environments catering for older people. *Journal of Advanced Nursing*, 34(5): 676-686.

Ferguson, T. (2002). From patients to end users. *British Medical Journal*, 324: 555-556.

Ferlie E and Pettigrew A (1996). Managing through networks: some issues and implications for the NHS. *British Journal of Management*, 7 (special issue), S81-99.

Foresight Ageing Population Panel. (2000). *The age shift – Priorities for action*. London, Department of Trade and Industry.

Fraser, S.W., Greenhalgh, T. (2001). Coping with complexity: educating for capability. *British Medical Journal*, 323:799-803.

- Fruin, D. (1998). *A Matter of Chance for Carers? Inspection of local authority support for carers*. London: Department of Health Social Care Group Social Services Inspectorate. CI (98) 19
- Gagliardi, A., Jahad, A.R. (2002). Examination of instruments used to rate quality of health information on the internet: chronicle of a voyage with an unclear destination. *British Medical Journal*, 324: 569-573.
- Gantley, M., Harding, G., Kumar, S. & Tissier, J. (1999). *An Introduction to Qualitative Methods for Health Professionals*. London: Royal College of General Practitioners.
- George, S. (2002). NHS Direct audited. *British Medical Journal*, 324: 558-559.
- Giliham, B. (2000). *Developing a Questionnaire*. London: Continuum.
- Glasby, J. & Littlechild, R. (2000). *The Health and Social Care Divide*. Birmingham: PEPAR Publications.
- Glendinning, C., Hardy, B., Hudson, B., Young, R. (2002). Building a United Front. *Community care*. No.1448, 14-18 November, pp. 30-32.
- Glendinning, C., Hudson, B., Hardy, B., Young, R. (2002a). *National Evaluation of Notifications for the Use of The Section 32 Partnership Flexibilities in the Health Act 1999. Final Project Report*. University of Manchester: National Primary Care Research and Development Centre.
- Glendinning, C., Hudson, B., Hardy, B., Young, R. (2002b). Building a united front. *Community Care*, 1448:30-32.
- Godfrey, M. & Callaghan, G. (2000). *Exploring unmet need: The challenge of a user-centred response*. York: Joseph Rowntree Foundation.
- Goldsmith, L. & Beaver, R. (1999). *Recording with Care: Inspection of case recording in social services departments*. London: Social Care Group, Social Services Inspectorate, Department of Health. Report CI(99)1.
- Golodet A., Evans, R. and Heinritz G. (1967). The care of chronic illness: the responsor role. *Medical Care*, 7: 385-394.
- Gomm, R., Needham, G. & Bullman, A. (Eds.). (2000). *Evaluating Research in Health and Social Care*. London: Sage Publications.
- Gorman, P.N. (1995). Information Needs of Physicians. *Journal of the American Society for Information Science*, 46(10): 729-736.
- Gray, J.A.M. (2001). *Evidence-based Healthcare: How to make health policy and management decisions*. Edinburgh: Churchill Livingstone.
- Greatbatch, D., Heath, C., Campion, P. & Luff, P. (1995). How do desk-top computers affect the doctor – patient interaction? *Family Practice*, 12 (1): 32-36.
- Greenhalgh, T. (1998). The Database of Individual Patient Experience. In T. Greenhalgh & B. Hurwitz (Eds.) *Narrative Based Medicine: Dialogue and discourse in clinical practice*. London: BMJ Books.
- Greenhalgh, T., Hughes, J., Humphrey, C., Rogers, S., Swinglehurst, D., Martin, P. (2002). A comparative case study of two models of a clinical informaticist service. *British Medical Journal*, 324: 524-529.
- Greenwood, L. (2002). Caring for the carers. *NHS Magazine*, March: 20-21.
- Gregson, B., Smith, M., Lecouturier, N., Rodgers, H., Bond, J. (1997). Issues of recruitment and maintaining high response rates in a longitudinal study of older hospital patients in England – pathways through care study. *Journal of Epidemiology and Community Health*, 51: 541-548.

- Gregson, B.A., Cartlidge, A., Bond, J. (1991). *Interprofessional Collaboration in Primary Health Care Organizations. Occasional Paper No. 52*. London: Royal College of General Practitioners.
- Griew, A. & Nicklin, P. (2000). *A Compendium of Scenarios for Security*. Report commissioned by NHS Information Authority. London: NHS.
- Grundmeijer, H. (1996). General Practitioner and specialist: why do they communicate so badly? *European Journal of General Practice*, 2: 53-54.
- Hagerdoorn, J, Link AN and Vonortas, NS. (2000). Research partnerships. *Research Policy*, 29, 567-586.
- Ham, C. (1999). *Health Policy in Britain: The Politics and Organisation of the National Health Service*. (4th ed.) Basingstoke: Macmillan.
- Harrison, A., Pablo, A. & Verhoef, M. (1999). The Consumer's Role in Co-ordination: making sense of transitions in health care. In A.L. Mark & S. Dopson (Eds.) *Organisational Behaviour in Health Care: The Research Agenda*. Basingstoke: Palgrave.
- Hart, E. & Bond, M. (1995). *Action research for health and social care. A guide to practice*. Buckingham: Open University Press.
- Hastie, I.R. (1994). In Acute Medicine: The Traditional Model. *Age and Ageing*, 23: S27.
- Hayden C, Boaz A and Taylor F. (1999) *Attitudes and Aspirations of Older People: A qualitative study* (DSS Research Report No 102). London, The Stationery Office, October.
- Hayden C and Benington J. (2000). Multi-level networked governance – Reflections from the Better Government for Older People programme in *Public Money and Management*, 20 (2), 27-34.
- Hayden, C., Boaz, A. & Taylor, F. (2001). *Information Poverty in the Knowledge Society: Responding to the spectrum of older people's information needs*. Warwick: Local Government Centre University of Warwick. Better Government for Older People Series. Research Paper 5.
- Haynes, R. (1991). Inequalities in health and health services use: Evidence from the General Household Survey. *Social Science and Medicine*, 33(4): 361-368.
- Haynes, R.M. & Bentham, C.G. (1979). Accessibility and the use of hospitals in rural areas. *Area*, 11: 186-191.
- Heath, I. (2002). Long term care for older people. *British Medical Journal*, 324: 1534-1535.
- Heimes, M. (2003). Download blues. *The Sunday Times, Culture. Doors: Your Guide to the Internet*, Jan, 19, p54.
- Henwood, K. & Pidgeon, N.F. (1992). Qualitative research and psychological theorising. *British Journal of Psychology*, 83 (1): 97 - 112.
- Henwood, M. (1993). Age discrimination in health care. In J. Johnson & R. Slater (Eds.) *Ageing and later life*. London: Sage Publications.
- Henwood, M. (1998). *Ignored and invisible? Carers' experience of the NHS*. London: Carers National Association.
- Henwood, M. (2001). *Future Imperfect? Report of the King's Fund care and Support Inquiry*. London: King's Fund Publishing.
- Henwood, M., Lewis, H. & Waddington, E. (1998). *Listening to Users of Domiciliary Care Services: Developing and Monitoring Quality Standards*. Leeds: Nuffield Institute for Health, University of Leeds.

- Herbert, R.D., Maher, C.G., Moseley, A.M. Sherrington, C. (2001). Effective physiotherapy. *British Medical Journal*, 323: 788-90.
- Hill K. (2001). Developing a joint mental health strategy for elders. *The Mental Health Review*; 6: 14-21.
- HM Government (1999). *Caring about Carers - A National Strategy for Carers*, HM Government, London February 1999.
- Hochschild, A.R. (2000). An Old Age Community. In J.F.Gubrium & J.A.Holstein (Eds.) *Aging and Everyday Life*. Oxford: Blackwell.
- Hoggett, P (2001). Agency, rationality and social policy. *Journal of Social Policy*, 30 (1), 37-56.
- Holt, T. (2002). Clinical knowledge, chaos and complexity. In K. Sweeney & F. Griffiths (Eds.) *Complexity and Healthcare: An Introduction*. Oxford: Radcliffe Medical Press.
- Horton, R. (2003). *Second Opinion: Doctors, Diseases and Decisions in Modern Medicine*. London: Granta.
- Howard, M. (2001). *Paying the price: Carers, poverty and social exclusion*. London: Child Poverty Action Group in association with Carers UK.
- Huberman, A.M. & Miles, M.B. (1998). Data Management and Analysis Methods. In N.K.Denzin & Y.S.Lincoln (Eds.) *Collecting and Interpreting Qualitative Materials. Handbook of Qualitative Research Volume 3*. Thousand Oaks: Sage Publications.
- Hudson, B., Hardy, B., Henwood, M. & Wistow, G. (2003). In pursuit of inter-agency collaboration in the public sector: what is the contribution of theory and research? In J. Reynolds, J. Henderson, J. Seden, J. Charlesworth & A. Bullman (Eds.) *The Managing Care Reader*. London: Routledge.
- Iliffe, S. & Drennan, V. (2000). *Primary Care for Older People*. Oxford: Oxford University Press.
- Iliffe, S., Goldenberg, E., Tai, S.S., Morgan, P., Haines, A., Gallivan, S. & Booroff, A. (1993). Assessment of elderly people in general practice. 4. Depression, functional ability and contact with services. *British Journal of General Practice*, 43: 371-374.
- Johansen, K.S. (1988). WHO concept on health technology assessment. *Health Policy*, 9: 349-351.
- Jones, L. J. (1994). *The Social Context of Health and Health Work*. Basingstoke: Macmillan.
- Kay, S. & Purves, I. (1998). The electronic medical record and the "story stuff": a narrativistic model. In T. Greenhalgh & B. Hurwitz (Eds.) *Narrative Based Medicine: Dialogue and discourse in clinical practice*. London: BMJ Books.
- Kenny, R.A.M., Richardson, D.A., Steen, N., Bexton, R.S., Shaw, F.E., Bond, J. (2001). Carotid Sinus Syndrome: A Modifiable Risk Factor for Nonaccidental Falls in Older Adults (SAFE PACE). *Journal of the American College of Cardiology*, 38(5): 1491-1496.
- Kenny, T., Wilson, R.G., Purves, I.N., Clark, J Sn., Newton, L.D., Newton, D.P. & Moseley, D.V. (1998). A PIL for every ill? Patient information leaflets (PILs): a review of past, present and future use. *Family Practice*, 15(5): 471-479.
- Kernick, D. (2002). Complexity and healthcare organisation. In K. Sweeney & F. Griffiths (Eds.) *Complexity and Healthcare: An introduction*. Oxford: Radcliffe Medical Press.
- Kirkwood, T. (2001). *The end of age*. BBC Radio 4 The Reith Lectures. London: Profile Books.
- Kitwood, T. (1993). Towards a reconstruction of an organic mental disorder. In A. Radley (Ed.) *Worlds of illness: Biographical and cultural perspectives on health and illness*. London: Tavistock/Routledge.
- Kiuge, B-H. W. (2001). *The Ethics of Electronic Patient Records*. New York: Peter Lang.

Klein, K.L., Conn, A.B. & Sorra, J.S. (2001). Implementing Computerized Technology: An Organizational Analysis. *Journal of Applied Psychology*, 86(5): 811-824.

Kluge, E-H. W. (2001). *The Ethics of Electronic Patient Records*. New York: Peter Lang.

Kunst, H., Groot, D., Latthe, P.M., Latthe, M., Khan, K.S. (2002). Accuracy of information on apparently credible websites: survey of five common health topics. *British Medical Journal*, 324: 581-582.

Lærum, H., Ellingsen, G., Faxvaag, A. (2001). Doctors' use of electronic medical records systems in hospitals: cross sectional study. *British Medical Journal*, 323: 1344-1348.

Lawler, E. E., Mohrman, A. M., Mohrman, S. A., Ledford, G. E., Cummings, T. G. & Associates. (1985 / 1999). *Doing Research that is Useful for Theory and Practice*. Lantham: Lexington Books.

Leonard, K.J., Pink, G., Johnson, L.M. & Schraa, E.G. (2000). Information systems for healthcare: a conceptual framework for improving decision making through better information, not technology. *International Journal of Healthcare Technology and Management*, 2, Nos.5/6: 557-575.

Leonard, K.J., Pink, G., Johnson, L.M. & Schraa, E.G. (2000). *Information systems for healthcare: a conceptual framework for improving decision making through better information, not technology*. *International Journal of Healthcare Technology and Management*. 2 Nos. 5/6: 557-575.

Levin E, Moriarty J, Gorbach P. (1994). *Better for the Break*. HMSO.

Lewis, R. (2000). Sharing professional knowledge in the health care sector. *International Journal of Healthcare Technology and Management*, 2, Nos. 5/6: 456-476.

Lewycka, M. (1998). *The carer's handbook: What to do and who to turn to*. London: Age Concern Books.

Lindsey Davis L. (1996). Dementia Caregiving Studies: A Typology for Family Interventions. *Journal of Family Nursing*, 2(1): 30-55.

Little, M. (2002). Improving Older People's Services – Policy into Practice: The second phase of inspections into older people's services. London: Department of Health, Social Services Inspectorate.

Macdonald, S. (2002). *The IT productivity paradox revisited: technological determinism masked by management method?* *International Journal of Entrepreneurship and Innovation Management*, 1: 1-29.

Macintyre, S. (1994). Understanding the social patterning of health: the role of the social sciences. *Journal of Public Health Medicine*, 16(1): 53-59.

Mahoney, F.I. & Barthel, D.W. (1965). Functional Evaluation: The Barthel Index. *Maryland State Medical Journal*, February: 61-65.

Malone-Rising, D. (1992). Rural Research: The Lamoille County Experience. In P. Winstead-Fry, J. C. Tiffany, R.V. Shippee-Rice (Eds.) *Rural Health Nursing: Stories of Creativity, Commitment, and Connectedness*. New York: National League for Nursing Press.

Mark, A.L. & Dopson, S. (1999). *Organisational Behaviour in Health Care: The Research Agenda*. Basingstoke: Hampshire.

Marks, L. (1994). *Seamless Care or Patchwork Quilt: Discharging patients from acute hospital care*. Research Report 17. London: King's Fund Institute.

Means R, Morbey H and Smith R (2003). *From Community Care to Market Care?: The Development of Welfare Services for Older People, 1971 – 93*. Bristol, Policy Press.

McColl, E., Jacoby, A., Thomas, L., Soutter, J., Bamford, C., Garratt, A., Harvey, E., Thomas, R. & Bond, J. (1998). Designing and using patient and staff questionnaires. In N. Black, J. Brazier, R.

- Fitzpatrick, B. Reeves (Eds.) *Health Services Research Methods: A guide to best practice*. London: BMJ Books.
- McDaid, D. & Sassi, F. on behalf of TASIE group. (2001). The burden of informal care for Alzheimer's Disease: carer perceptions from an empirical study in England, Italy and Sweden. *Mental Health Research Review*, 8: 34-36.
- McDonald, A., Langford, I., Boldero, N. (1997). The future of community nursing in the United Kingdom: district nursing, health visiting and school nursing. *Journal of Advanced Nursing*, 26(2): 257-265.
- McLeod, E. & Bywaters, P. (2000). *Social Work, Health and Equality*. London: Routledge.
- McNamee, P., Bond, J. & Buck, D. (2001). Costs of dementia in England and Wales in the 21st century. *British Journal of Psychiatry*, 179: 261-266.
- McNamee, P., Gregson, B., Buck, D., Bamford, C.H., Bond, J., Wright, K. (1999). Costs of formal care for frail older people in England: the resource implications study of the MRC cognitive function and ageing study (RIS MRC CFAS). *Social Science and Medicine*, 48: 331-341.
- Melzer, D., McWilliams, B., Brayne, C., Johnson, T., Bond, J. (1999). Socioeconomic status and the expectation of disability in old age: estimates for England. *Journal of Epidemiology and Community Health*, 54: 286-292.
- Melzer, D., McWilliams, B., Brayne, C., Johnson, T., Bond, J. (1999). Profile of disability in elderly people: estimates from a longitudinal population study. *British Medical Journal*, 318: 1108-1111.
- Meric, F., Bernstam, E.V., Mirza, N.Q., Hunt, K.K., Ames, F.C., Ross, M.I., Kuerer, H.M., Pollock, R.E., Musen, M.A., Singletary, S.E. (2002). Breast cancer on the world wide web: cross sectional survey of quality of information and popularity of websites. *British Medical Journal*, 324: 577-581.
- Middleton T. (2001). Mental health services for older people – Towards an integrated approach. *The Mental Health Review*, 6: 22-24.
- Miles, A. (1991). *Women, health and medicine*. Milton Keynes: Open University Press.
- Mitchell, E., Sullivan, F. (2001). *A descriptive feast but an evaluative famine: systematic review of published articles on primary care computing during 1980 -97*. *British Medical Journal*, 322: 279-82.
- Monteagudo, J.L. & Redondo, J.R. (2004). EHealth and the Elderly: a new range of products and services? *The IPTS Report*, 81: 41- 47. Seville: Joint Research Centre of the European Commission. February 2004.
- Moriarty, J. & Webb, S. (2000). *Part of their lives: Community care for older people with dementia*. Bristol: The Policy Press.
- Morrell, R.W., Mayhorn, C. & Bennett, J. (2002). Older Adults Online in the Internet Century. In R.W.Morrell (Ed.) *Older Adults, Health Information, and the World Wide Web*. Mahwah, New Jersey: Lawrence Erlbaum Associates.
- Morris RG, Morris LW. (1993). Psychosocial aspects of caring for people with dementia; conceptual and methodological issues. In A. Burns (Ed.): *Ageing and Dementia A Methodological Approach*. London: Edward Arnold.
- Murphy, E. & Dingwall, R. (1998). Qualitative methods in health services research. In N. Black, J. Brazier, R. Fitzpatrick, B. Reeves (Eds.) *Health Services Research Methods*. London: BMJ Books.
- Murphy, E. & Dingwall, R. (1998). Qualitative methods in health services research. In N. Black, J. Brazier, R. Fitzpatrick, B. Reeves (Eds.) *Health Services Research Methods*. London: BMJ Books.
- Murphy, E. & Dingwall, R. (2001). Qualitative Methods in Health Technology Assessment. In A.

Myles S, Wyke S, Poppy J, Scott J, Campbell A and Girling J, (1998). *Total purchasing and community and continuing care: Lessons for future policy development in the NHS*. London, Kings Fund.

National Institute for Social Work. (1993). *Building Bridges between people who use and people who provide services: The user-centred services group*. http://www.elsc.org.uk/users_carers_floor/bridges/bridcont.html (accessed 26 October 2001)

Ness C. (1999). Galvanising enthusiasm in caring for people with dementia. In National Board for Nursing, Midwifery and Health Visiting for Scotland: *NBS Gazette Innovative approaches to practice development*. Edinburgh: NBS.

Net Value 2002 Silver Surfers Continue to Join the Internet Revolution. Press Release, London, 28th March 2002

NHS Information Authority (2002). National Health Informatics Competency: 2002 Annual Survey - Developing NHS IM&T Capability & Capacity. NHS Information Authority, 2002 (available at www.nhsia.nhs.uk, accessed October 2002) -

NHS Modernisation Board. (2001). *The NHS Plan: A Progress Report. Annual report 2000-2001*. London: Department of Health. www.doh.gov.uk/modernisationboardreport accessed January, 2002.

Nicholas, E. (2001). Implementing an outcomes approach in carer assessment and review. In H. Qureshi (Ed.). *Outcomes in Social Care Practice. Outcomes in Community Practice, No. 7*. York: Social Policy Research Unit, University of York.

Nocon, A. & Qureshi, H. (1996). *Outcomes of Community Care for Users and Carers: A Social Services Perspective*. Buckingham: Open University Press. (copy held by chess)

Nolan, M., Davies, S. & Grant, G. (2001). Integrating perspectives. In M. Nolan, S. Davies, G. Grant (Eds.) *Working with older people and their families: Key issues on policy and practice*. Buckingham: Open University Press.

Nolan, M., Davies, S. & Grant, G. (2001). Quality of life, quality of care. In M. Nolan, S. Davies, G. Grant (Eds.) *Working with older people and their families: Key issues on policy and practice*. Buckingham: Open University Press.

Nolan, M., Davies, S., & G. Grant. (2001). Introduction: the changing face of health and social care. In M. Nolan, S. Davies, G. Grant (Eds.). *Working with older people and their families: Key issues on policy and practice*. Buckingham: Open University Press.

Nolan, M., Grant, G. & Keady, J. (1996). *Understanding Family Care*. Buckingham: Open University Press.

Nolan, M., Grant, G. & Keady, J. (1998). *Assessing the Needs of Family Carers: A Guide for Practitioners*. Brighton: Pavilion Publishing Ltd.

Nolan, M., Keady, J., Grant, G. (1995). CAMI: a basis for assessment and support with family carers. *British Journal of Nursing*, 4(14): 822-826.

Nolan, M., Philp, I. (1999). COPE: towards a comprehensive assessment of caregiver need. *British Journal of Nursing*, 8 (20): 1364-1372.

Nuttal SR, Bussell BMH, Cornall MJ, Gatenby PL. (1993). Financing Long Term Care in Britain, presented to the Institute of Actuaries.

Nuttal SR et al (2001). *Caring about Carers* Policy Studies Institute 2001

Office of the e-Envoy, Cabinet Office. (2001). *e-Government: Benchmarking Electronic Service Delivery*. London: Cabinet Office. www.e-envoy.gov.uk/publications (accessed August 2002).

- Omu, N., Butt, A. & Shabbir, S. (2002). Old age psychiatry. *British Medical Journal Careers*, s153-154. (18 May)
- Oppenheim, A.N. (1992). *Questionnaire Design, Interviewing and Attitude Measurement*. London: Continuum.
- Øvretveit, J. (1999). Evaluating Interventions to Health Organisations. In A.L.Mark & S. Dopson (Eds.) *Organisational Behaviour in Health Care: The Research Agenda*. Basingstoke: Hampshire.
- Pandolfini, C., Bonati, M. (2002). Follow up of quality of public oriented health information on the world wide web: systematic re-evaluation. *British Medical Journal*, 324: 582-583.
- Parry, S.W., Steen, N., Galloway, S.R., Kenny, R.A., Bond, J. (2001). Falls and confidence related quality of life outcome measures in an older British cohort. *Postgraduate Medical Journal*, 77: 103-108.
- Pathways Through Care Study Group (Bond, J., Gregson, B., Lecouturier, J., Rodgers, H., Rousseau, N., Smith, M.). (1996). *Pathways Through Care: The processes and outcomes of hospital care for elderly people - An overview*. University of Newcastle upon Tyne: Centre for Health Services Research, Report No. 79.
- Patmore, C. (2001). Improving home care quality: An individual-centred approach. *Quality in Ageing – Policy, practice and research*, 2(3): 15-24.
- Peck E, Gulliver P and Towell D. (2002) *Modernising Partnerships: An Evaluation of Somerset's Innovations in the Commissioning and Organisation of Mental Health Services*. London, Kings Fund.
- Peckham, M. & Lee, M. (2001). *Health Trends Review*. Proceedings of a Conference, Barbican Centre, London, 18-19 October. (Chaired by authors).
- Peckham, S. & Exworthy, M. (2003). *Primary Care in the UK: Policy, Organisation and Management*. Basingstoke: Pa Macmillan.
- Pettit, G. & Kenny, D. (2000). *Carers count: a research report on carers in London*. London: The Princess Royal Trust for Carers.
- Pickard L, Wittenberg R, Comas-Herrera A, Davies B, and Darton R (2000). Relying on informal care in the new century? Informal care for elderly people in England to 2031, *Ageing and Society*: 20 (6) Nov 2000, p 745-72.
- Pratt, J. Gordon, P. & Plamping, D. (2001). Working Whole Systems. In T. Heller, R. Muston, M. Sidell & C. Lloyd (Eds.) *Working for Health*. London: Sage Publications. In association with the Open University.
- Pritchard EJ, Dewing J. (1999). *A Multi-Method Evaluation of SPECAL (Specialised Early Care for Alzheimer's)*. Royal College of Nursing Gerontological Nursing Programme, Oxfordshire Community Health Trust and SPECAL.
- Procter, S., Wilcockson, J., Pearson, P. & Allgar, V. (2001). Going home from hospital: the carer/patient dyad. *Journal of Advanced Nursing*, 35(2): 206-217.
- Purcell, G. P., Wilson, P., Delamothe, T. (2002). The quality of health information on the internet. *British Medical Journal*, 324: 557-558.
- Qureshi, H. & Henwood, M. (2000). *Older people's definitions of quality services*. York: Joseph Rowntree Foundation.
- Qureshi, H. (1992). Integrating methods in applied research in social policy: a case study of carers. In J. Brannen (Ed.). *Mixing Methods: qualitative and quantitative research*. Aldershot: Ashgate.
- Qureshi, H. (Ed.). (2001). *Outcomes in Community Care Practice, Number Seven: Outcomes in Social Care Practice*. York: Social Policy Research Unit, University of York.

- Rawlins, M. National Institute for Clinical Excellence. (2001). *Quality of Care in the NHS*. Guest lecture, University of Warwick, School of Postgraduate Medical Education. 5th June 2001.
- Raynes, N., Temple, B., Glenister C. & Coulthard, L. (2001). *Quality at home for older people: Involving service users in defining home care specifications*. York: Joseph Rowntree Foundation.
- Richards, S. (2000). Bridging the Divide: Elders and the Assessment Process. *British Journal of Social Work*, 30: 37-49.
- Risk, A. (2002). On the way to quality. Commentary. *British Medical Journal*, 324: 601-602.
- Roberts, C. & Fox, N. (1998). General practitioners and the Internet: modelling a 'virtual community'. *Family Practice*, 15(3): 211-215.
- Robson, C. (1993). *Real World Research*. Oxford: Blackwell.
- Rodgers, H., Soutter, J., Kaiser, W., Pearson, P., Dobson, R., Skilbeck, C. & Bond, J. (1997). Early supported hospital discharge following acute stroke: pilot study results. *Clinical Rehabilitation*, 11: 280-287.
- Rogers R. and Reardon J (1999). Barriers to a Global Information Society for Health: Recommendations for International Action, *Studies in Health Technology & Informatics Series* (Number 64), IOS Press (Amsterdam) 1999
- Rousseau, N., McColl, E. (1997). *Equity and access in rural primary care: An exploratory study in Northumberland and Cumbria*. Newcastle: University of Newcastle, Centre for Health Services Research. Report No: 83.
- Rousseau, N., McColl, E., Eccles, M. (1994). *Primary Health Care in Rural Areas: Issues of Equity and Resource Management – a literature review*. Newcastle: University of Newcastle, Centre for Health Services Research. Report No: 66.
- Rowlands, O. (1998). *Informal carers: Results of an independent study carried out on behalf of the Department of Health as part of the 1995 General Household Survey*. London: The Stationery Office.
- Rutland, C.M. (1999). Decision Support for Patient Preference – based Care Planning: Effects on Nursing Care and Patient Outcomes. *Journal of the American Medical Informatics Association*, 6(4): 304-312.
- Seale, C. & Silverman, D. (1997). Ensuring rigour in qualitative research. *European Journal of Public Health*, 7: 379-384.
- Sedon, D. (1999). *Carers of Elderly People with Dementia: Assessment and the Carers Act. Final Report to NHS Wales Office of Research and Development for Health and Social Care*. Bangor: University of Wales, Centre for Social Policy Research and Development.
- Shearman, C. (2002). *Local Connections: Making the Net Work for Neighbourhood Renewal. Communities Online response to the Social Exclusion Unit's Report: Bringing Britain Together: a national strategy for neighbourhood renewal*. <http://www.communities.org.uk/> (accessed January 2002).
- Shepperd, S., Charnock, D. (2002). Against internet exceptionalism. *British Medical Journal*, 324: 556-557.
- Shippee-Rice, R.V., Mahoney, D.F. (1992). Training Family Caregivers of Rural Elderly. In P. Winstead-Fry, J. C. Tiffany, R.V. Shippee-Rice (Eds.) *Rural Health Nursing: Stories of Creativity, Commitment, and Connectedness*. New York: National League for Nursing Press.
- Shucksmith, M., Roberts, D., Scott, D., Chapman, P., Conway, E. (1996). *Disadvantage in rural areas*. Salisbury: Rural Development Commission.

- Simon, C. & Kendrick, T. (2001). Informal carers – the role of general practitioners and district nurses. *British Journal of General Practice*, 51: 655-657.
- Simon, C., Kumar, S. & Kendrick, T. (2002). Who cares for the carers? The district nurse perspective. *Family Practice*, 19(1): 29-35.
- Sinclair, I., Gibbs, I., Hicks, L. (2000). *The Management and Effectiveness of the Home Care Service*. York: Social Policy Research Unit, University of York.
- Sittig, D.F., Kuperman, G.J., Fiskio, J. (1999). Evaluating Physician Satisfaction Regarding User Interactions with an Electronic Medical Record System. *Proceedings of the American Medical Informatics Association*, 400-404.
- Sixsmith A (1994). New Technology and Community Care *Health and Social Care in the Community* 1994: 2 (6): 367-370
- Skaiff M.M. and Perlin I.I. (1992). Caregiving: Role engulfment and the loss of self. *The Gerontologist*, 32: 656-664.
- Smeeth, L., Fletcher, A. E. (2002). Improving the response rates to questionnaires. *British Medical Journal*, 324: 1168-1169.
- Smeeth, L., Fletcher, A.E., Stirling, S., Nunes, M., Breeze, E., Ng, E., Bulpitt, C.J., Jones, D. (2001). Randomised comparison of three methods of administering a screening questionnaire to elderly people: findings from the MRC trial of the assessment and management of older people in the community. *British Medical Journal*, 323: 1-7.
- Smith, G.C., Smith, M.F. & Toseland, R.W. (1991). Problems Identified by Family Caregivers in Counseling. *The Gerontologist*, 31(1): 15-22.
- Smith, J.A., Jarman, M. & Osborne, M. (1999). Doing Interpretative Phenomenological Analysis. In M. Murray & K. Chamberlain (Eds.). *Qualitative Health Psychology; Theories and Methods*. London: Sage Publications.
- Smith, M., Rousseau, N., Lecouturier, J., Gregson, B., Bond, J. Rodgers, H. (1997). Are older people satisfied with discharge information? *Nursing Times*, 93(43): 52-53.
- Spencer, P. (1999). Communications. In J. Cox & I. Mungall (Eds.) *Rural Healthcare*. Oxford: Radcliffe Medical Press.
- Spurgeon, P. (1999). Organisational Development: from a reactive to a proactive process. In A.L. Mark & S. Dopson (Eds.) *Organisational Behaviour in Health Care: The Research Agenda*. Basingstoke: Palgrave.
- Stanberry, b. A. (2002). Legal aspects of health on the internet: a European perspective. *British Medical Journal*, 324: 605-606.
- Statham, D. (2000). Guest editorial: partnership between health and social care. *Health and Social Care in the Community*, 8(2):87-89.
- Stevens, K. Abrams, J. Brazier, R. Fitzpatrick & R. Lilford (Eds.) *The Advanced Handbook of Methods in Evidence Based Healthcare*. London: Sage Publications.
- Strauss, A. & Corbin, J. (1990). *Basics of Qualitative Research*. London: Sage Publications.
- Stuart-Hamilton, I. (2000). *The Psychology of Ageing: An Introduction*. (3rd edition). London: Jessica Kingsley Publishers.
- Szczepura, A., Biggerstaff, D., Roberts, J. (forthcoming). *Optimising the use of existing ICTs to inform health & social welfare professionals and carers in the community. Final Report to the Department of Health*. University of Warwick: Centre for Health Services Studies.

- Szczepura, A., Biggerstaff, D., Vinogradova, Y., Fagan, R., Clay, D. (2003). *Improving Support for Carers in South Warwickshire: Final Report*. University of Warwick: Centre for Health Services Studies.
- Tabachnick, B.G. & Fidell, L.S. (1996). *Using Multivariate Statistics*. New York: Harper Collins.
- Tattersall, R., Page, S. (1998). Managing diabetes in residential and nursing homes. *British Medical Journal*, 316: 89.
- Terry, N. (2002). Regulating health information : a US perspective. *British Medical Journal*, 324: 602-605.
- The Princess Royal Trust for Carers. (1998). *Eight hours a day and taken for granted?* The Princess Royal Trust for Carers, published September 1998
- The Princess Royal Trust for Carers. (1999). *Seven and a half minutes is not enough*, The Princess Royal Trust for Carers, 1999.
- The Princess Royal Trust for Carers. (2000). *Carers count: a report on carers in London*, The Princess Royal Trust for Carers, 2000.
- The Princess Royal Trust for Carers. (2002). *Reaching out to carers. Annual Review 2001/2002*. London: The Princess Royal Trust for Carers.
- The Royal College of Psychiatrists. (2001). *Mental health and growing up (2nd ed). Parental mental illness – the problems for children. Fact Sheet 17*. The Royal College of Psychiatrists London.
- Thomas, A. (1994). In Acute Medicine: The Integrated Model. *Age and Ageing*, 23:S22-24.
- Thompson C, Thompson G. (1999). Support for carers of people with Alzheimer's type dementia. Cochrane Review, *The Cochrane Library*; Issue 3.
- Toseland RW, Rossiter CM. (1989). Group intervention to support family caregivers: A review and analysis. *The Gerontologist*, 29(4), 430-448.
- Tourangeau, R., Rips, L.J., & Rasinski, K. (2000). *The Psychology of Survey Response*. Cambridge: Cambridge University Press.
- Tukey, J.W. (1977). *Exploratory Data Analysis*. Reading, MA: Addison Wesley.
- Twigg, J. & Atkin, K. (1994). *Carers Perceived: Policy and practice in informal care*. Buckingham: Open University Press.
- Twigg, J. Models of Carers: How Do Social Agencies Conceptualise Their Relationship with Informal Carers? *Journal of Social Policy*, 18(1): 53-66.
- Vallon, A.G. (1994). In Acute Medicine: The Age-defined Model. *Age and Ageing*, 23:S25-26.
- Van der Kam, W.J., de Jong, B.M., Tromp, Th.F.J., Moorman, P.W. & van der Lei, J. (2001). Effects of electronic communication between the GP and the pharmacist. The quality of medication data on admission and after discharge. *Family Practice*, 18(6): 605-609.
- Walker, A. (1996). *Young carers and their families. A survey carried out by the Social Survey Division of ONS on behalf of the Department of Health*. London: The Stationery Office.
- Walshe, K. The rise of regulation in the NHS. *British Medical Journal*, 324: 967-970.
- Wanless, D. (2001). Securing Our Future Health: Taking a Long Term View. Consultation Document. November, 2001. <http://www.hm-treasury.gov.uk> An interim Report, accessed January 2002

- Wanless, D. (2002). *Securing our future health: taking a long-term view. Final report*. London: HM Treasury. www.hmtreasury.gov.uk/Consultations_and_Legislation/wanless/consultfinal.cfm (accessed August 2003)
- Ward, A. (1999). Teamwork. In J. Cox & I. Mungall (Eds.) *Rural Healthcare*. Oxford: Radcliffe Medical Press.
- Warner, L. & Card, C. (1999). "Seven and a half minutes is not enough". London: The Princess Royal Trust for Carers.
- Warnes, A. M., Warren, L. & Nolan, M. (2000). *Care Services for Older People: The Forward Agenda*. In A. M. Warnes, L. Warren & M. Nolan (Eds.) *Care Services for Later Life: Transformations and Critiques*. London: Jessica Kingsley Ltd., British Society of Gerontology.
- Warschauer, M. (2003). *Technology and Social Inclusion: Rethinking the Digital Divide*. Cambridge, Mass: The MIT Press.
- Watt, I. (1999). Access to care. In J. Cox & I. Mungall (Eds.) *Rural Healthcare*. Oxford: Radcliffe Medical Press.
- Watt, I.S., Franks, A.J., Sheldon, T.A. (1994). Health and health care of rural populations in the UK: is it better or worse? *Journal of Epidemiology and Community Health*, 48: 16-21.
- Werity, C., Nicoll, A. (2002). Consent, confidentiality, and the threat to public health surveillance. *British Medical Journal*, 324: 1210-1213.
- Wetle, T. (2002). The Use of New Information Technology in an Aging Population. In R.W.Morrell (Ed.) *Older Adults, Health Information, and the World Wide Web*. Mahwah, New Jersey: Lawrence Erlbaum Associates.
- Whitehouse, C.R. (1985). Effect of distance from surgery on consultation rates in an urban practice. *British Medical Journal*, 290: 359-362.
- Whitfield, L. (2003). The unicycle. *Health Service Journal, Special Report on Training and Development*. 20 Feb:17.
- Williams, S.J. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness*, 22(1): 40-67.
- Willig, C. (2001). *Introducing Qualitative Research in Psychology: Adventures in theory and method*. Buckingham: Open University Press.
- Wilson, P. (2002). How to find the good and avoid the bad of ugly: a short guide to tools for rating quality of health information on the internet. *British Medical Journal*, 324: 598-600.
- Wistow, G. & Hardy, B. (1999). The development of domiciliary care: mission accomplished? *Policy and Politics*, 27(2): 173-186.
- Woods R.T. (1997). Why should family caregivers feel guilty? In M. Marshall (Ed.): *State of the art in dementia care*. London: Centre for Policy on Ageing.
www.doh.gov.uk/ipu/whatnew/deliveringit/nhsitimplan.pdf (accessed August 2002)
- Young Carers Research Group. (1998). *Young carers in the UK*. Loughborough University, CAN.
- Zaatar, A. (2002). Halfway home. *Health Service Journal*, 31 January: 28-29.

Appendix 1

Description of Study Areas

1 Study Area 1: Warwickshire

Warwickshire agreed to be the first study site, with the research focused on services in the South of the HA for Community Care and across the whole of Warwickshire for Social Care and Primary Care. Due to differences in boundaries, South Warwickshire primary care did not encompass Coventry and its surrounding districts while Social Care *did* include Coventry. Warwickshire as a whole was representative of other parts of the country at the time in that responsibility for health and social care in the community was shared between a wide range of NHS and local government organisations including:

- 76 General Practices in 5 Warwickshire PCGs plus 1 in a Coventry PCG
- South Warwickshire Combined Care NHS Trust
- North Warwickshire NHS Trust
- Warwickshire Health Authority
- Warwickshire County Council (including Warwickshire Adult Social Services)
- Warwick & District Local Council for local initiatives (covering Warwick, Leamington Spa, Kenilworth and surrounding districts)

In addition, there were three acute hospital trusts in the area: South Warwickshire General Hospitals NHS Trust, Warwick; George Eliot Hospital NHS Trust, Nuneaton; and the Hospital of St Cross, Rugby (part of the Walsgrave Hospitals NHS Trust, Coventry). The study was actively supported by senior staff in both Health and Social Services.

The population covered by Warwickshire services is approximately 500,000 in size, of which 61% live in the towns of Nuneaton, Bedworth, Rugby, Leamington Spa, Kenilworth and Stratford upon Avon. The remaining 39% live in rural areas. In terms of health needs, Warwickshire is close to the national average for England and Wales on most indicators; although there are considerable variations across the County.

2 Study Area 2: Leicester City

Leicester City were recruited as the second study site, with data collection focused on social care and primary care staff in Leicester City East PCT, and informatics provision considered across both PCTs. The city is representative of other metropolitan locations in that a wide range of NHS and local government organisations share responsibility for health and social care in the community, including:

- 2 Primary Care Trusts (Leicester East & Leicester West PCTs)
- 31 General Practices in Leicester East PCT
- 39 General Practices in Leicester West PCT
- Leicester Royal Hospital Trust incorporated into University Hospitals of Leicester Trust
- Leicester Strategic Health Authority
- Leicester City Council (including Leicester Social Services Department)

In addition, there were three acute hospital trusts in the city when the study started: Leicester General Hospital Trust (LGHT), Leicester Royal Infirmary (LRI), and Glenfield Hospital Trust. In 2001/02 these were amalgamated and the University Hospitals of Leicester NHS (acute) Trust (UHL) was created to deliver unified working across these three acute hospitals. Proposals were also being developed to integrate the provision of mental health services across the health and social care community. As part of the development of PCTs, non-acute services previously provided by Leicester and Rutland Healthcare Trust (LRHT) were to be managed by a lead PCT or by the acute trust, the University Hospitals of Leicester (UHL), but the allocations had not yet (October 2002) been made.

The population covered by Leicester is approximately 320,000, somewhat smaller in size than Warwickshire. Leicester is a mid-ranking metropolitan city with a diverse population. The city has a great deal of social disadvantage (it has the 11th highest deprivation Jarman score of all local authorities). Over one in four of the population is of ethnic origin, and one quarter of households are pensioner households. Leicester is also recognised for its innovative approaches to health and healthcare, and was one of the early authorities to be successful in its bid for Health Action Zone (HAZ) status.

Appendix 2

Overview of Local Informatics Contexts

2A: Warwickshire Overview

A1: Warwickshire Health Care

i) Applications

During the course of the study there were major changes in the application system types used in Warwickshire (for example, approximately one in three GP practices changed their supplier during this period). The supplier of the Hospital PAS (Hyder/ IBA) also demerged and the portfolio of IBA Europe in Health was bought by InHealth Solutions (a spin off from Bull systems). Had the emphasis of the study been on the hospital/ social care interface this hiatus would have caused us challenges; as it was, it is included as an indication of the rapidly changing market.

Although the community applications had not progressed as far as anticipated by 2002, health care staff were moving from the FIP Community system which focussed on logging client contacts to a Community Information Support System (CISS) introduced in 2001. This was developed in-house and had a changed focus, away from counting community contacts and towards referrals, waiting times, recording episodes of care and utilising care plans.

ii) End-user access

By 2002, community nurses were beginning to have access to the GP systems in the Warwickshire area on an outreach basis, and to have direct access to the hospital PAS data. There were residual issues around the sharing of person-identifiable data but the move towards collective systems' use was promising. All clinic sites had end-user access; terminals were shared between professions and could be used for the new CISS system and intranet activities by all, subject to personal password permissions (see below).

iii) Internet access

All terminals were Internet (by 2002) enabled but end-users were required to sign a Confidentiality Code and be aware of the Code of Practice before being given permission through their password to use the Internet, after training.

At the start of the study, some general clinical information for patients/ carers available on the Internet was accessible through the local public libraries 'Open Door' project or personal Internet connections; this was not Warwick specific or provided by them *per se* and it was still at an early stage.

iv) Training

Centrally provided learning resources (10 types) were available by 2002 through clinic sites to teach individuals how to use Internet, email, critical appraisal skills for using the available evidence base (wherever located) etc. All staff were required to undertake the relevant training before using the applications for which they had permission, although there was evidence, both from our surveys and from in-depth qualitative interviews (see section 6.7), that some professionals experienced difficulties in taking up these training opportunities. Certain additional functionality was limited to managers (for example - Outlook Diaries).

v) Privacy issues

Addressing of privacy issues became more important over the period of the study. By 2002, it was considered to need a designated officer rather than being part of a wider staff remit, and a specific appointment was made to lead the Caldicott Guardian process locally.

vi) Future IS plans

In terms of IS plans, the PCT in Warwickshire was by 2002 exploring the use of hand-held terminals and Personal Digital Assistants (PDAs). It was considered that widespread use would be costly but could provide another plank in the platform for access to Internet-based shared data in due course.

Other local activities were also encouraging more staff to see technology as a necessary and integral part of their work, including:

- Health and Social Care staff were planning to look at the overall health needs picture and were exploring the necessary taxonomy for this through local meetings.
- The requirement for a Single Assessment Process (SAP) for older people, involving both health and social welfare, was seen as potentially creating a considerable volume of work. Guidance on SAP was considered to be basic information that could readily be shared to ease the introduction and ensure consistency.
- Mental Health was an area with considerable collaborative working but as yet little computerised interconnection, with social care staff having to use both the health IT system and their 'own' social care system.

A2: Warwickshire Social Services

i) Applications

At the beginning of 2002, Warwickshire Social Services upgraded from the old Client Related Management System (CRMS) to the new CareFirst variant. Local custom determined whether field workers entered their own data, or not, on these systems; there was no strict mandate although there was movement towards more self-input by the end of the study period. Staff predominantly chose to input their own data for client records, although some professionals were still relying on administrative and clerical staff for data entry.

At the start of the study, Warwickshire was beginning to develop a multi-agency assessment project with an overall objective to prevent admissions and to make early discharge 'safer'; this project was predominantly paper-based. At the end of our study, this project was still only able to provide profiles of patients from the systems through pre-set reports, and there were concerns about counting and dealing with hidden populations (including the target elderly population considered in this study). Warwickshire planned, in future, to move towards assessing patients by presenting criteria, not by the amount of services required and their source. Staff wished to proactively make informed judgements about what services needed setting up.

ii) End-user access

The area reported extensive end-user access points, and increasingly (subject to cost, training and management approval) the end-users and the terminals were becoming Internet enabled.

Warwickshire contained of the order of 12 bases for staff conducting assessments and commissioning services for the Older Person. There were 65 Social Services office locations overall, including in Homes for Older People. There was little cross-over between formal team responsibilities, for example for Older People and Adult Services. A central statistics team carries out analysis and profiling of team activities by geographic areas. As pointed out above, the distribution of end-user access points in Social Services increased by 30% during the course of the project.

iii) Internet access

Internet access was enabled by the password permission of an individual; 181 staff had this permission at the start of 2002. There were ten social work offices with 'Internet café' facilities for general use by staff, subject to published protocols for use and authorisation by their line management. Internet access had not previously (at the beginning of our study) been available to field staff. In addition to work-based access, 15 managers and 5 Emergency Duty staff had official access from home.

iv) Training

This was reported to be available and taken up on an as required basis, subject to management authorisation.

v) Privacy issues

Social Services worked within the framework of Warwickshire County Council policies on security, confidentiality and privacy. Warwickshire was part of the Association of Directors of Social Services working group on citizens' access.

vi) Future IS plans

There were plans for a considerable increase in the number of Social Services staff given Internet access in the financial year 2002/03. This was predominantly to enable staff to take advantage of external web-based information like that of the Residential Care Homes Association that provides a picture of care home vacancies across the country.

2B: Leicester: Overview of Local Informatics Contexts

B1: Leicester Health Care

i) Applications

During the period of the study, the Leicester Health Informatics Service was facing the challenge of facilitating all practices in migrating to accredited systems, predominantly from the EMIS vendor. At the same time, the Informatics Service was also harmonising multiple hospital systems. By October 2002 a new variant of the FIP Community Nursing application (called TCS) was also being rolled out across the city, in conjunction with the replacement of dumb terminals.

ii) End-user access

Typically each GP was reported to have 3.5 terminals notionally for themselves and their staff. This figure was confused by the larger than average number of branch surgeries in Leicester City which had additional terminals that were not used all the time. The 2001 local implementation strategy indicated that a recommendation had been made to introduce functionality within the GP systems to support integrated working across the primary care team in pilot mode before a full roll-out, anticipated for completion by 2003/04. Additional knowledge management functionality was introduced to support clinical governance. The introduction of functionality was viewed as increasing the pressure for additional end user access points.

iii) Internet access

All PCs used in the city were Internet-enabled and local, low cost, in-house training was available. However, there was no mandate to complete the formal training before using the Internet, and many professionals were known to learn from peers and informally. Various local Internet-related actions were outlined in the 2001 local strategy. Citizens could also access the Internet, and therefore NHS Direct Online, through terminals in various locations supported by Leicester County Council.

In order to address information provision for patients and staff, the following projects were being progressed that complemented and supported work on NHS Direct and Care Direct, the telephone triage systems:

- further development of web-based delivery of information, including MAGNET with Leicestershire County Council;
- enhanced library facilities and staff up-skilling to support knowledge management.

iv) Training

Training provision was predominantly system-specific and addressed 'how to use certain systems' rather than general informatics awareness. By 2002, a training plan for the whole of the Leicester area, including the study site, had been produced with multi-agency stakeholder input and a large designated financial allocation attached. These training plan were still to be ratified and, if endorsed, progressed alongside the development of clinical learning networks, a University for Industry project, and the national NHS promotion of the European Computer Driving Licence for all health staff. Internet training was available in-house at low cost, but was not mandatory. Some professionals learnt on the job or through personal use. All PCs were Internet-enabled but there was no link between personal user name/ email address/ password, formal training and what functionality someone was permitted to use.

v) Privacy issues

The health community conducted a gap analysis on the BS7799 standard (relating to good practice) in 2001/2002 to determine compliance with data protection requirements. The Caldicott recommendations were being rolled out, but an unanticipated resource requirement in the field had necessitated Leicester Health Informatics Service staff supporting this process.

vi) Future IS plans

During the course of the project there were major amalgamations and re-organisations of the Leicester health organisations into the 'Leicester Health Community'. In line with these, Leicester health informatics support was delivered through a collective team that supported acute, community and primary care informatics. The informatics context in Leicester City was therefore both fluid and complex. As can be seen from this extract from the local strategy document at the time:

'University Hospitals of Leicester NHS Trust (UHL) being a recent merger of three acute trusts, is faced with historic problems of system age and duplication. For example there are 3 PAS systems, 2 Order Communication systems, 3 systems for managing medical records, 3 radiology systems, 1 PACS and multiple e-mail systems. Most of the systems are old and in need of replacement, meaning that the Trust cannot effectively operate cross-site services.'

During the study period, as part of the local strategy, the community hospitals implemented a new PAS system (through the Leicester and Rutland Healthcare Trust) and progressed a mental health information strategy to address the Mental Health National Service Framework. Once the University Hospitals of Leicester structure and that of the recently established Health Informatics Service were stabilised, Leicester intended to explore further cross-sectoral and collaborative informatics projects.

B2: Leicester Social Services

i) Applications

Leicester City, like Warwickshire, was using a modified version of CareFirst (newer version of CRMS), which started to be rolled out in May 2002. This application covered client information including CareTime for home care planning (implemented by July 2002), Financial functionality including that to cover home care invoicing to support independent home care, payment for Foster care (implemented in September 2002) and payments for Residential care and assessment (which went live in January 2003). The application did not include SAP, a submission for which was to go to the local implementation strategy board in due course. The system did include management of clients by the whole Social Services team. When a module went 'live' it went live across the whole of Leicester, rather than one pilot location getting all functionality before any other.

Although the intention was that all staff did their own data input, in order to improve data accuracy, some were still using clerical assistants for data entry. However, central data quality checks were reported to be reducing as a result of direct staff input.

ii) End-user access

Between twenty and thirty locations had direct connections to the local intranet in Service Provider units, providing fast robust access to the applications systems. Homes for Older People had 15 (on dial-up access) that were used less frequently and therefore did not warrant the faster connections. Social Services staff teams in Leicester were well-defined by client cohorts, the only overlaps were traditional e.g. cross-overs between Learning Disabled and Physically Disabled. The service had a central informatics team of 12 to provide a Help Desk, training and central reports.

As described above, Social Work teams had end-user points for their manager, clerk and social workers. The end-user access points on the Desktop might be directly inter-linked or linked through other servers. These staff and their terminals were able to access CareFirst and the Local and County information systems. The Emergency Out of Hours Access Team also had home-based terminals, as did the home-based Emergency Duty Team for the whole County (approximately 20 terminals). There was reported to be no pressure from other staff for home access.

iii) Internet access

In Leicester, Internet-enablement was only introduced if a manager paid and authorised this. It was established by physical terminal location rather than personal password access.

The Social Services Department worked within County Council and e-government regulations and the pertinent legislation for the UK and European Community. It was reported by the Head of Information Systems for Social Services that, as the requirement for Citizens' access to Social Services emerged, systems would need changing/ mirroring, and information would probably be put on the Internet through the Leicester County Council portal. By the end of 2002, citizens could access the Internet through terminals in various locations supported by Leicester County Council but there was no citizen access to the Social Services systems locally, other than as references within collective local authority reports for information.

iv) Training

Training modules were being developed to cover CareTime for home care planning, financial functionality including that to cover home care invoicing to support independent home care, payment for Foster care and payments for Residential care and assessment. These were timed to coincide with implementation timelines. In total, it was estimated that 1,200 people would need to pass through the ongoing training programme for the CareFirst application.

v) Privacy issues

Leicester Social Services reported adherence to the privacy, confidentiality, security and data protection requirements of the Leicester County Council. These were, as with every other UK organisation, defined within the relevant European Directive.

vi) Future IS plans

Leicester Social Services reported that they had no short term plans for hand-held terminals, PDAs or and wireless links. The main strategy was to facilitate field workers entering data from their bases rather than whilst in the community or on domiciliary visits.

2C: Example of Activity Profiling Tool (Main Surgery)

YOUR COMPUTER SYSTEM IN BRANCH SURGERY															
Practice ID (PLEASE COMPLETE A SEPARATE ATTACHED SHEET FOR EACH BRANCH SURGERY)															
1. How many computer screens do you have in your branch surgery premises?	How many computer screens do you have in the following locations? GP consulting rooms Practice Nurse room Health Visitors / District Nurses / Midwives etc. offices Reception area Practice Manager / Administration area(s) Other places (e.g. Dispensary) (please specify)														
2. Are any of these computers <i>not</i> linked to the GP practice system? No / Yes (please circle one choice)	If Yes, for what sorts of tasks do you use the stand-alone / separate computers? (e.g. Internet searches, e-mail, sending information to the HA/PCT) On average, how many hours a week are these computers used? <table border="1"> <thead> <tr> <th>Task (please list)</th> <th>Hours per week</th> </tr> </thead> <tbody> <tr><td>.....</td><td>.....</td></tr> <tr><td>.....</td><td>.....</td></tr> <tr><td>.....</td><td>.....</td></tr> </tbody> </table>			Task (please list)	Hours per week				
Task (please list)	Hours per week														
.....														
.....														
.....														
3. Does your branch surgery have computer terminals linked to the main surgery?	No / Yes (please circle one choice) If Yes, how many are linked to your main surgery?..... <table border="1"> <thead> <tr> <th>Location:</th> <th>Number:</th> </tr> </thead> <tbody> <tr><td>GP consulting room.....</td><td>.....</td></tr> <tr><td>Practice nurse's office.....</td><td>.....</td></tr> <tr><td>Practice Manager / Administration.....</td><td>.....</td></tr> <tr><td>Reception.....</td><td>.....</td></tr> <tr><td>Other place (please specify).....</td><td>.....</td></tr> </tbody> </table>			Location:	Number:	GP consulting room.....	Practice nurse's office.....	Practice Manager / Administration.....	Reception.....	Other place (please specify).....
Location:	Number:														
GP consulting room.....														
Practice nurse's office.....														
Practice Manager / Administration.....														
Reception.....														
Other place (please specify).....														
4. Do you use the same system for patient/client records management in your Branch Surgery as in your main surgery? Yes / No (please circle one choice)	If you answered 'No' please specify system used in branch surgery: (e.g. InPractice (VAMP Vision), EMIS, Torex, other commercial or in-house produced) Name:..... Version:.....														
5. How many different staff members typically use the computer system in an average working week in your Branch Surgery ? (regardless of location) Please give an estimate of how many 'hours' each of these staff groups spends on the computer in your Branch Surgery in an average week	Number	Staff members	Hours spent on the computer by each staff group in an average week												
.....	GPs.....												
.....	Practice nurse(s).....												
.....	Health Visitor(s).....												
.....	District Nurse(s).....												
.....	Midwife.....												
.....	Physiotherapist(s).....												
.....	Practice Manager.....												
.....	Receptionists.....												
.....	Administration.....												
.....	Other staff (please specify) (e.g. Chiropodist, Counsellor, Consultant's clinic)												
.....												
.....												
.....												

Thank you

Appendix 3

Survey Questionnaire (Health Care Professionals)



Centre for Health Services Studies

MAKING INFORMATION WORK SHARING & COMMUNICATION ISSUES

This survey is being carried out as part of a Department of Health funded project to establish the needs of health and social welfare professionals and carers in the community, regarding current communication technologies and current practice. Enhanced communication and sharing of information can provide benefit to patients and professionals alike.

Please fill in this questionnaire giving as much detail as you can. **Please answer all questions** and return it to the Centre as soon as possible in the pre-paid envelope provided. If you have to leave a question blank please tell us why. It should not take more than fifteen minutes of your time.

We value your comments. Feel free to give any additional information or feedback in the space provided on the last page. *All information you give us will be made anonymous* and no information will be used which could personally identify you.

If you have any questions or would like to talk about the study please contact us on the telephone numbers below. Thank you for giving your help. Your support with this important study is very much appreciated.

A handwritten signature in black ink, reading "Deborah Biggerstaff".

Deborah Biggerstaff Research Fellow
Contact telephone number: 024 7652 8206

A handwritten signature in black ink, appearing to read "Ala Szczepura".

Ala Szczepura Director
Contact telephone number: 024 7652 2958



SECTION ONE

This section is about you and your professional training

1.1 Are you: Female ☐ Male ☐ (please tick **one** box)

1.2 Your age group (please tick **one** box)

16-20	21-30	31-40	41-50	51-60	61-65	Over 65
-------	-------	-------	-------	-------	-------	---------

1.3 Please give your **current** job title

1.4 Please describe your role

1.5 Please select the **one** area that is most applicable in your day to day work

☐

Clinical responsibility (e.g. your own case load)

☐

Clinical management responsibility

(Please tick **one** box only)

1.6 How many years have you worked in your current job? years

1.7 Do you work **full time**? Yes ☐ Please go to 1.9 No ☐ Please go to 1.8

1.8 If **part time** please give the **average** hours you work for **each** week hours per week

1.9 Do you have training in IT?

(Please list all training with the year of training and any qualifications gained)

1.10 In relation to using IT, do you rate your self as:

Expert ☐ Competent ☐ Some experience ☐ Non user ☐

*(Please tick **one** box only)*

NOW PLEASE GO TO SECTION TWO

SECTION TWO

This section is about you and your patients

2.1 What are the **main categories** of patients you deal with? (E.g. children, mental health, elderly)

1 _____ (Please list **up to four** patient groups)

2 _____

3 _____

4 _____

2.2 Do you have **face to face** contact with **patients**? E.g. as a nurse, doctor, receptionist, carer.

(Please tick **either** Yes or No)

Yes ☐

If Yes please go to **2.2.1**

No ☐

If No, please go to **2.2.2**

2.2.1 If you ticked 'Yes' above, please specify **where** you have face to face contact with patients

☐

Patient's home (please tick as many as may apply to you)

☐

Your own work base

☐

Intermediate location (e.g. day centre, social club, community centre, lunch club)

☐

Other (please specify) _____

2.2.2 Do you have **indirect** contact with patients? E.g. manage a department/ hospital unit/ telephone advice service/self help group

(Please tick **either** Yes or No)

Yes ☐

If Yes please go to **2.2.3**

No ☐

If No please go to **2.3**

2.2.3 If you ticked 'Yes' above, please state **what** indirect contact you have with patients:

2.3 Do you have **face to face** contact with **other professionals or voluntary groups** in relation to patients? E.g. social services, other health professionals, voluntary groups

(Please tick **either** Yes or No)

Yes ☐ If Yes please go to **2.3.1**

No ☐ If No please go to **2.3.2**

2.3.1 If you answered 'Yes' above, which groups of professionals do you have contact with?

2.3.2 Do you have **non face to face** contact with **other professionals or voluntary groups**, in relation to patients? E.g. letter, telephone contact (Please tick **either** Yes or no)

Yes ☐ If Yes please go to **2.3.3**

No ☐ If No please go to **2.4**

2.3.3 If you answered 'Yes' above please select **what** form of indirect contact you have
(Please tick as many as may **apply to you** in your work)

☐ Telephone

☐ Letter/mail

☐ Fax

☐ E-mail

☐ Other (please specify)_____

This next section asks a little bit more about the patient groups you have responsibility for

2.4 Which of the following patient groups do **you have contact with?**

- ☐ Mental health (e.g. dementia) *(Please tick the groups that apply to **you**)*
- ☐ Substance abusers
- ☐ Diabetic
- ☐ Disabled, physical
- ☐ Disabled, learning
- ☐ Rehabilitation (e.g. after stroke)
- ☐ Children
- ☐ Homeless
- ☐ Lone parents
- ☐ Carers
- ☐ Ethnic groups
- ☐ Voluntary groups (please specify which group/s) _____
- ☐ Other group (please specify) _____
- ☐ Other group (please specify) _____

2.5 What proportion of your work relates to **patients aged 65 years and over?**

*(Please estimate the proportion and select **one** category only)*

- ☐ None or very little ☐ Up to a quarter ☐ Quarter to a half
- ☐ Half to three quarters ☐ Three quarters plus ☐ All your workload

NOW PLEASE GO TO SECTION THREE (A)

SECTION THREE (A)

The following questions relate to accessing information to help patients.

This section gives some examples of common situations, which might apply to you in your professional role. Please read them in turn and answer the questions in Section 3 (B). We have tried to keep the situations broad so as to apply to as many professionals as possible. Not every detail of the cases below will be relevant to you but some of it should. **Try to imagine you are professionally involved** with the situation in order to help us.

*Please choose **one** situation and then answer the questions in **SECTION THREE (B)***

SITUATION 1 'COMING HOME'

Gwen is a diabetic woman in her late 60s. She lives on her own after her husband died suddenly three years ago. Her daughter, Jo, is very supportive, but does not live nearby. She has a demanding job and works long hours in her career as a Personal Assistant. Jo has a round journey of over forty five miles to visit her mother.

Gwen developed diabetic complications and was admitted to hospital after an ulcer on her leg became infected. She needed surgery to remove the dead tissue. She was discharged, over a bank holiday, in a wheel chair, as the leg was still inflamed. However, the wound needed dressings changed daily. As there was no transport available, her daughter, Jo, had to make a round trip to the hospital and then to Gwen's house. This was a journey of over a hundred miles.

When they arrived at Gwen's home, the wheelchair she had been given did not fit through the entrance to her home. This meant that Jo had to lift and carry her mother by herself, as there was no one else to help her. Once in her home, Gwen became a virtual prisoner as she had difficulties coping with the wheelchair, because her home was not adapted for wheelchair access. Gwen needed the wheelchair for ten weeks because the leg wound was slow to heal.

During this period it became apparent to Jo, who is in her mid forties, that she would have to consider giving up her job to care for her mother. This would mean that she would lose out in pension contributions, as well as her salary.

After a delay of eleven days her daughter telephoned her mother's GP because she was worried how her mother was coping.

The main services that became involved were:

Her GP, district/community nursing, home help, physiotherapy, housing benefits officer, council tax, voluntary sector

SITUATION 2 'DEVELOPING CRISIS OF CARE'

Fred and Jean are a couple in their early seventies. They have lived in the same home since they were married, in a small rural community. They are both very independent characters and, having worked hard all their lives, were looking forward to their retirement.

Jean and the family's GP had realised, for some time, that Fred's health was deteriorating. Fred was experiencing increasing problems with his memory. Three years ago, Fred was finally diagnosed as having Alzheimer's disease.

Recently Fred has become very anxious and irritable. Jean has had to work very hard to look after him. She has taken over all the maintenance of the house and their large garden, which was work they both used to share. Fred's anger and frustration have led to arguments and, on the latest occasion, he lashed out at Jean before storming out of the house. A neighbour who recognised him found Fred wandering around the churchyard, in the nearby village. The neighbour managed to persuade Fred to come back home to Jean and gave him a lift back in his car.

Over the past six months Jean has been experiencing chest pains. Lately, the pains have got worse and she has now been diagnosed with angina. She is due to go to the local hospital next month, prior to being admitted for tests. Her consultant has warned her that she must do less, or her health could deteriorate further and her condition would, effectively, make her disabled.

She has started to feel weepy and has problems sleeping, often waking in the early hours of the morning, unable to go back to sleep.

Last week, at her friend's prompting, she went into the advice centre of the nearest town, to ask for some advice. When she sat down she started sobbing uncontrollably as she described her worries and concerns, both for her husband and herself, "I don't know who to turn to, I'm at my wit's end," she says, "Nobody knows what it's like trying to live with him, and I feel so guilty even talking about it to anyone. I can't go on, but I must. Life won't be worth living if we cannot stay in our own home."

The main services that became involved were:

Her GP, GP counselling service, social services assessment care management, home help, housing benefits officer, council tax, voluntary sector support group

Try to imagine you are professionally involved with one of these situations. Please choose **one** situation and answer the questions in **SECTION THREE (B)**, thinking about the scenario you have selected.

NOW PLEASE GO TO SECTION THREE (B)

SECTION THREE (B) Please read SECTION THREE (A) first before you answer this next section

Please select **one** situation from **Section 3 (A)** for your answers (not every detail will apply to your work)

Situation 1 ☐ Situation 2 ☐ (Please tick the situation you have chosen)

3.1 Have you ever had to deal with a similar situation in the course of your work? (It does not have to be exactly the same)

Yes ☐ No ☐ Please tick **either** Yes or No

3.2 Do you have a local procedure or good practice guidelines for this type of situation?

Yes ☐ If Yes please go to **3.2.1** No ☐ If No please go to **3.3**

3.2.1 If you answered 'Yes' above, please could you give brief details/title of the document or guidelines and where you found it?

Details	Format	Where located

3.3 When dealing with this type of situation, what types of information do you think other professionals involved could helpfully provide you with? (Please give as much information as possible)

3.4 Have you ever needed to ask other professionals for information in a similar situation? E.g. writing a letter, telephone call. (Please tick **either** Yes or No)

Yes ☐ If Yes please go to **3.4.1** No ☐ If No please go to **3.5**

3.4.1 If you answered 'Yes' above, what information did you need?

3.4.2 How did you try to get this information at the time?

3.5 How easy do you think it has been in the past to access this type of information?

☐ Difficult ☐ Acceptable ☐ Easy *(Please tick **one** box only)*

3.6 In such a situation what information do **you** have access to which you think other people providing care might find helpful?

3.6.1 Could you share this information you have with other professionals?

*(Please tick **either** Yes or No)*

Yes ☐ *If Yes please go to 3.7* No ☐ *If No please go to 3.6.2*

3.6.2 Please can you tell us why you would be unable to share information?

3.7 If you have shared any information with other professionals what were their professions?

3.8 How did you share this information at the time?

*(Please select **all** those that apply to you)*

- ☐ Multi disciplinary assessment/sharing of written assessment
- ☐ Told colleagues formally (e.g. at a meeting either within or outside your department)
- ☐ Circulated memo/notice
- ☐ E-mailed round department/discussion group
- ☐ Told line manager/senior member of staff
- ☐ Informed team members (e.g. at change of shift)
- ☐ Told colleagues informally (e.g. discussion at coffee break/telephone call)
- ☐ Other (please specify) _____

3.9 Moving on from the situations we gave you as examples in **Section 3 (A)**, here is a list of types of information about patients that someone in your work situation might need. *(Please select those areas that **apply to your work** and tick the relevant columns)*

Situation	Have information already	Need info & can find it if needed	Need info & don't know where to find it	Don't need info/not applicable
Emergency & next of kin				
Carer arrangements				
Respite care				
Health status (physical)				
Health status (mental)				
Multi disciplinary assessment needs / specialist assessment				
Discharge from hospital process				
Medication				
Rehabilitation				
Disability issues / needs				
Ethnicity needs / issues				
Care in home / home help etc.				
Entitlements (e.g. financial claims)				
Housing Adaptation of home				
Other (please give details) -----				

NOW PLEASE GO TO SECTION FOUR

SECTION FOUR

This section asks for your views about communication and sharing information to help patients

4.1 What do **you** think are the main areas where information could be best shared among professionals?

*(Please answer all the categories and tick as many as **apply to you**)*

Situation/Information need	Applies to me	Does not apply to me	Not sure
Informing other health professionals			
Informing other social services professionals			
Informing your patient			
Informing carers			
Improving care for your patient			
Improvement in your work structure			
Reducing work stress for yourself			
Reducing work stress for colleagues			
Better use of resources			
Better use of time			
Reduced duplication of work load across services			
Improving communication			
Improving coordination of care			

4.2 In your **own** work experience, do you think that communication of information between different groups of people providing care is:

☐ Excellent ☐ Good ☐ Reasonable ☐ Poor *(Please tick **one** box only)*

4.2.1 From your answer above, please give a brief explanation for the answer you have given

The following questions are about the information systems in your workplace

4.3 In support of **your work** do you use: (please tick as many as apply to **you**)

Information system	For your work	At home
Computer		
Palm top / Psion etc.		
Telephone / fax		
Information kiosk		
Diary or day book		
Other (please state) -----		

4.4 Do you have access to a computer or computer terminal at work?

Yes ☐ If Yes please go 4.6

No ☐ If No please go to 4.5

4.5 If you have **no** access to a computer, how do you think **you** would benefit from access to a computer for your work? (This assumes you would receive training)

----- (Now please go to 4.12)

4.6 If you have access to a computer terminal at work, is this computer

For your own use? Yes ☐ No ☐

Computer shared with your team/unit/ward? Yes ☐ No ☐

General open access to all staff Yes ☐ No ☐

4.6.1 Is the computer you use part of a network? Yes ☐ No ☐

4.7 If you use a computer at work, how frequently do you use the computer system for professional activity? Please think about your average day and indicate your **average hours per day of actual use** (please count **actual time used**, not hours logged on)

- ☐ Under 1 hour
 ☐ 1 hour & up to 2 hours
 ☐ 2 hours & up to 4 hours
☐ 4 hours & up to 6 hours
 ☐ 6 hours & up to 8 hours
 ☐ 8 hours & over

4.8 When you use the computer system what functions do you use it for, in relation to patient care?

- Patient specific/identifiable ☐ (please tick as many as may apply to you)
 Management/audit/routine administration ☐
 Personal research ☐
 Other (please specify) ☐ -----

4.9 Are you able to change data on the computer at work?

Yes ☐ If Yes please go **4.9.2**

No ☐ If No please go to **4.9.1**

4.9.1 If you answered No above, what is the job title of the person who can change data?

4.9.2 If you answered Yes above, what type of data can you change on the computer?

4.10 Is the computer linked up to the Internet Yes ☐ No ☐

4.11 Please could you give the names of the applications systems you use at work?

4.12 Within your current information system at work, what changes would **you** like, to help you handle your work more easily?

4.13 If we needed to contact you further for our research would you be willing to help us please?

Your name-----

Address-----

Telephone----- (These details are optional)

Please select which prize draw vouchers you would prefer if you win a prize:

W.H.Smith vouchers

Boots vouchers

(Please ring one choice)

Thank you for your help in completing our questionnaire. Your time and effort are very much appreciated and we value your professional information and opinions. Once again we should like to stress that *any information you give us will be made anonymous and will not be personally identified*. If you have any other comments please feel free to write on the blank space below.

YOUR COMMENTS:

If you have any further questions that you would like to ask, or if you would like more information about the project you are very welcome to contact us on the numbers below.

Deborah Biggerstaff Research Fellow
Contact telephone number: 024 7652 8206

Ala Szczepura Director
Contact telephone number: 024 7652 2958

Appendix 4

Information Sharing (Professionals' Survey)

Figure 1: Types of information requested from other professionals in scenario situations

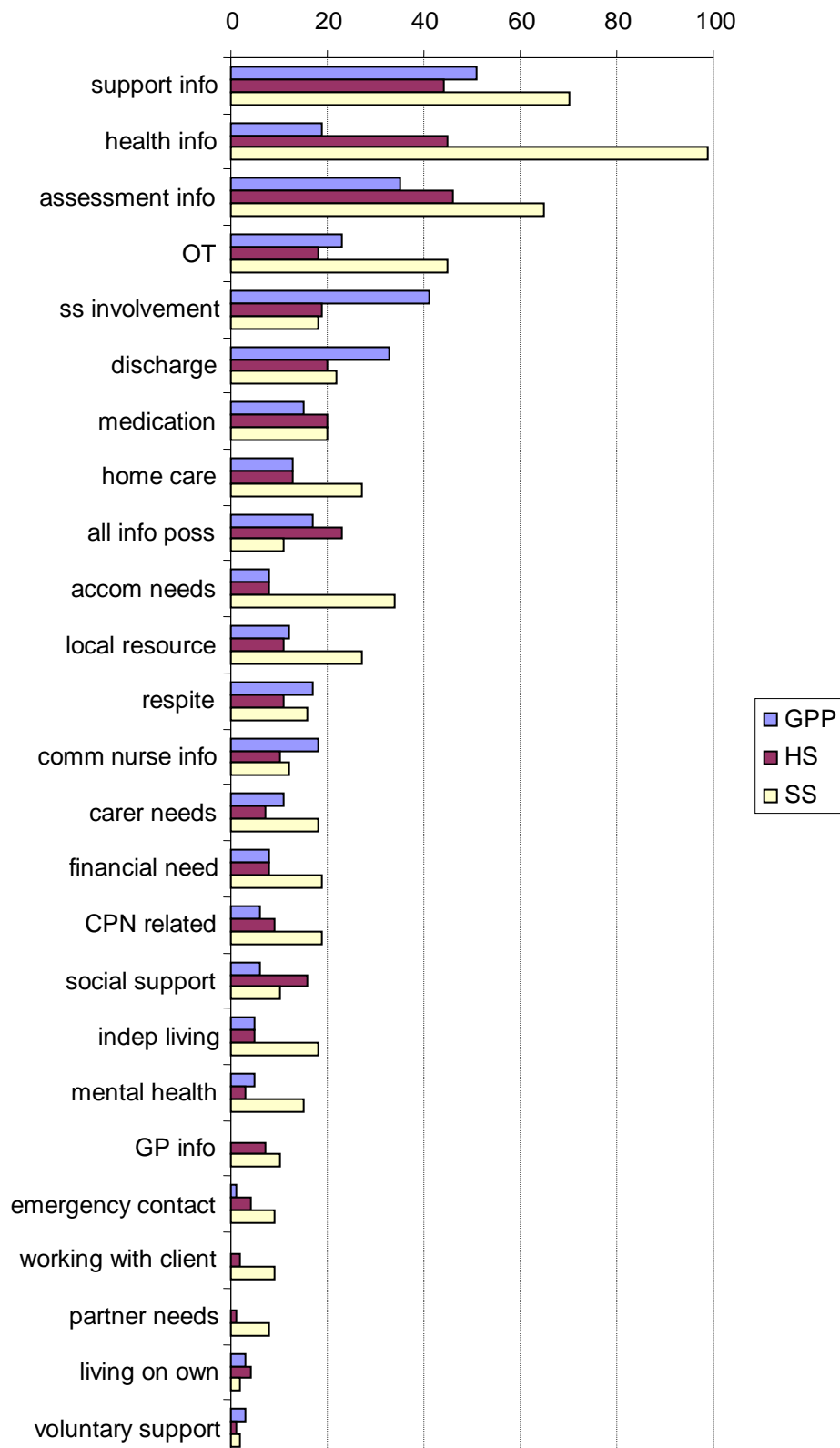
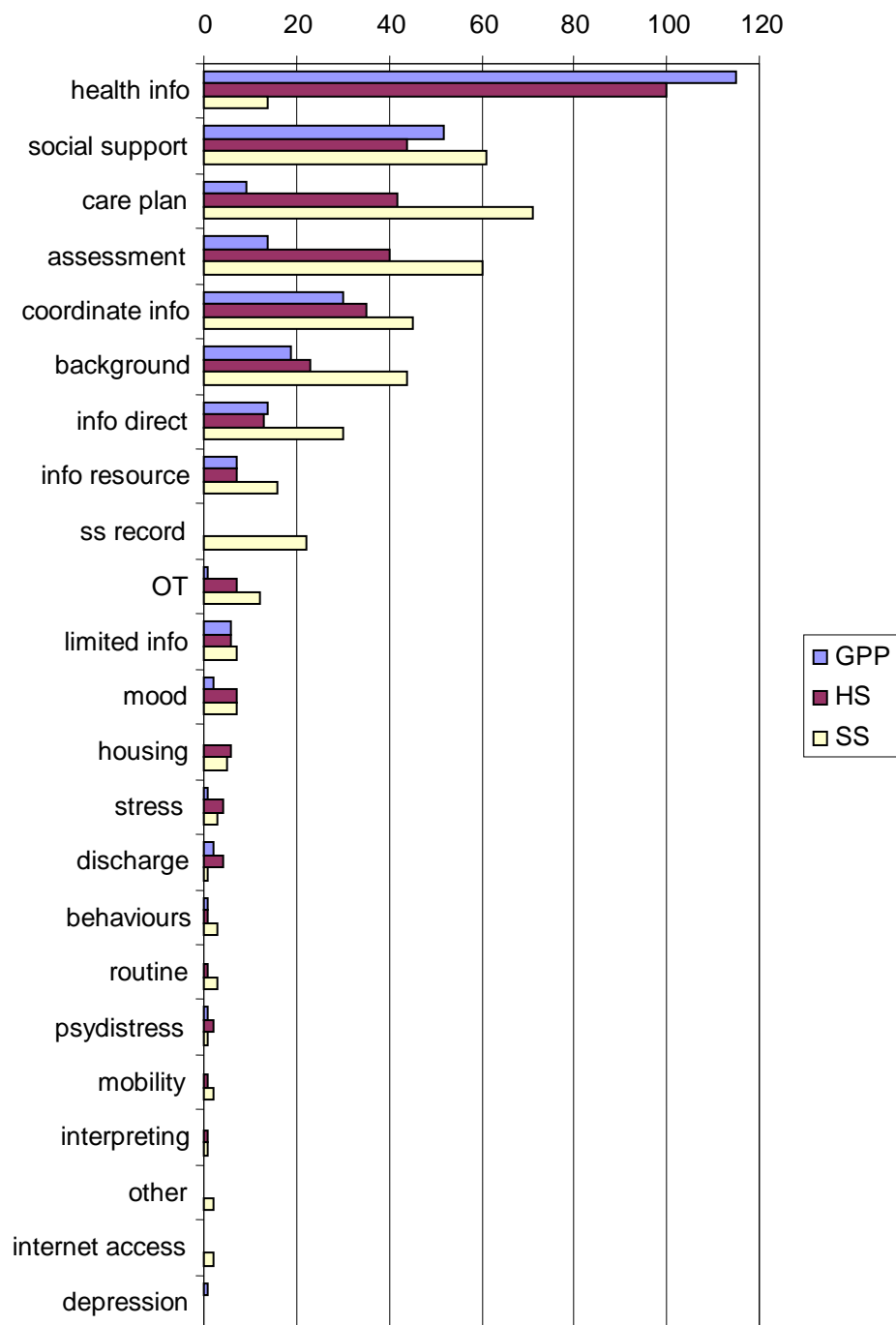


Figure 2 Types of information held by staff groups that could be helpful to other professionals



Appendix 5

In-Depth Interviews (Professionals)

Table 1: Summary of Interview Participants

Participant	Male or female	Health or social care role	Location <i>Location at start of study listed first</i>	Direct / indirect care older people	Professional role(s)	Date of interview *
<i>Interview 1</i>	Female	Health	Leicestershire, (LEPCT)	Indirect care	PCT role Public Health & Caldicott role	July 2002
<i>Interview 2</i>	Female	Social Care	Warwickshire social services (North Warks. PCT)	Both care roles	Care home manager older adults	August 2002
<i>Interview 3</i>	Female	Social Care	Warwickshire social services (Rugby PCT)	Direct care	Hospital Social Worker	August 2002
<i>Interview 4</i>	Male	Health	Warwickshire HA (Rugby PCT)	Both care roles	PCT role & general practitioner	August 2002
<i>Interview 5</i>	Female	Health	South Warwickshire Combined Care Trust (South Warks. PCT)	Indirect care	PCT Executive Officer (nursing & quality)	September 2002
<i>Interview 6</i>	Male	Health	Warwickshire HA (North Warks. PCT)	Both care roles	PCT role IT & Caldicott role general practitioner	October 2002
<i>Interview 7</i>	Male	Social Care	Warwickshire social services (South Warks. PCT Mental health team)	Direct care	Mental Health Team Social Worker	October 2002
<i>Interview 8</i>	Male	Health	Warwickshire HA (South Warks. PCT)	Both care roles	PCT role & general practitioner rural practice	October 2002
<i>Interview 9</i>	Male	Social Care	Warwickshire social services (North Warks. PCT)	Indirect care	Executive Officer – care of older adults	December 2002
<i>Interview 10</i>	Female	Health	South Warwickshire Combined Care Trust (South Warks. PCT)	Direct care	Community Nurse for Older Adults (attached to GP practice with high proportion of older adults on practice list)	December 2002

Table 2: Interview Invitation Letter & Interview Schedule

SAMPLE INVITATION TO INTERVIEW

Dear (name),

Making Information Work: Sharing and Communication Issues

You may remember being part of this study, funded by the Department of Health, looking at communication and how sharing information can help professionals and carers in the community.

You were kind enough to complete a questionnaire for us and your help in this has been most valuable. As part of finding out about the way information sharing can help service delivery we are asking a sample of professionals from the study to tell us about their experiences in more detail.

Your volunteered that you would be willing to help us further with our research and your name has now been selected at random, from study participants. This letter is an invitation to take part in a confidential interview.

The interview will involve an informal discussion with me, at a time and place to suit you. If you prefer, we can arrange a telephone interview. The interview should take about half an hour and will, with your permission, be recorded on a tape recorder so that I have an accurate record of your views and comments about sharing information.

This will be transcribed so that I can code and analyse the text for key themes. You are welcome to have a copy of both the audio-tape and transcript of our conversation if you wish. As with the earlier part of the study, *all information you give us is treated as confidential* and no information used which might identify you (e.g. I remove your name, place of work etc.).

Some of the themes I'd like to ask you about might include the following but you are very welcome to talk about whatever you feel is relevant.

- Your views on sharing information (especially in relation to health and social care)
- NSF Older People and how it might affect sharing information in delivering care
- Problems which may arise with sharing information
- Future directions – where you think IT is going in your sector
- Where would you like information sharing to take you and your colleagues – your 'wish list'

I shall contact you by telephone within the next week to ask if you are able to help me.

If you have any questions or would like to talk about any part of the study please feel free to contact me on the number below. Thank you for all your help so far. Your support with this important study is very much appreciated.

With kind regards.

Deborah Biggerstaff
Research Fellow
Tel: 02476 528206 (direct line)
E-mail: chssdb:wbs.warwick.ac.uk

ICT INTERVIEW SCHEDULE

Introduction

This interview is to help me understand your views about sharing information. I shall hope to ask for your views and comments about sharing information. With your permission I shall tape-record this conversation so that I have an accurate record of our discussion. This will be transcribed so that I can analyse the text for key themes. You are welcome to have a copy of both the audio-tape and transcript if you wish.

I would aim for this discussion to be quite informal - nothing too prescriptive. Some of the themes I would like to discuss might include the following but you are very welcome to talk about whatever you feel is relevant. The idea is that you set the agenda. If you wish to, you are invited to comment on the transcript content. Some of the themes I thought we might consider are:

- Your views on sharing information (especially in relation to health and social care)
- Confidentiality & your role as(e.g. Social Worker, doctor, nurse)
 - Please could you describe your job?

- How did you come to take on this role?
 - Motivation?
 - Information?

- *NSF for Older People* & how this might affect sharing information in the delivery of care
- What are your expectations for sharing information across health and social care?
- Problems / difficulties which may arise with sharing information?
- What do you get out of your role?
 - Personally?
 - Conceptually?

- Future directions - where do you think IT is going in your sector?
- Where would you like information sharing to take you and your colleagues - your 'wish list'?

My contact details:

Deborah Biggerstaff

Making Information Work for Health and Social Care study

Centre for Health Services Studies

University of Warwick

Coventry CV4 7AL

Tel: 024 7652 8206 (direct) or 024 7652 3985 (office)

E-mail: D.L.Biggerstaff@warwick.ac.uk & Deborah.Biggerstaff@wbs.ac.uk

Table 3: Categories and Main Themes Identified by Thematic Data Analysis

Super-ordinate category	Identified Theme	Int 1	Int 2	Int 3	Int 4	Int 5	Int 6	Int 7	Int 8	Int 9	Int 10
IT	Information needs	√	√	√	√			√	√	√	√
IT	Sharing information & challenges	√	√	√	√	√	√	√	√	√	√
IT	ICT now & future expectations	√			√	√	√	√	√	√	
IT	IT as an enabler not a driver / use of IT	√	√	√				√	√	√	
IT	IT as taking time away from care role & lack of time	√		√			√	√			√
TEAMS	Inter-agency working / liaison with health &/or social care. Working together	√	√	√	√	√	√	√	√	√	√
TEAMS	Inter-agency working – challenges & different philosophies	√	√	√	√	√	√	√		√	√
TEAMS	Assessments & related issues e.g. discharge / intermediate care		√	√	√	√	√	√	√	√	√
TEAMS	Colleagues / staff attitudes / professional barriers	√	√		√	√	√		√	√	√
TEAMS	Lessons learned	√		√			√	√	√	√	√
TEAMS	Solutions – what's proposed / in place	√		√		√	√		√	√	
CHANGE	Uncertainty – what direction	√	√	√	√	√	√	√	√	√	√
CHANGE	Coping with change Modernisation of services	√	√	√		√		√	√	√	
CHANGE	Acknowledgement of work still to do	√	√	√	√	√	√	√	√	√	√
CHANGE	Time-scales – too short. More time needed	√	√		√	√	√		√	√	
CHANGE	Facing problems don't feel prepared / trained for		√	√	√			√			√
CHANGE	How they cope – coping strategies		√		√				√		√
CONFIDENTIALITY	Vulnerable groups Mental health. Stigma, isolation, disadvantage, privacy	√	√	√	√	√	√	√	√	√	√
CONFIDENTIALITY	Confidentiality issues. Ethics e.g. disadvantaged groups	√	√	√	√	√	√	√	√	√	√
CONFIDENTIALITY	Care of older people Empathy – putting themselves in older person's shoes		√	√	√		√				√
MANAGEMENT	Strategy – spotting where to go / best guessing / forecasting	√	√	√	√		√		√	√	
MANAGEMENT	Finance investments budgets	√	√	√	√		√	√	√	√	√
MANAGEMENT	Rhetoric & 'spin' (from management)	√	√	√	√		√		√	√	

Super-ordinate category	Identified Theme	Int 1	Int 2	Int 3	Int 4	Int 5	Int 6	Int 7	Int 8	Int 9	Int 10
MANAGEMENT	Problems with service organisation & delivery			√	√		√	√	√	√	√
MANAGEMENT	Frustration with depression / organisational difficulties & funding			√	√	√	√	√	√		√
MANAGEMENT	Negotiations at PCT level & difficulties	√			√				√	√	√
THEORY	NSF Older People & information sharing etc. Aware / not aware	√	√	√	√	√	√	√	√	√	√
THEORY	Piloting / local initiatives / negotiations e.g. PCT level	√			√	√	√	√	√	√	√
THEORY	Hopes for future / way forward e.g. patient centred care	√	√		√	√	√	√	√	√	√

Appendix 6

Survey Questionnaire (Users/ Carers)



Centre for Health Services Studies

MAKING INFORMATION WORK FOR CARERS SHARING AND COMMUNICATION ISSUES

This survey is being carried out as part of a Department of Health funded project to establish the needs of health and social welfare professionals and carers in the community, regarding current communication technologies and current practice. We are trying to identify the information needs of carers in Warwickshire, on behalf of South Warwickshire Carers' Support Service, since improved communication and sharing of information can provide benefit to patients, professionals and carers alike.

Please fill in this questionnaire giving as much detail as you can. It should take about fifteen minutes of your time. **Please answer all questions** and return it to the University of Warwick as soon as possible in the **pre-paid envelope provided**. If you have to leave a question blank please tell us why.

We value any comments which you are able to provide. Feel free to give any additional information or feedback in the space provided on the last page. *All information you give us will remain anonymous* and no information will be used which could personally identify you.

If you have any questions or would like to talk about the study please contact us on the telephone numbers below. Thank you for your help. Your support with this important study is very much appreciated.

DB signature here

AS signature here

Deborah Biggerstaff Research Fellow
Contact telephone number: 024 7652 8206

Ala Szczepura Director
Contact telephone number: 024 7652 8206



A member of the Princess Royal
Trust Carers' Centre Network

SECTION ONE: *This section is about you and your involvement as a carer*

1.1 Are you: 1 Female ☐ 2 Male ☐ (Please tick **one** box)

1.2 Please could you give your date of birth / / (Day/Month/Year)

1.3 Please could you identify which group below best describes you? (Please tick **one** box)

- | | |
|--|--|
| 1. British / European White <input type="checkbox"/> | 6. Other Asian background <input type="checkbox"/> |
| 2. Indian <input type="checkbox"/> | 7. African <input type="checkbox"/> |
| 3. Pakistani <input type="checkbox"/> | 8. Caribbean <input type="checkbox"/> |
| 4. Bangladeshi <input type="checkbox"/> | 9. Other black background <input type="checkbox"/> |
| 5. Chinese <input type="checkbox"/> | 10. Other _____ <input type="checkbox"/> |

1.4 Where do you live? (Please tick **one** box)

- | | |
|---------------------------------------|---|
| 1. Urban <input type="checkbox"/> | 3. Village <input type="checkbox"/> |
| 2. Town/City <input type="checkbox"/> | 4. Isolated rural area <input type="checkbox"/> |

1.5 Are you in paid employment? (Please tick **one** box only)

- | | |
|---|--|
| 1. Full time employment <input type="checkbox"/> | 4. Voluntary work <input type="checkbox"/> |
| 2. Part time employment <input type="checkbox"/> | 5. Retired <input type="checkbox"/> |
| 3. Not currently working <input type="checkbox"/> | |

1.6 Do you care for **one** person only? (Please tick **either** Yes or No)

- | | |
|---------------------------------|--------------------------------|
| 1. Yes <input type="checkbox"/> | 2. No <input type="checkbox"/> |
|---------------------------------|--------------------------------|

1.7 Please could you tell us what your relationship is to the main person you currently care for? (e.g. your mother, sister, son etc.)

Please give relationship

1.8 Please could you tell us their age? Please give age in years

1.9 Please could you tell us what type of disability or illness the person you care for has?

SECTION TWO: *This section is about your role as a carer & your information needs*

2.1 How many years have you been caring for the person you are looking after?

(Please give **number of years**)

2.2 How many hours in a **typical day** (i.e. over 24 hours) do you spend in either caring for your cared-for person or being available in case they need your help?

(Please give **number of hours**)

2.3 Some people consider that a carer moves through different stages of caring over time. If you were to think of yourself in this way please could you **indicate which group you think you belong to** at the present time. (Please tick **one box only**)

- | | |
|---|--|
| 1. Just beginning informal caring <input type="checkbox"/> | 3. Experienced carer <input type="checkbox"/> |
| 2. Recently realised I am formal carer <input type="checkbox"/> | 4. Recently finished caring <input type="checkbox"/> |

2.4 Thinking about your personal experience please could you tell us at what stage(s) you **most needed information** to help you as a carer. (You may tick **more than one box** for this question)

- | | |
|---|---|
| 1. When just beginning informal caring <input type="checkbox"/> | 3. As an experienced carer <input type="checkbox"/> |
| 2. When I realised I am a formal carer <input type="checkbox"/> | 4. When I finished caring <input type="checkbox"/> |

2.5 Please could you describe your views about your current information needs in relation to caring? (Please tick **one box only**)

- | |
|---|
| 1. I feel as if I need information about everything <input type="checkbox"/> |
| 2. I need a moderate amount of information <input type="checkbox"/> |
| 3. Very occasionally I feel I need a small amount of information <input type="checkbox"/> |
| 4. I'm uncertain if I need any information <input type="checkbox"/> |
| 5. I don't need any information at the present time <input type="checkbox"/> |

2.6 If you have needed help or advice as a carer please could you tell us **the people you mostly spoke to / asked for advice?** (You may tick **more than one box** for this question)

- | | |
|---|--|
| 1. Your doctor (GP) <input type="checkbox"/> | 8. Clergy (vicar, rabbi, minister etc.) <input type="checkbox"/> |
| 2. Nurse <input type="checkbox"/> | 9. Neighbour / friend <input type="checkbox"/> |
| 3. Occupational therapist <input type="checkbox"/> | 10. Carers' support service <input type="checkbox"/> |
| 4. Health Visitor <input type="checkbox"/> | 11. Other support / voluntary service <input type="checkbox"/> |
| 5. Social worker <input type="checkbox"/> | 12. Samaritans <input type="checkbox"/> |
| 6. Social services <input type="checkbox"/> | 13. Other person (please give details) <input type="checkbox"/> |
| 7. Hospital discharge team <input type="checkbox"/> | |

2.7 Please could you tell us a little about your main information needs *at present*?

As a carer I would currently like more information about: (Please tick the categories that most apply to you & your needs)

- | | | | |
|--------------------------------|--------------------------|-------------------------------------|--------------------------|
| 1. Benefits | <input type="checkbox"/> | 8. Illness of cared for person | <input type="checkbox"/> |
| 2. Carer's Assessment | <input type="checkbox"/> | 9. Care plan for cared for person | <input type="checkbox"/> |
| 3. Housing, adaptation of home | <input type="checkbox"/> | 10. Occupational therapy/appliances | <input type="checkbox"/> |
| 4. Carer support, befriending | <input type="checkbox"/> | 11. Access to other health services | <input type="checkbox"/> |
| 5. Transport / travel | <input type="checkbox"/> | 12. Access to social worker | <input type="checkbox"/> |
| 6. Day care | <input type="checkbox"/> | 13. Other social care provision | <input type="checkbox"/> |
| 7. Respite / short breaks | <input type="checkbox"/> | 14. Other _____ | <input type="checkbox"/> |

2.8 There are a number of ways in which information such as that described above can be accessed/provided. We would like to know which methods you prefer. How do you prefer to access/receive information such as that described above (2.7).

For each choice please ring the number that **best describes your preferences, as a carer**, using these codes:

1 = Strongly prefer 2 = Prefer 3 = Uncertain 4 = Might use 5 = Wouldn't use

(For each of your answers please rate by circling **one number only**)

Strongly prefer (SP) Prefer (P) Uncertain (U) Might use (MU) Not use (NU)

	SP	P	U	MU	NU
1. By telephone	1	2	3	4	5
2. By fax	1	2	3	4	5
3. Brochures / information leaflets	1	2	3	4	5
4. Using own computer	1	2	3	4	5
5. Using other computer (e.g. library, relative's/friend's)	1	2	3	4	5
6. Via television	1	2	3	4	5
7. Via radio	1	2	3	4	5
8. Via digital TV	1	2	3	4	5
9. Touch screen kiosk	1	2	3	4	5
10. Face to face e.g. advice bureau	1	2	3	4	5
11. Via GP surgery / health centre	1	2	3	4	5
12. Carers' support services	1	2	3	4	5
13. Carers' support group	1	2	3	4	5
14. Other voluntary services (please specify) _____	1	2	3	4	5
15. Other support group (please specify) _____	1	2	3	4	5
16. Other (please give details) _____	1	2	3	4	5

2.9 Below are some statements about information and communication. Please ring the number that **best matches how you feel, as a carer**, for each statement using the codes below.
(For each of your answers please rate by circling **one number only**)

Codes:

1 = Strongly agree 2 = Agree 3 = Uncertain 4 = Disagree 5 = Disagree strongly

- | | | | | | |
|---|---|---|---|---|---|
| 1. My needs for information are generally met | 1 | 2 | 3 | 4 | 5 |
| 2. Information is important to me in my role as a carer | 1 | 2 | 3 | 4 | 5 |
| 3. Information I've received has been useful to me in my role as carer | 1 | 2 | 3 | 4 | 5 |
| 4. Sometimes I've needed information and not known whom to ask | 1 | 2 | 3 | 4 | 5 |
| 5. Sometimes I've been given information that was inappropriate | 1 | 2 | 3 | 4 | 5 |
| 6. As a carer I can find it difficult to ask someone else for information | 1 | 2 | 3 | 4 | 5 |
| 7. I do not always realise I need help until someone gives me the information | 1 | 2 | 3 | 4 | 5 |
| 8. Occasionally I've received useful help/advice by chatting to my friends | 1 | 2 | 3 | 4 | 5 |
| 9. Information from professionals is always of good quality | 1 | 2 | 3 | 4 | 5 |
| 10. Information from carers' services can be very helpful | 1 | 2 | 3 | 4 | 5 |
| 11. It can be difficult to get the information I need at the time I need it | 1 | 2 | 3 | 4 | 5 |
| 12. Sometimes I find out about things but needed the information earlier | 1 | 2 | 3 | 4 | 5 |
| 13. At times I feel as if I receive more information than I can handle | 1 | 2 | 3 | 4 | 5 |
| 14. When I have a problem there is someone there I can trust to talk to | 1 | 2 | 3 | 4 | 5 |

15. Your own view of information _____

SECTION THREE: This section is to help South Warwickshire Carers' Support Service (SWCSS) plan to meet carers' needs.

3.1 Have you been in contact with a Carers' Support Service?

1. Yes ☐ 2. No ☐ (If "No" please go to question 3.7)

3.2 If 'Yes' was this South Warwickshire Carers' Support Service (SWCSS)?

1. Yes ☐ 2. No/Other ☐ (Please give details) _____ (Now go to 3.7)

If 'Yes' please could you tell us about the contact you have had with South Warwickshire Carers' Support Services (SWCSS) **over the past year?**

3.3 How often have you had contact with SWCSS? number of times in past year

3.4 Was this contact with SWCSS

- | | | | |
|------------------------------|------------------------------|---|-----------------------------|
| 1. Spoken on telephone? | Yes <input type="checkbox"/> | <input type="text"/> number of times in past year | No <input type="checkbox"/> |
| 2. Written to? | Yes <input type="checkbox"/> | <input type="text"/> number of times in past year | No <input type="checkbox"/> |
| 3. Received home visit? | Yes <input type="checkbox"/> | <input type="text"/> number of times in past year | No <input type="checkbox"/> |
| 4. Attended a group? | Yes <input type="checkbox"/> | <input type="text"/> number of times in past year | No <input type="checkbox"/> |
| 5. Attended a social event? | Yes <input type="checkbox"/> | <input type="text"/> number of times in past year | No <input type="checkbox"/> |
| 6. Used befriending service? | Yes <input type="checkbox"/> | <input type="text"/> number of times in past year | No <input type="checkbox"/> |

3.5 When you have contacted SWCSS what is the most helpful support you feel you have received?
For each choice please ring the number that **best describes, as a carer, how helpful you found SWCSS** using these codes:

1 = Very helpful 2 = Helpful 3 = Neither helpful nor unhelpful 4 = Unhelpful 5= Very unhelpful

(For each of your answers please rate by circling **one number only**)

- | | | | | | |
|---|---|---|---|---|---|
| 1. Someone who listens? | 1 | 2 | 3 | 4 | 5 |
| 2. Links with other carers? | 1 | 2 | 3 | 4 | 5 |
| 3. Information about Benefits? | 1 | 2 | 3 | 4 | 5 |
| 4. Help with officials (e.g. filling in forms)? | 1 | 2 | 3 | 4 | 5 |
| 5. Help with aids / adaptations? | 1 | 2 | 3 | 4 | 5 |
| 6. Information on respite care? | 1 | 2 | 3 | 4 | 5 |
| 7. Information on short breaks for yourself? | 1 | 2 | 3 | 4 | 5 |
| 8. Carers' assessments? | 1 | 2 | 3 | 4 | 5 |
| 9. Befriending service (volunteer to talk to)? | 1 | 2 | 3 | 4 | 5 |
| 10. Counselling? | 1 | 2 | 3 | 4 | 5 |
| 11. Information on transport / travel? | 1 | 2 | 3 | 4 | 5 |
| 12. Housing advice? | 1 | 2 | 3 | 4 | 5 |
| 13. Learning caring skills? | 1 | 2 | 3 | 4 | 5 |
| 14. 'Sign-posting' to other organisations for help? | 1 | 2 | 3 | 4 | 5 |
| 15. Information on medical care? | 1 | 2 | 3 | 4 | 5 |
| 16. Information on residential care? | 1 | 2 | 3 | 4 | 5 |
| 17. Information on day care? | 1 | 2 | 3 | 4 | 5 |
| 18. Other? (Please give details) _____ | 1 | 2 | 3 | 4 | 5 |

So that SWCSS can best help carers in the future, please could you tell us a bit more about your experiences as a carer?

3.6 For each statement below please ring the number that **best describes, as a carer, how you feel** about using SWCSS using these codes:

1 = Strongly agree 2 = Agree 3 = Neither agree / disagree 4 = Disagree 5 = Disagree strongly.
(For each of your answers please rate by circling **one number only**)

- | | | | | | |
|---|---|---|---|---|---|
| 1. It's just knowing there is someone there at SWCSS when I need them | 1 | 2 | 3 | 4 | 5 |
| 2. Through SWCSS I have met other people in the same situation as myself | 1 | 2 | 3 | 4 | 5 |
| 3. Because of SWCSS I feel less stressed | 1 | 2 | 3 | 4 | 5 |
| 4. Because of SWCSS I now have more confidence that I can cope as a carer | 1 | 2 | 3 | 4 | 5 |
| 5. If SWCSS was not there I wouldn't have known where to turn to for help | 1 | 2 | 3 | 4 | 5 |
| 6. Although SWCSS is useful I could manage without them most of the time | 1 | 2 | 3 | 4 | 5 |
| 7. SWCSS is a useful source of information | 1 | 2 | 3 | 4 | 5 |
| 8. SWCSS can be a help with bureaucracy/advocacy | 1 | 2 | 3 | 4 | 5 |

3.7 As a carer, would you be interested in training / attending courses on any of the following?

- | | | |
|---|------------------------------|-----------------------------|
| 1. Disability / illness of person you are caring for? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 2. Moving and Handling? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 3. Other caring needs of person you look after? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 4. Computer training / use of the internet? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 5. Stress management / relaxation techniques? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 6. Emergency aid / first aid? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7. Hobbies / recreational activities? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 8. Other (details)_____ | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

3.8 Which of the following services would you be interested in using in the future?

- | | | |
|---|------------------------------|-----------------------------|
| 1. Carers social group in locality? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 2. Carer support worker based in a GP surgery? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 3. Advocacy service / help with bureaucracy? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 4. Befriending service? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 5. Social events? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 6. Training events? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7. Provision of day care in order for you to attend training? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

SWCSS tries to make sure that carers are actively involved with developing the service. Please could you answer the following questions about your views for the future.

3.9 Would you like to be more involved with SWCSS in future?

1. Yes ☐ (Please complete pull slip - see last page) 2. No ☐ (Please go to question 3.10)

3.10 If you would like to be more involved with SWCSS in the future, would you be interested in joining a panel of carers who would be sent key documents to read and provide comments / feedback on? (Training would be given for this)

1. Yes ☐ (Please complete pull slip - see last page) 2. No ☐ (Please tick **one box only**)

3.11 Would you be interested in helping SWCSS by becoming a trustee? (Meetings take place 6 times a year, usually on a Wednesday morning)

1. Yes ☐ (Please complete pull slip - see last page) 2. No ☐ (Please tick **one box only**)

If you would like to be entered in the **prize draw** for £25 Boots vouchers please provide your contact details-Thank you.

Name: _____

Address: _____

Tel: _____

Thank you for your help in completing our questionnaire. Your time and effort are very much appreciated and we value your opinions and the information you are kind enough to give us. Before you move on to **SECTION FOUR** please feel free to write any further comments in the blank space below.

YOUR COMMENTS: