Use of Evidence and Knowledge Translation Approaches Facilitating Co-creation of Evidence in Public Health

by

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A Thesis submitted for the Degree of Doctor of Philosophy by Published Work

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Abbreviations

CoE - Centres of Expertise

CHC- Clostridium histolyticum collagenase

EBPH – Evidence-based Public Health

EIDM – Evidence-informed decision making

EIPH – Evidence-informed Public Health

EC - European Commission

HEPA - Health-enhancing physical activity

NHS – National Health Services

REPOPA – Research into Policy to enhance physical activity

SARS – Severe Acute Respiratory Syndrome

PAR – Population Attributable Risk

PIM – Population Impact Measures

POLKA – Patients' Consensus on Preferred Policy Scenarii for Rare Disease

URAM - Unité Rhumatologique des Affections de la Main

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In the name of Allah, the Most Gracious and the Most Merciful

This thesis is the end of a long journey in obtaining my Doctor of Philosophy. I have not travelled in a vacuum through this journey. There are many people who made it possible and the least I can do is express my gratitude to them.

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This work is dedicated to my parents, who raised me with love, prepared me to face challenges and provided me with unparalleled support in all my endeavours. It is to them I owe what I am and what I will be. I am grateful to my brothers for their endless love and encouragement.

I thank my friends and all those who have helped me directly or indirectly in the successful completion of my thesis.

All praises to Allah, the Almighty. I thank Him for the endless bounties he has bestowed upon me.

Declaration

I, Mohamed Ahmed Syed, declare that the publications presented in this thesis have not been previously submitted or are currently being submitted whether published or in unpublished form, for a degree, diploma, or similar qualification at any university or similar institution. The published work included in this thesis was carried out between 2006 and 2017.

The thesis includes eight published works - Publications 1-8. The author undertook the published works whilst working in a public health academic or a public health practitioner role. Publications 3 & 4 were undertaken whilst working in a research role at an academic institution. The remaining publications were undertaken while working in various public health practitioner roles. Publications 1, 2, 3, 4 & 5, were undertaken as part of larger European Commission (EC) funded research projects namely 'SARSControl', 'Research into POlicy to enhance Physical Activity (REPOPA)' and Patients' Consensus on Preferred Policy Scenarii for Rare Disease (POLKA) projects. Publications 6, 7 and 8 were undertaken independently by the author and his colleagues.

The five published works, wherein the author of the thesis is the first author (Publications 3, 4, 5, 6 and 7); he was principal investigator and undertook the data collection, analysis and drafting of the published work. For publications 1 and 2, undertaken as multi-country collaborative studies, the author of the thesis undertook the data collection and analysis for the studies in the capacity of a principal investigator within the UK country research team. These published works and Publication 8 were drafted by the first author of the individual studies and the author of the thesis contributed to drafting and revising them.

"If we knew what it was we were doing, it would not be called research, would it?"

Albert Einstein (1879 -1955)

<u>Abstract</u>

Best available research evidence is essential but not the only type of evidence needed in public health decision making. Decisions are also influenced and must take into account factors other than research evidence. This approach in public health is called evidence-informed public health (EIPH). A fundamental concept of EIPH is to take into account realities of a specific real-world environment when translating research evidence into policy and practice. Therefore approaches to co-creation of best available evidence for decision making - evidence that is informed by best available research evidence but that also incorporates other types of information to address decision makers' needs - are necessary for knowledge translation in public health. This thesis includes published works which report findings on 1) the use of research and other types of evidence and barriers and facilitators of its use and 2) KT approaches facilitating co-creation of best available evidence in public health policy making and practice. The eight publications included in this thesis studied factors associated with evidence use and present examples of co-creating evidence. The published works on evidence use (Publications 1 and 2) were undertaken using qualitative methods, specifically, content analysis of policy documents and interviews with decision makers within physical activity policy-making. Examples of co-creating evidence to address barriers identified in Publication 2 (such as relevance of research, lack of resources, lack of applicability of research etc.) used the Delphi technique, Population Impact Measure and Coverage with Evidence Development methodologies. They were applied to inform public health policy and practice in areas which include SARS and SARS-like diseases (Publications 3 and 4), rare diseases (Publication 5), cardiovascular diseases, strokes, cancers (Publication 6) and Dupuytren's disease (Publication 7 and 8). It is essential that approaches supporting the use of research and other types of evidence in public health continue to be developed and documented, and this thesis represents such an endeavour. Usefulness and effectiveness of different KT approaches facilitating evidence use and reduce its barriers must also be continuously evaluated as they are adopted or modified to deal with different issues in different settings. Effective interventions along with strategies facilitating their delivery and implementation can then be utilised by public health professionals and policy makers who wish to promote EIPH.

Section 1: Background

Section 1.1: Evidence and Public Health

Research continually produces new findings that can contribute to effective and efficient healthcare (Eccles and Mittman 2006). However, such research cannot change health outcomes unless healthcare decision makers adopt findings into healthcare services. Public health, defined as 'the science and art of promoting and protecting health and well-being, preventing ill-health and prolonging life through the organised efforts of society' (WHO 1998), influences health outcomes at population level through public health policy and practice.

In the context of public health policy and practice, two types of evidence are used - explicit (or research) evidence and implicit (or tacit) evidence. Explicit evidence comes from "articulated theories and empirical observations" made using systematic processes and scientific methods (Bhattacharyya et al 2009). Implicit (or tacit) evidence, on the contrary, comes from the "judgement of individuals with extensive experience in an area" (Bhattacharyya et al 2009) and as such is built and shaped by the experiences and values of individuals within a given setting or context. This type of evidence is difficult to formalise and communicate with other people, but is seen as closely "linked to action in context" (Greenhalgh and Wieringa, 2011). Implicit evidence is often called 'other types' of evidence (as oppose to research evidence). In this thesis, the term 'evidence' is generally used in its broad sense encompassing both research evidence and other types of evidence unless otherwise specified.

Systematically incorporating research evidence in public health policies and practice supports the provision of high-quality, effective, and efficient health services and improved health outcomes. This further ensures a more responsible use of the financial and human resource investments that are made in public health (Grimshaw et al 2012, Straus et al 2009). Therefore, in recent years, the use of research evidence to underpin public health policy and practice has been strongly promoted (Orton et al 2011). This has occurred as a natural conceptual development from the well-established

evidence-based medicine movement (Harpham and Taun 2006, Kirkwood et al 2004). Increased focus on Evidence-Based Public Health (EBPH), defined as the development, implementation, and evaluation of effective policies and programs in public health through application of principles of scientific reasoning i.e use of research evidence (Brownson et al 2003), has numerous direct and indirect benefits (Brownson et al 2009). However, decisions are also influenced and must take into account factors other than research evidence. Best available research evidence is essential but not the only type of evidence that needs be taken into account in public health decision making (Satterfield et al 2009 and Oxman et al 2009). Given the benefits of using other types of evidence in public health decisions, public health professionals and decision makers are increasingly expected to engage in Evidence-Informed Decision Making (EIDM).

Section 1.2: Evidence-informed Decision Making and Public Health

EIDM involves integrating the best available research evidence along with other types of evidence which consists of contextual factors including community preferences, local issues (*e.g.*, health, social), political preferences, and public health resources (Brownson et al 2009 and Nu tley et al 2003). EIDM considers research evidence as one form of a range of sources of evidence that are used to inform policy and practice (Bowen et al 2005). In EIDM, best available evidence includes two core components - best available explicit evidence and best available implicit evidence. Decision makers must draw on explicit and implicit evidence and their expertise to incorporate all the relevant factors into the final decision, conclusion or recommendation. The weight and influence that each have on the decision-making process will depend upon the specific circumstances, as well as the skills and values held by the individuals and groups involved in the process. In an ideal scenario which involves developing public health policy or practice, explicit evidence forms the primary source of information in the decision making process and is supplemented by implicit evidence in order to make it relevant and applicable to the local context and need. This approach in public health is called evidence-informed public health (EIPH)

and its benefits include adoption of the most effective and cost-efficient interventions (Lavis et al 2009), minimized harm to people and communities (Macintyre and Petticrew 2000, Chalmers 2003, Chalmers 2005) and better health outcomes for individuals and communities (Task Force on Health Systems Research 2004).

It is recognised that strengthening the use of evidence, and the ability of policymakers (and public health practitioners) to make appropriate judgements about its quality and relevance, is a critical challenge that holds the promise of helping to achieve significant health gains and better use of resources (Oxman et al 2009). Therefore, in recent years, concepts such as 'Knowledge Translation (KT)' and 'Implementation Science (IS)' have been developed and are also increasingly being used in public health. Furthermore, frameworks such as the "knowledge-to-action" (which includes the concepts of KT and implementation Science) have been conceptualized by many authors, notably by Graham and colleagues (Canadian Institutes of Health Research 2010, Graham et al 2006). They describe the dynamic process from knowledge creation to application. Such frameworks are recommended as a way of preparing for the multiple, dynamic and interactive factors that influence the uptake of evidence in developing public health policy and practice.

Section 1.3: Knowledge Translation and Implementation Science

The term KT is used in public health research, policy and practice settings to describe the processes needed to facilitate EIDM (Armstrong 2006). KT is defined as approaches to increasing the use of evidence within policy and practice decision-making contexts and is critically important given the many gaps that exist between what we know and what is actually done (evidence-to-policy and evidence-to-practice gaps). It includes approaches to co-creating evidence. Designing interventions to foster the use of evidence requires an understanding of the processes through which public health professionals and decision makers assess and use evidence, including barriers and facilitators related to evidence uptake. KT does not, however, cover how to implement knowledge to achieve its intended outcomes (Khalil 2016). Implementation science addresses this gap of how to adopt a new

intervention (Khalil 2016) to achieve its intended outcomes. It is defined as the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services (Eccles and Mittman 2006).

Kiefer et al (2005) highlight that KT approaches have not provided the positive changes in EIPH that had been anticipated (Kiefer et al 2005). One possible reason for failure could be the narrow definition of evidence as research evidence in the earlier KT literature (Kothari et al 2011), where KT in public health has typically adopted a narrow scope, with formal, explicit scientific research represented as the evidence being translated for use in practice and/or policy decision-making (Kothari et al 2012). Therefore there is a need to explore KT approaches facilitating co-creation of evidence in its broader sense to foster EIPH.

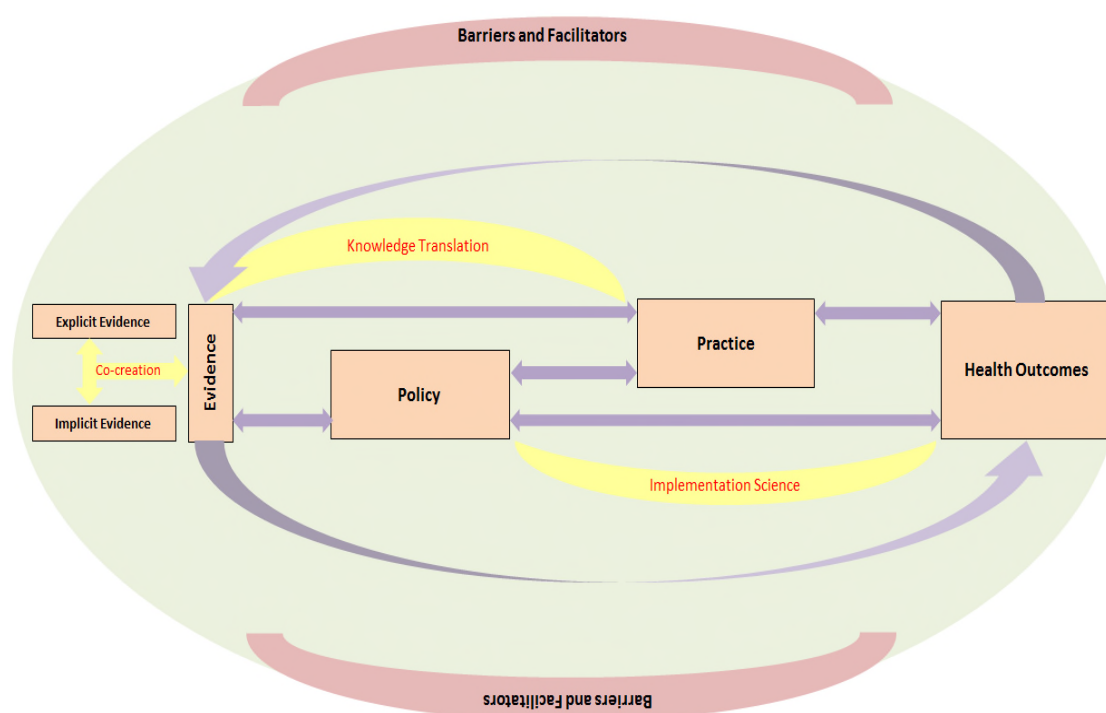## Section 1.4: Co-creation of Evidence in Public Health

A fundamental concept of EIPH is to take into account realities of a specific real-world environment when translating evidence into policy and practice. Early literature tended to overemphasize internal validity (i.e. explicit evidence) (e.g., risk and burden of diseases for narrowly-defined populations and precise estimates from well-controlled efficacy trials) while giving sparse attention to external validity (i.e. implicit evidence) (e.g., the translation of science to the various circumstances of practice) (Glasgow et al 2006, Green et al 2006). However, integrating both explicit and implicit evidence is essential (Kamper-Jõrgensen, 2000) as explicit evidence is rarely perfect. As noted by Muir Gray (1997), "the absence of excellent evidence does not make decision making impossible; what is required is the best evidence available not the best evidence possible". Therefore approaches to co-create best available evidence for decision making - evidence that is informed by best available research evidence but that also incorporates other types of evidence to address decision makers' needs - are necessary for EIPH. Co-creation of evidence is therefore defined in this thesis as any approach to integrate best available research evidence together with best available other types of evidence such as patient's expectations, clinicians' perspectives,

local data, resources etc. to inform EIPH/EIDM. This is consistent with the definition of co-creation in the published literature (Greenhalgh et al 2016).

Section 1.5: Conceptual Framework for Evidence-informed Public Health

EIPH consists of certain key elements and their interactions – 1) Evidence; 2) Public Health Policy; 3) Public Health Practice; 4) Heath Outcomes. In EIPH, both research evidence and other types of evidence are used to support development of public health policy and practice which in turn impacts on health outcomes of populations. Interactions between these elements are influenced by barriers and facilitators from the environments and their context in which the policies and practice are developed. Figure 1 illustrates a conceptual framework for EIPH featuring its key elements and their interactions.

Figure 1: Evidence-informed Public Health Framework

Gaps between elements of the EIPH framework exist due to the existence of barriers and/or absence of facilitators. These gaps include:

- "Evidence-to-policy" gaps exist when evidence is not adequately or appropriately considered and integrated in the development of policies.

- "Evidence-to-practice" gaps exist when evidence is not adequately or appropriately considered and integrated in the development of interventions.

- "Policy-to-outcomes" gaps exist when policies are not implemented adequately or appropriately.

- "Practice-to-outcomes" gaps exist when practice is not implemented adequately or appropriately.

The thesis presents the author's published works undertaken to understand the 'evidence-to-policy and practice gaps' and demonstrate the use of approaches to bridging these gaps.

Section 1.6: Aim and Objectives of the Thesis

The thesis includes eight published works which report findings on 1) the use of evidence and barriers and facilitators of its use (Publications 1 and 2) and 2) KT approaches facilitating co-creation of evidence in public health policy making and practice (Publications 3 to 8) – See Table 1. The objectives of this covering document are to highlight the significance of the published works as a contribution to original knowledge within the field and to provide a reflection on what has been learned through undertaking these works. The published works included are wide-ranging in terms of public health topics, contexts as well as the methodologies used. However, the fundamental theme common to all of them is EIPH.

The eight papers were published in peer reviewed journals between 2009 and 2017) and their full-texts are provided in Appendix 2. In sections 2 and 3, a summary of the published works is presented followed by their significance as a contribution to original knowledge. Section 4 provides an overall reflection on the strengths and limitations of the published works in the context of existing literature and discusses their implications for future research.

Table 1: Published works mapped to research aims

Section	Research Aim	Reference of Published Work
Section 2	Use of research and other types of evidence in developing public health policies	**Publication 1** Hämäläinen, R.M., Aro, A.R., van de Goor, I., Lau, C.J., Jakobsen M.W., Chereches, R.M., Syed, A.M., REPOPA Consortium.and On behalf of the REPOPA Consortium. (2015) Exploring the use of research evidence in health-enhancing physical activity policies. *Health Research Policy and Systems.* 13:43.
	Barriers and facilitators in the use of research and other types of evidence in developing public health policies	**Publication 2** van de Goor I., Hämäläinen R-M., Syed A.M., Lau, C.J., Sandu, P., Spitters, H., Eklund Karlsson, L., Dulf, D., Valente, A., Castellani, T., Aro A.R. (2017) Determinants of evidence use in public health policy making: Results from a study across six EU countries. *Health Policy.* 121(3):273-281
Section 3	Knowledge translation approaches facilitating co-creation of evidence to inform public health policy and practice	**The Delphi Technique**
		Publication 3 Syed, A.M., Hjarnoe, L., and Aro, A.R. (2009) The Delphi Technique In Developing International Health Policies: Experience From The SARSControl Project. *The Internet Journal of Health.* 8:2.
		Publication 4 Syed, A.M., Hjarnoe, L., Krumkamp, R., Reintjes, R., Aro. A.R. (2010) Developing policy options for SARS and SARS-like diseases – a Delphi study. *Global Public Health.* 16:1-13.
		Publication 5 Syed, A.M., Camp, R., Mischorr-Boch, C., Houÿez, F., Aro, A.R. (2015) Policy recommendations for rare disease centres of expertise. *Evaluation and Program Planning.* 20 16;52:78-84
		Population Impact Measure
		Publication 6 Syed, A.M., Talbot-Smith, A. and Gemmell, I. (2012) The use of epidemiological measures to estimate the effectiveness of planned interventions: Experiences from Herefordshire, UK. *Journal of Epidemiology and Global Health.* 2(3) 111-124.
		Coverage with evidence development
		Publication 7 Syed, A.M., Mcfarlane, J., Chester, T., Powers, D., Sibly, F., Talbot-Smith, A. (2014) Clinical efficacy and cost-effectiveness of Clostridium histolyticum collagenase injections in a subpopulation

Section	Research Aim	Reference of Published Work
		of Dupuytren's contracture patients. *European Orthopaedics and Traumatology*. 5(3): 311-316
		Publication 8 McFarlane, J., Syed, A.M., Sibly, T.F. (2015) A single injection of collagenase clostridium histolyticum for the treatment of moderate Dupuytren's contracture: a 2 year follow-up of 47 patients. *Journal of Hand Surgery (European Volume)*. 41(6):664-5.

Section 1.7 Author's Contribution to Published Works

The author undertook the published works whilst working in a public health academic or a public health practitioner role. Publications 3 & 4 were undertaken whilst working in a research role at an academic institution. All publications were undertaken while working in various public health practitioner roles. Publications 1, 2, 3, 4 & 5, were undertake as part of larger European Commission (EC) funded research projects namely 'SARSControl', 'Research into POlicy to enhance Physical Activity (REPOPA)' and Patients' Consensus on Preferred Policy Scenarii for Rare Disease (POLKA) projects. Publications 6, 7 and 8 were undertaken independently by the author and his colleagues.

The five published works, wherein the author of the thesis is first author (Publications 3, 4, 5, 6 and 7); he was the principal investigator and undertook the data collection, analysis and drafting of the published work. For publications 1 and 2, undertaken as multi-country collaborative studies, the author of the thesis undertook the data collection and analysis for the studies in the capacity of a principal investigator within the UK country research team. These published works and Publication 8 were drafted by the first author of the individual studies and the author of the thesis contributed to drafting and revising them.

Section 2: Use of Evidence and its Barriers and Facilitators in developing Public Health Policies

The use of best available evidence to support public health policy and practice has been strongly advocated. However, it is recognised that public health evidence must cover, not just the question of effectiveness of interventions; but also other pertinent information such as organisation, implementation and feasibility, which are less commonly covered by research evidence (Klein 2003). In this regard, public health evidence is neither perfect, complete nor unequivocal. Nevertheless, the large number of people affected by public health policy and practice highlights the need for robust decision making. Therefore it is essential to understand and map the use of evidence as well as identify barriers and facilitators for its use. This understanding will prove useful to develop approaches and interventions to promote and foster evidence use in line with EIPH. This section includes publication 1 which explores the use of evidence (i.e. establish an understanding of evidence-to-policy gaps) and publication 2 which explores the barriers and facilitators of evidence use in physical activity policy making (i.e. establish why evidence-to-policy gaps exist).

Section 2.1: Use of Research and Other Types Evidence

Publication 1: Exploring the use of research evidence in health-enhancing physical activity policies (Hämäläinen et al 2015)

Background

The health benefits of physical activity are supported by research evidence as well as the international public health community and its policies, including the World Health Organization (WHO 2010). The integration of physical activity as part of everyday life has been shown to be beneficial, especially for people with a sedentary lifestyle (Bucksch and Schlicht 2006, Proper et al 2011, Lim et al 2012, Ekelund et al 2016). The urgency for global action is strengthened by new evidence in the Lancet's 2016 Series about the effect of physical inactivity on dementia, the large health-care costs of inactivity, the additional health risks from excessive sitting, and, most importantly, the

observation that physical activity is not improving worldwide, despite an increased number of countries having a national physical activity policy or plan (Das and Horton 2016). The evidence of effective interventions is also increasing. Therefore action can be taken to reduce the impact of physical inactivity. However there still appears to be an overall lack of success in developing and implementing effective policies and interventions at the population level. This highlights a need to develop better approaches and interventions to bridge the evidence-to-policy and practice gaps. In order to accomplish this, it is essential to gain a better understanding of how research and other types of evidence are used in real-life physical activity policy development.

In 2011, the EC funded the REPOPA project (www.repopa.eu). The overall aim of REPOPA was to integrate scientific research knowledge, expertise, and real world policy making processes to stimulate evidence-based physical activity policies. The aim, design, methods and preliminary baseline results of the overall REPOPA project are available in 'Integrating research evidence and physical activity policy making-REPOPA project' (Aro et al 2015). The aim of this published work was to explore the use of research evidence in health-enhancing physical activity (HEPA) policies, identify when research evidence was used, and indicate which other types of evidence were used in HEPA policy making.

Methods

In the REPOPA project, 21 HEPA policies implemented at local, regional and national levels in six European countries (Finland, Italy, Romania, UK, The Netherlands and Denmark) were selected for content analysis. Semi-structured interviews were undertaken using a standard topic guide across all six participating countries. The interviews focused on perceptions and experiences of how research and other types of evidence were used in the policy making process and what factors facilitated or hindered their use in this process. The interviews were done by researchers from the respective countries in their native language. Each interview took about 1.5 hours, was tape-recorded and transcribed (tape-recording was done only when consent was given, otherwise notes were taken).

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By purposeful sampling a total of 86 stakeholders which included policy makers, researchers, public sector officers and other influential stakeholders, who were directly involved in the policy making process of the selected policies and who could provide information about the use of research or other evidence in the policy making process were interviewed. All interviewees were contacted via email or phone by the research team in the country with information on the project and consent forms in the local language. The data collected were analysed by each country team using a common guideline for qualitative content analysis (analysis were carried out manually or using software packages for qualitative research such as NVivo, MaxQdata). Coding was done by two researchers independently from each other in the country teams. Each country produced a report presenting its findings which were integrated into a single project report in English.

Results

Based on the content analysis of policy documents and interviews, the types of evidence used were listed, the items from which were classified and categorised into research evidence and other types of evidence such as societal framework, media, everyday knowledge and intuition.

Explicit citable use of research evidence was mostly found in the justification of HEPA policies and as a trigger to start development of a policy on the basis of a specific study or publication. The visions and goals of the policies were rarely validated by research evidence but by other types of evidence. It was found that implicit evidence, such as common knowledge, facts, and practices, were primarily used in policies. Policymakers obtained other types of evidence from experiences, such as earlier national or international good practices, projects or programmes, or information gathered from personal networks.

Where research evidence was used, it was identified in an ad hoc manner in the policy making phase and consisted of epidemiological research, population studies or statistics, and case studies. Peer-reviewed research articles and research based on surveys, as well as monitoring, evaluation, and implementation studies were rarely used. When the HEPA policies used

citable research evidence, it was not necessarily peer-reviewed scientific articles. Instead, various types of national and international reports and recommendations were used. In most cases, when paragraphs in the policy documents suggested being informed by scientific knowledge, explicit research evidence was seldom referenced.

Section 2.2: Barriers and Facilitators in the Use of Research and Other Types Evidence

Publication 2: Determinants of evidence use in public health policy making: Results from a study across six EU countries (van de Goor et al 2017)

Background

Evidence-to-policy gaps related to evidence use are reported in Publication 1 and other literature (Lomas 2000, Liverani et al 2013, McCaughey and Burning 2010, Orton et al 2011, Shine and Bartley 2011). This is despite strong economic and moral, and occasionally political, arguments for making better use of research evidence in policy making (Sebba 2011). Hence there is a need to understand why these gaps exist in order to develop approaches to bridge them.

Preliminary results from the REPOPA project showed that supportive institutional resources, access to applicable context-relevant research evidence, media attention, good personal relationships and networks, joint language and collaboration between researchers and policy makers were found to facilitate the use of research evidence (Aro et al 2015). Barriers appeared to be related to a non-supportive institutional management, lack of easy access to best available evidence, limited contacts between administrative personnel, experts and researchers (Aro et al 2015). The aim of this published work was to further explore barriers and facilitators in the use of research and other evidence to developing HEPA policies.

Methods

Multidisciplinary teams from six European Union member states analysed the use of research evidence and other kinds of evidence in 21 HEPA policies and interviewed 86 key policymakers involved in the policies. Qualitative content analysis was conducted on both policy documents and interview data in each country (as described in methods section of Publication 1).

From the country reports, lists of the inductively identified facilitators and barriers for the use of research evidence were grouped and categorized using a concept map tool available online. The concept map tool helped to find associations and pull together similar items and separate differing items mentioned in interviews. By using the concept map tool the qualitative data from interviews formed a pattern of facilitators and barriers for the use of research evidence in HEPA policy making.

Results

A number of facilitators and barriers for the use of evidence in the process of policy development were identified when interviews were undertaken. Although facilitators and barriers were to some extent in itself complementary, the results show those factors that interviewees brought up as being mainly facilitating or mainly hindering the process of the use of evidence as they experienced it in their involvement in real world of policy making. Factors found to facilitate or hinder the use of evidence can be categorised into four main domains of which the first three are mainly about process and the last one mainly about collaboration between stakeholders:

- Domain 1- Organizations, systems and infrastructure;
- Domain 2- Media engagement and support;
- Domain 3- Access and availability of relevant evidence;
- Domain 4- Networking and collaboration between researchers and policy makers.

In addition to the findings in these domains, factors that appeared specific within the country or policy context are described.

Significance of published works

Findings from Publication 1 suggest there is a lack of use of research evidence to support visions and goals of HEPA policies. Other types of evidence such as common knowledge, facts, and practices are primarily used. In EIPH, even though use of other types of evidence is essential, it is not the only type of evidence required. Other types of evidence are usually required to supplement research evidence, not to act as the primary and only source of evidence. These findings highlight a need to shift use of best

available research evidence as a primary source while other types are considered along with it as secondary sources in developing HEPA policies.

This published work examined the use of research and other types of evidence by stage of policy making. It established that use of research evidence was mostly to justify initiating policy development and a specific study or publication was used as a trigger to initiate it. The contents of the actual policies were not backed up by research evidence but by other types of evidence. For the justification of the policies where research evidence was used, instead of using peer-reviewed scientific articles, the policymakers used various types of secondary publications, such as national and international reports and recommendations. The use of these secondary publications may be justified when they have been compiled through a transparent and rigorous process, but it was often unclear if their contents were evidence-informed and if they were critically appraised before their findings were quoted. In defining the details of policies, such as setting of targets or actions for population groups, explicit research evidence was rarely used. These results help understand what type of evidence is used to inform policy development and at which stage, in effect mapping evidence types with their use in policy making stages. These findings whilst highlighting shortcomings in the use of research evidence also help understand how ideas spread through systems, how decisions are being made and the capacity required to use evidence. A systematic review by Orton et al (2011) reports types of research evidence preferred by public health decision makers and professionals. Studies on the actual use of research evidence were not reported potentially because they are lacking. Therefore findings from this published work are valuable to inform and improve EIPH by providing information on evidence-to-policy gaps related to evidence use. The information will help develop approaches to bridging these gaps in developing more effective HEPA policies. Such information is useful in developing interventions that can enhance the use of research evidence in real life policy making. An example of an approach where locally tailored interventions to increase levels of knowledge integration in evidence informed policy making demonstrated is demonstrated by Bertram et al

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(2016). The study used a 'Stewardship' approach to build needs and context based policy interventions with close collaboration between researchers and policy makers. The Stewardship approach guided the interventions which were designed on the basis of context- and needs assessments, and all activities were performed in close collaboration between researchers and policy makers. The 'Knowledge to action' framework was used to identify the various steps necessary to integrate evidence and knowledge in the policy process. The level of research evidence and knowledge use was measured with pre-, post- and 12-month post-post measurements which showed an improvement in six policy development cases across three countries.

Publication 2 reports on why evidence-to-policy gaps exist in real world HEPA policy making. Three findings from the study shed new light on the barriers and facilitators of evidence use in the policy making process. First, the results showed that the attitude of media towards underpinning policy with evidence (as done in television debates, newspapers, social media) is of influence on evidence uptake in policy. Policy decision makers (e.g. politicians) may feel that the media's attitude has a large impact on voters and therefore act accordingly. Reviews in the literature on barriers and facilitators in evidence use in health policy mainly focus on factors influencing researchers, practitioners and policy officers as main stakeholders in the policy making process. Media was not found to play a substantial role among these (Hanney et al 2013, Oliver et al 2014, Wallace et al 2012, Lavis 2005, Orton et al 2011). The fact that the study found stakeholders mention media has impact on decision makers' opinions on the use of evidence adds new insight to this knowledge. In addition, the rapid development of social media highlights the need to further examine emerging evidence in this important and evolving field. These findings indicate that the tactical or political model of evidence utilization in public health policy resembles reality more closely than the problem-solving or knowledge-driven model (Bowen et al 2005, Nutbeam 2003, Weiss 1979, Petticrew et al 2004).

Second, personal characteristics of potential evidence users were highlighted as being important. Skills, attitudes and values of individual policy makers have an impact on the extent to which they will access and use best available

evidence. In a recent systematic review Oliver et al (2014) stated that improved skills are amongst the most frequently reported facilitators of evidence use. The study results also seem to be consistent with the 'interaction explanation' according to which 'knowledge utilisation depends on disorderly interactions between researchers and users' and interactions across the interface between policy makers and researchers which are important for the transfer of evidence-to-policy (Landry et al 2003, Hanney et al 2013). Furthermore, results showed that although a solid research infrastructure is seen as a facilitating factor for research evidence use in policy making, it is not a sufficient condition for actual use of research evidence in the policy making process. Intensive and timely interaction between researchers and policy makers are reported as important factors for the use of research evidence in policy. Actual use of research evidence requires both optimal policy relevance of available information and structural interaction between researchers and policy makers. Third and last, it was found that factors impacting evidence uptake in the policy making process interact in a complex way. Having ample access to research evidence is not a sufficient condition for policy decisions to be adequately evidence-informed. Decision makers' e.g. politicians' personal beliefs and perceptions as well as cultural circumstances and traditions in appreciating evidence or more system-oriented limitations will always interact with the mere availability or transferring of research evidence (Petticrew et al 2004, Best 2010).

These results highlight the need for interventions to improve skills and change attitudes of policy makers as well as improving networks between them and researchers. The results also suggest the need to have effective communication plans and strategies in place and work with media in order to influence the use of evidence to inform decisions.

Publication 1 and 2 were undertaken at EU level. This can be considered as their strength as findings provide an overview of evidence use in developing physical activity policies at EU level. This is based on the assumption that the six participating countries are similar and representative of other EU countries. However, individual EU countries vary in a number of ways. They have different infrastructures, processes, cultures, values etc. It must also be

noted that the findings are specific to the physical activity policies identified and included in the published work. Therefore caution must be exercised in interpreting the results as they cannot directly be generalised to other areas in public health, other countries and even other HEPA policies within countries from which the physical activity policies were selected for the study. Furthermore, the study used interviews as a data collection method, therefore the responses may have potentially been influenced by recall bias as some of the selected policies were developed some time before the interviews were conducted.

The aim of Publication 2 was to identify barriers and facilitators of research and other types of evidence. The publication reported barriers and facilitators, however, it did not break the results down by type of evidence i.e. research evidence and other types of evidence. The majority of the results focussed on research evidence. This is a drawback of the published work. Approaches to facilitating the incorporation of other types of evidence with research evidence will be described and discussed in Section 3 of this thesis.

Publication 1 and 2 were undertaken as part of work package 1 'Use of evidence in policy making' of an EC – funded REPOPA project which included a total of seven work packages. The author of the thesis undertook the work as a principal investigator for work package 1 for UK as one of six countries involved. In addition to being published, its findings have been reported to the EC for consideration in its work to enhance EBPH policy development. Since becoming available in October 2015, the publication 1 has been cited seven times and accessed 1523 times. Publication 2 was recently published and has not yet been cited.

Section 3: Knowledge Translation Approaches facilitating Co-creation of Evidence to inform Public Health Policy and Practice

Publication 1 reported evidence-to-policy gaps in evidence use and Publication 2 reported why these gaps exist. These findings are useful in developing and employing approaches to bridging evidence-to-policy gaps and facilitate KT.

Publication 2 also found, in public health, evidence of what works well may not be available or applicable in all settings, making it difficult to know precisely what policies or services to support for the best outcomes. Therefore, ensuring adoption of effective interventions is likely to depend on many factors such as what evidence is available and brought into play; what stakeholders want (managers, practitioners, the public, the government); what resources are available etc. To address this, evidence provided to policymakers needs to be in a form that is useful to them (Campbell et al 2009, Woolf et al 2015). Policymakers require synthesised and localised data that demonstrates the need for a policy response, contrasts and prioritises policy options, demonstrates effectiveness, cost-effectiveness and impact of interventions, reflects the level of public support for a particular issue and personalises the problem as found in Publication 2.

This section includes published works which utilised three approaches (the Delphi technique, Population Impact Measures and Coverage with Evidence Development) to facilitate knowledge translation to support EIDM. It illustrates how these approaches enable co-creation of evidence to inform public health policy or practice. The approaches presented in this section demonstrate how they can address findings related to evidence use in Publication 1 and some of the barriers and promote facilitators identified in Publication 2, such as relevance of research, lack of resources, lack of applicability of research etc.

Section 3.1: The Delphi Technique

The Delphi technique, originally developed by the RAND Corporation (Adler and Zigilo 1996), helps in structuring a group communication process that is particularly useful when there is little knowledge or uncertainty surrounding a complex area being investigated (Dalkey and Helmer 1963, Linstone and Turoff 1975, McKenna 1994, Crisp et al 1997). This section includes three published works featuring the Delphi technique. Publication 4 and Publication 5 demonstrate its application in co-creation of evidence to develop policy options in areas where there was a lack of knowledge and substantial uncertainty. Publication 3 evaluates the use of the Delphi technique based the experience of using it in Publication 4.

Publication 3: The Delphi technique in developing international health policies: Experience from the SARSControl Project (Syed et al 2009)

Background

The Delphi technique needs to be applied systematically and rigorously to produce reliable and valid results (Hardy et al 2004) and to avoid discrepancies (Keeney et al 2001). Based on literature, the five core criteria when using the Delphi technique are: a) panel composition: geographic and professional representativeness, size, heterogeneity (Hasson et al 2000, Jones and Hunter 1995); b) participant motivation: response rate, written consent, clarity of questions, reminders; c) problem exploration (Keeney et al 2001); d) consensus definition e.g. as percentage of agreement /medians (Hardy et al 2004, Dajani et al 1979); and e) format of feedback e.g. individual responses, measures of tendency and spread of responses (Crisp et al 1997), different statistical description using median, mean or percentage (Jones et 1992) which can decrease unnecessary disagreement (McDonnell et al 1996). Other criteria include number of rounds, anonymity to encouraging open expression of opinions (Goodman 1987), and sufficient resources which include time and administrative services (Duffield 1993). Appropriately addressing the issues while carrying out a Delphi process, determines efficient application of the method to obtain the desired result (Delphi outcome). The methodological challenges while carrying out

the SARSControl Delphi study (Publication 4) led to this evaluation study. The study assesses practical applicability of the Delphi technique in a real world setting and presents findings based on the criteria identified.

Methods

This study uses criteria identified from the literature to assess the process of using the Delphi technique in the SARSControl project. The evaluation was done using the qualitative description of the processes of SARSControl Delphi study and carrying out a critical analysis of different aspects of each criterion.

Results

The main weaknesses in the Delphi process employed in the SARSControl study were found to be the lack of experts in infectious diseases amongst the Delphi team, use of a 9-point Likert scale without clear verbal labels, lack of representatives from countries with SARS experience, discontinuity in the Delphi panel composition from the 1st to the 2nd round to the face-to-face meeting and delays in data gathering due to collaboration with another project. Despite the challenges, the Delphi study still proved to be a useful exercise that produced valuable policy options in an area where there was a lack of research evidence taking into account context. Future work can explore the applicability of this technique for other topics and settings of public health policy making, assess the relative importance and impact of adherence to commonly specified criteria for Delphi technique, and compare its effectiveness with other methods in promoting EBPH.

Publication 4: Developing policy options for SARS and SARS-like diseases – a Delphi study (Syed et al 2010)

Background

The 2002/2003 Severe Acute Respiratory Syndrome (SARS) epidemic shook the world, causing more fear and social disruption than any transmissible disease of our time. Like SARS, the H1N5 (bird flu) and H1N1 (swine flu) influenza outbreaks have also shown how emerging infectious disease pandemics can have social, economic and security implications on a global scale.

The EC works to protect and promote the European population's health, and thus considered it a priority to develop and implement policies on SARS and SARS-like diseases. To achieve its goal, the EC funded a three-year research project called 'SARSControl'. The project's main aim was to develop 'Effective and acceptable strategies for the control of SARS and newly emerging infections in China and Europe'. This study was part of the 'Policy evaluation' work package of the SARSControl project, the aim of which was to develop policy options using methodologies such as literature review, Hazard Analysis and Critical Control Points (Krumkamp et al 2009) and the Delphi technique to meet the project's wider objectives. The final results of the SARSControl project were reported to the EC in 2008.

The objective of the SARSControl Delphi study was to develop options for national and international emerging infectious diseases policies. These were lacking due to a lack of research evidence and uncertainty regarding SARS and SARS-like diseases as they were novel at the time. Therefore, there was an urgent need to gather the best available evidence to inform policy options to prevent and plan for future pandemics. The aim of the published work was to present results of the study, which co-created evidence to fill in the gaps and resolve inconsistencies concerning preparedness and response planning for SARS and SARS-like diseases.

Methods

The SARSControl Delphi study was carried out using the Delphi technique. It consisted of a pilot round, two written rounds and a face-to-face meeting. A

total of 60 experts were selected to represent the Delphi panel. Out of the 60 experts selected (the majority of whom represented their countries on the Advisory Forum of the European Centre for Disease Control), 47 accepted the invitation; 38 experts from 22 countries (21 European countries and one South-East Asian country) replied in the first round and 28 of the 38 experts replied in the second round. Eleven experts were newly recruited for the face-to-face meeting, as none of the experts from the written round could participate in it. The Delphi questionnaire was prepared with a focus on addressing gaps and inconsistencies in pandemic preparedness and response planning identified by: reviewing scientific literature; reports on emerging infectious diseases; pandemic plans; guidelines and policies available in the 'MEDLINE' database, as well as through the 'Google' search engine using the search terms 'emerging infectious diseases, SARS, pandemic influenza, health policies, pandemic plans, SARS guidelines, influenza guidelines'; using results from the SARSControl Project Hazard Analysis and Critical Control Points analysis (Krumkamp et al 2009); and by gathering input from the other SARSControl project work packages.

Results

The Delphi technique helped develop a number of policy options that focussed on gaps and inconsistencies in pandemic preparedness and response planning whilst taking into account context at national and European levels. The Delphi panellists highlighted the necessity to test plans and stressed the importance of surveillance measures for the swift containment of communicable disease outbreaks and the inclusion of detailed triage plans in national pandemic plans. The experts also suggested a need to define criteria for testing pandemic preparedness plans at different regional levels. New policy alternatives were identified, such as the need for generic plans on pandemics and universal access to healthcare during an outbreak. The usefulness of some non-medical interventions, such as bans on travel, could not be established and were deemed to need further research. The findings were disseminated to help bridge gaps and rectify inconsistencies in pandemic planning and response strategies for SARS and SARS-like diseases, as well as added valuable knowledge towards the

development of national and international emerging infectious disease policies. The technique therefore helped co-create evidence by utilising knowledge and experiences of experts in the field.

Significance of published works

Approaches and methods for KT are increasingly being adopted to facilitate EIPH. However, the real life consideration in their application is not always documented and discussed. Publication 3 evaluated the practical use of the Delphi technique in developing policy recommendations based on its application described in Publication 4. It identified a number of limitations in its application. This included the lack of experts in infectious diseases amongst the Delphi team, use of a 9-point Likert scale, lack of representatives from countries with SARS experience and discontinuity in the Delphi panel composition. In addition, Publication 3 provides advice and guidance on the key elements of the technique that need to be considered for anyone who may wish to utilise it to develop public health policy recommendations and highlighted some potential challenges. Publication 3 attempts to do this in order to support future use of the Delphi technique. To the author's knowledge, no published studies have explored and reported practical issues and know-how associated with using and evaluating the technique in real world health policy settings. More such evaluations are needed on both the Delphi technique and other similar tools that facilitate KT. They will be useful in developing guidance and training for public health professionals in their use.

Publication 4 is an example of the Delphi technique and its use as an approach to support co-creation of evidence to inform development of public health policy options. In Publication 4, it was employed as an innovative approach to develop public health policy recommendations in the field of SARS and SARS-like diseases. It was an area of policy development which was new and emerging at the time of the study with little previous research evidence and understanding of it to inform policy options. This was one of the key reasons why the Delphi technique was chosen to undertake the studies: To enable structured communication and reach consensus on the basis of the limited research evidence and experience available to facilitate

co-creation of evidence to inform policy options. The Delphi technique as a KT approach facilitates co-creation of evidence taking into account research and other types of evidence. Such approaches are not abundant or well described in published literature. The results of Publication 4 add valuable knowledge towards the development of international policy options for SARS and SARS-like diseases. It also demonstrates the use of the technique and its value in areas where there is little previous research evidence available. Such scenarios are often encountered by policy makers in new areas and new interventions within public health. The Delphi could potentially offer an EIPH based solution – supporting KT through co-creating evidence.

Limitations and challenges of using the Delphi technique are reported in Publication 3. Both Publications 3 and 4 were funded by the EC and their results have been reported to the funder to inform future polices in the fields. The policy recommendations developed in in Publication 4 were reported to the EC who intended to bridge the gaps and rectifying inconsistencies in pandemic planning and response strategies to SARS and SARS-like diseases across the EU. The detailed technical report underpinning Publication 4 submitted to EC is available at https://survey.erasmusmc.nl/SARSControlproject/picture/upload/D_8_5%20 Delphi%20rounds.pdf. Publication 3 has been cited 16 times since it was published in 2009 and Publication 4 has been cited 15 times since it was published in 2010.

Publication 5: Policy recommendations for rare disease centres of expertise (Syed et al 2015)

Background

Rare diseases, defined as diseases that affect 1 (or fewer?) in 2000 population, are a serious public health concern and are a priority in the European Union. In 2008, European member states and at European level there was a need for robust strategies, plans and specific policies on rare diseases (European Commission, 2008). Few European countries have specialised provision of health services for rare diseases. Despite a significant European Union population being affected by rare diseases healthcare systems in member states are not set up adequately to provide care for rare disease patients. In many European member states, rare disease patients are subject to marginalisation in classic healthcare systems designed for non-rare diseases (Kole & le Cam, 2010). As a result, patients with rare diseases do not experience equal access to timely, high quality health services they deserve (Kole & le Cam, 2010). The restructuring of healthcare systems to better reflect the values of equity and solidarity amongst rare disease patients, professionals, and policy makers across Europe needs to be accomplished.

As part of the EC's commitment to improving healthcare for rare disease patients, in 2008 a 3-year project called POLKA project was funded and supported by the EC. The main objective of the POLKA project was to facilitate the consultation of the European rare disease community, with the aim of building consensus on preferred public health policy scenarios for rare diseases, including the quality of care available at rare disease Centres of Expertise (CoEs), and if that level of quality was sufficient.

In order to achieve the POLKA project's objective of gathering expert advice and experience and building consensus on policies for CoEs on rare diseases, a study within POLKA called 'The POLKA Delphi study' was undertaken. There was a lack of existing research evidence to develop policy options in order improve patients' experiences and meet expectations at CoEs as the concept was still new at the time. The Delphi technique was

employed to co-create evidence for this purpose whilst considering   the specific experiences, setting and context. This published work presents the results of the POLKA Delphi study and the policy recommendations developed from them aimed at better provision of healthcare for rare disease patients in Europe.

Methods

The POLKA Delphi study was initially planned to be carried out in rare disease CoEs from three countries ofDenmark, the UK and France. The countries were chosen as their healthcare systems were amongst the most developed ones set up to provide specialised care for patients with rare diseases in Europe. In majority of the member states, there is a lack of specialised services for patients with rare diseases through specialist healthcare centres/CoEs. This study presents results from Denmark and the UK as the French arm of the study encountered significant issues recruiting healthcare professionals, therefore was abandoned. The first step of the Delphi process was the selection of participants for the Delphi panel followed by administering a questionnaire survey (Round 1). The results of the questionnaire survey were fed back to the participants and used to facilitate discussions at face-to-face meetings (Round 2). The results of both rounds were collated and used to develop policy recommendations. The draft policy recommendations were sent to participants for validation and sign-off (Round 3).

A total of eight CoEs, one in Denmark and seven in the UK, participated in the study. A contact person at each of the eight CoEs was identified to recruit a total of 160 participants as the Delphi panel and coordinate the study – 8 healthcare professionals and 12 patients (or patient representatives and carers) per CoE. Of these 134 participated in Round 1 and 65 participated in Round 2.

Results

The Delphi technique, by bringing together rare disease patients (or patient representatives and carers) and healthcare professionals, helped undertake a structured discussion on each policy area. The technique helped reach

consensus on the policy areas thereby supporting co-creation of evidence by utilising best available evidence and knowledge as well as experiences of individuals who had first-hand experience of the services that exist. The results suggested the need to make improvements within current CoE environments, access to CoEs and the need for coordination and cooperation of services within and outside CoEs. It was recommended that CoEs are not overly 'medicalised', while at the same time they should be established as research facilities. The importance of including patient representatives in CoE performance management was also highlighted. Raising awareness and provision of appropriate training amongst non-specialist healthcare professionals was seen as a priority for early and correct diagnosis and ensuring high quality care. Similarly, provision of targeted information about patients' illness and care was considered essential along with access to social assistance within CoEs.

Policy recommendations were developed in areas previously recognised as having gaps. Their implementation is expected to strengthen and improve current care provision for rare disease patients.

Significance of published work

Publication 5 is another example of how the Delphi technique can be used as an approach to support co-creation of evidence to inform development of public health policy options. Even though the development and establishment of CoEs and European Reference Networks was recommended and advocated, there was a lack of policy recommendations for CoEs and European Reference Networks. The area of policy development was new and emerging at the time of the study with little previous research evidence and understanding of it to inform policy options. This was one of the key reasons why the Delphi technique was chosen to undertake the studies. Its application in Publication 5 was based on the learning from Publications 3 and 4.

Successful use of the Delphi technique in Publication 4 led to an invitation to undertake Publication 5. It was commissioned by the European Organisation for Rare Disease (EURORDIS) as they had recognised the potential of the

Delphi technique in developing policy recommendations for SARS and SARS-like disease in Publication 3 and 4. Implementation of policy recommendations developed using the Delphi study in areas previously recognised as having gaps is expected to strengthen and improve care provision for rare disease patients. In member states where national plans and strategies are being developed, EURORDIS is advocating the methodological approach used in Publication 5 as it proved to be a helpful tool in supporting disease CoEs policy development of rare disease CoEs in the UK and Denmark. As in Publication 4, the use of the Delphi technique in Publication 5 allowed a structured communication and informed development of policy options in areas with limited research evidence. It helped KT facilitating co-creation of evidence by addressing some of the barriers (such as lack of applicable research, exclusion of stakeholders, jointly working with researchers etc.) identified in Publication 2. The success of the Delphi technique and value shown by publications 3, 4 and 5 has also led to a fourth Delphi study in which it was used to develop evidence informed policy making indicators (Syed et al 2016).

In Publication 5, the Delphi technique allowed bringing together a reasonably large number of participants for the study despite being geographically dispersed and required minimum resources. It must be noted that the majority of the study participants were from the UK which might be a limitation to the results of the study as UK recommendations might have been voiced more strongly compared to the Danish ones. This issue arises due to having separate face-to-face meetings in the two countries. It would have been ideal to have one face-to-face meeting for all participants rather than 7 (6 in the UK and 1 in Denmark) which would probably have resulted in a more constructive debate and equally voiced policy recommendations. However, this was not possible for three reasons, first because we were unable to coordinate patients to one venue given the severity of their conditions and ability to travel long distances, second because it was not possible to get availability of all HCPs on a given date and thirdly due to language. These are also the reasons why the proportion of participants in round 2 was lower (55% HCPs and 33% patients). In the UK, it was a

challenge to coordinate a face-to-face meeting in seven CoEs. Even though the results were from mainly form the UK and for specific rare disease CoEs, the results will be valuable to other EU countries and health planners.

Publication 5 was funded by the EC and it has not yet been cited however it has been downloaded 471 times since it was published in 2015.

Section 3.2: Population Impact Measures

Publication 6: The use of epidemiological measures to estimate the effectiveness of planned interventions: Experiences from Herefordshire, UK (Syed et al 2012)

Background

Coronary heart diseases, stroke and cancers are the major causes of mortality in the UK and are responsible for significant amounts of morbidity and healthcare costs. This published work examined the proportion of coronary heart diseases, stroke and cancer owing to specific risk factors in Herefordshire, UK. Therefore, this study was undertaken to co-create evidence by estimating the population impact of a number of interventions being implemented to reduce these risk factors, through the National Health Service (NHS) Health Check program and the Herefordshire Health Improvement Plan (HHIP). The NHS Health Check program is a screening programme mandated nationally, however the primary prevention interventions provided through it are decided locally. This study aimed to provide the evidence needed to help inform local decision makers prioritise investment of resources on primary prevention interventions based on the estimated health impacts on the population of Herefordshire by the NHS Health Check and HHIP.

Methods

The epidemiological measures – 'Population Attributable Risk (PAR)' and 'Population Impact Measures (PIM)' – were used to assess the impact of interventions to reduce the burden of coronary heart disease, stroke and cancer.

Results

Application of PAR and PIM estimated that implementation of the NHS Health Check program will prevent 63 coronary heart disease events, 90 myocardial infarction events and 125 stroke events, and one lung cancer over a period of 5 years. Reducing specific risk factors by 5% annually through the HHIP will prevent 65 coronary heart disease events, 25

myocardial infarction events, 140 stroke events, four lung cancer, one breast cancer and four colorectal cancer cases in Herefordshire if targets are met over a period of 5 years.

The study, with help of PAR and PIM approaches, helped co-create evidence to inform public health practice. The epidemiological measures helped quantify the impact of public health interventions outlined in the NHS Health Checks program and the HHIP on health events for coronary heart disease, strokes and cancers if implemented locally. This was necessary as there was a lack of evidence-based impact information, in particular, intervention effectiveness expressed as adverse health events averted, to enable and influence decision makers to make informed decisions on prioritising and investing resources into public health interventions to prevent these conditions.

Significance of published work

Mobilizing research evidence for decision-making is challenging for health system decision-makers (Ellen et al 2014). Publication 2 identified the lack of applicable research as a barrier in the use of evidence to support public health policy and practice. This results in society paying a high opportunity cost when interventions that yield the highest health return on an investment are not implemented (Fielding 2001). Furthermore, resource investments in primary prevention interventions are often diverted because decision makers are unable to justify investing in them because they do not have evidence of their impacts as outcomes are seen after long periods of time. Their preference tends to favour investment in interventions to treat acute conditions as they demonstrate outcomes in the short term. As highlighted in Publication 2, this may be because decision makers would like to have appositive impact on the public via the media. Such impacts cannot easily be demonstrated for primary prevention interventions. An example of such investment in England is that of the Cancer Drugs Fund from 2010 to 2016. £1.27 billion of tax payers money was spent based on an election promise that it would give patients increased survival[1]. Another potential reason for

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[1] http://www.bbc.co.uk/news/health-39711137

not investing in primary prevention interventions is the lack of evidence of benefit as well as ability to quantify outcomes of primary prevention interventions at local level.

Publication 6 was undertaken to overcome the highlighted barriers in the County of Herefordshire, UK. It is an example wherein epidemiological measures were used in providing evidence-informed public health information in local policy making to aid decision makers when prioritising investments and optimal use of resources. Publication 6 demonstrates an innovative application of PARs and PIMs to support KT facilitating co-creation of evidence. The epidemiological measures used in the study proved to be useful tools and their use can be recommended to support prioritisation of primary prevention interventions in similar settings. The findings of Publication 6 helped utilise research evidence to demonstrate the potential population impacts that can be achieved by implementation of primary prevention measures, through the NHS Health Check program and HHIP locally in Herefordshire.

Publication 6 highlighted that physical inactivity and obesity levels are the most significant causes of coronary heart disease and stroke events in Herefordshire. Their impact is greater than the combined effect of hypercholesterolemia and hypertension together, both of which are well recognized and treated risk factors. These findings have helped assist local decision makers when prioritising investments and ensuring optimal use of resources.

It must also be noted that approaches used in Publication 6 also have limitations (such as availability and quality of local data, varying disease definitions etc.) which must be considered. The findings from Publication 6 are inherently dependent on the quality of the source data as PARs and the PIMs methodology use published risk estimates (i.e., baseline risk of disease, risk ratio (RR) and the relative risk ratio (RRR) of the intervention of interest), which carry a margin of error. Furthermore, published data sources use different definitions of disease status and outcome and present their results over different time-frames, age groups, and may or may not split them by gender. To limit the risks associated with using isolated published

sources, the parameters used in this study were derived from systematic reviews or meta-analyses; whose study question matched closest to this study's target population and planned interventions. However, this was not always possible owing to limitations in the availability of data in the literature, and being itself a time-consuming and challenging process, which could be seen as a limitation to the use of these epidemiological measures.

It is well known that decision makers hesitate to invest resources in public health as they are unsure of the impact compared to investing in acute healthcare interventions (Orton et al 2011a). The application of the PIMs and PARs was an innovative approach to mitigate this and to support and advocate investment at local level. Through the combined use of published literature and local data, it provided information on the potential benefits of public health interventions in the form of potential adverse health events prevented. This was particularly helpful as it gave local decision makers a 'currency' to demonstrate potential local impact. The approach was however not without drawbacks. Many assumptions needed to be made, and extensive background data collection was required in order to produce estimated for PIMs and PARs. Had a population cost impact analysis tool been used as part of the study to add an additional dimension in terms of cost impact for decision makers, it would have added further value. However, this was not possible due to the lack of resources and skills within the research team. Nevertheless, the work has proven useful within these limitations, and it has been used and replicated by other organisations for their local populations. It highlights the need for improved local health information systems and enhanced training of public health professionals that facilitates KT.

This study is the first of its kind to use both epidemiological measures (PARs and PIMs) to model outcomes of two complex public health programs. It included six interventions and three disease areas. This is advantageous as it represents real life public health programs; however it is difficult to estimate the interactions between modifications of different risk factors. Consequently, it may not reflect precisely the impact of combined interventions on the outcomes, for example weight management and physical activity

interventions will both have an effect on the need for antihypertensive treatment in some individuals. However, an advantage of this study is that wherever possible, compliance to interventions was considered, using values derived from the literature. Therefore, the outcomes were based on the assumption that health behaviour factors of the local population were similar to the population included in the study.

Cost-effectiveness of the interventions was not considered in this study as it was not its primary aim. The NHS Health Check program is a national 'must-do', and the study's aim was to achieve organization support locally to aid implementation. However, an advantage of using the PIMs methodology is that a cost dimension can be introduced to it if an economic assessment of interventions is required by health planners. One possibility is to adopt a methodology called 'population cost-impact analysis' described by Heller et al. (2006). It helps add a new dimension to economic analysis, the ability to identify costs and benefits of potential interventions to a defined population, which may be of considerable use for policy makers working at the local level.

Following the publication of the study, a number of other healthcare organisations responsible for public health funding in the UK have approached the authors for support and advice in undertaking a similar studies for them. The published work has been cited 5 times since it was published in 2012.

Section 3.3: Coverage with Evidence Development

One of the barriers in the use of evidence identified in Publication 2 was the lack of relevant research evidence to inform public health policy and practice. In order to address this barrier, a KT approach is 'Coverage with evidence development' (CED). The CED approach attempts to ensure that access to new interventions is not prevented due to uncertainties associated with available research evidence but is managed in a coordinated way, while also generating additional evidence to inform policy and practice (Lexchin 2011). This section includes two published works on CED. Publication 6 and 7 demonstrate its application in co-creating evidence to inform public health practice for an intervention with uncertainties associated with available evidence. Publication 7 reports findings at 12-month follow-up and Publication 8 reports findings at a longer follow-up of 24 -months. The summary and significance of both published works is presented together after publication 8.

Publication 7: Clinical efficacy and cost-effectiveness of Clostridium histolyticum collagenase injections in a subpopulation of Dupuytren's contracture patients (Syed et al 2014)

Background

There is increasing interest in the use of Clostridium histolyticum collagenase (CHC) injections to treat Dupuytren's contractures. However, the reported efficacy varies between studies and it remains unclear which patients would benefit most from CHC injections. In addition, there is a lack of national guidelines on its use. Therefore, there has been considerable debate in funding CHC injections by the UK's National Health Service. This study uses the 'coverage with evidence development' concept to facilitate co-creation of evidence to inform local policy and practice on CHC injections to treat Dupuytren's contracture.

Methods

A literature review was undertaken to establish the best available evidence on CHC injections. This was analysed and translated to develop clinical criteria wherein the intervention is likely to be most clinically and cost-

effective. A pilot study using the criteria was designed, and 56 patients were included. Efficacy assessments were undertaken by measuring contracture angle of the effected metacarpophalangeal (MCP) joint using goniometry and the Unité Rhumatologique des Affections de la Main (URAM) scale with follow-ups at 1, 3, 6 and 12 months.

Results

Significant improvements were seen in contracture angles as well as URAM scores when mean baseline and post-intervention outcomes were compared at 1, 3 and 6 month follow-ups. The mean contracture angle at 1 month follow-up (n = 56) was −0.9° (±8.1) and at 6 months follow-up (n = 29) was 0.4° (±2.4), compared to 43.2° (±9.0) and 41.8 (±9.7) at baseline, respectively, showing mean improvements of over 40°. Mean URAM scores improved from 16.3 (±9.6) at baseline to 1.9 (±3.3) at 1 month of follow-up (n = 56) and from 16.9 (±9.8) to 0.8 (±2.8) at 6 months of follow-up (n = 39), showing improvements of over 13 points. Most treatment-related adverse events were mild or moderate in intensity and resolved without intervention within a median of 10 days. An overall cost savings of £104,732 was made in the cohort of 56 patients compared with alternative treatments available. This study, with the help of the CED approach, helped co-create evidence to inform local public health policy and practice for the interventions where there were uncertainties previously.

Publication 8: A single injection of collagenase clostridium histolyticum for the treatment of moderate Dupuytren's contracture: a 2 year follow-up of 47 patients (McFarlane et al 2015)

Background

This published work is a further follow-up of Publication 7 - Syed et al (2014). 49 consecutive patients were treated with a single injection of collagenase for MCPJ contractures due to Dupuytren's disease were followed up for a period of 2 years and their clinical and cost-saving outcomes are reported.

Methods

Ranges of motion and contracture were measured with a handheld goniometer, pre-operatively and at the final follow-up to assess clinical efficacy. URAM scores were measured to assess subjective change. Costs of the injection of collagenase, partial fasciectomy, and percutaneous needle fasciotomy treatment were computed from the cost to the hospital of the treatment, outpatient appointments, and hand therapy sessions.

Results

Significant improvements were seen in contracture angle and URAM scores. The mean contracture angle improved from 42° pre-injection, to 11° at 24 months. The mean URAM scores improved from 17 prior to treatment, to 3 at 24 months. A saving of £1870 per patient was made for CHC injections compared with partial surgical fasciectomy. Relative to percutaneous needle fasciotomy, CHC injection treatment is £604 more expensive per patient.

Recurrence, defined as a contracture angle of greater than 20°, occurred in 25% of patients (range 22° to 36°); of those, only one patient (2% of the whole group) with a contracture angle of 35° required further treatment with a fasciectomy. Overall, 76% of the patients who received collagenase reported at least one treatment-related adverse effect. Most side-effects were mild and resolved without intervention within a median of 10 days. The common side effects were skin tears, bruising, and axillary swelling. No severe adverse effects were reported.

On the basis of the results at 2 years following intervention, a single injection of CHC in selected patients with moderate Dupuytren's contracture affecting only one MCPJ can be recommended as both a clinical and cost-effective treatment regime.

This study, with the application of the CED approach, helped co-create evidence to inform local public health policy and practice for the CHC injections when there were uncertainties and added further confidence in findings reported in Publication 7 due to its longer follow-up.

Significance of published works

The quality of existing evidence is often insufficient to address the needs of decision makers as identified in Publication 2. There is often residual uncertainty following systematic reviews, mainly due to inadequate evidence of efficacy. Evidence may be lacking or may not be generalizable. For these reasons, contextualized "real-world" effectiveness data may be useful in aiding the decision-making process (Ung et al 2009) The unwillingness to make decisions in the presence of uncertainty may lead to passive diffusion and intuitive decision making with or without public pressure (Levin et al 2011). This may affect health system sustainability. There is increasing interest in post-market evaluation to address residual uncertainty regarding effectiveness and cost-effectiveness.

CED is another KT approach that was adapted to support decision making in the use of CHC injections to treat Dupuytren's contractures. It was particularly useful in an area where there is uncertainly on clinical benefit of the intervention from existing clinical trials. Even though Publication 7 and 8 do not provide conclusive evidence to support decision making, they set out a robust hypothesis which needs to be tested further in more rigorously designed studies. The study could be used to support potential future funding requests to undertake more robust clinical studies. It would have been more beneficial had Publication 7 and 8 adopted a randomised study design with a comparator group and larger sample size to increase reliability of the results. However, given the studies were undertaken in a non-research health

organisation with an imperative to make decisions quickly, it was not considered possible.

CED is a mechanism for going beyond a binary yes/no decision about coverage for new technologies or drugs by offering coverage in the context of prospective studies (Chalkidou et al 2008). It provides an alternative in situations where an intervention does not appear to meet the standard criteria for reimbursement, predominantly because of uncertainty surrounding the existing evidence base and when additional data collection could reduce this uncertainty (Claxton et al 2012). CED is an approach which allows conditional funding of a promising health intervention while more conclusive evidence is gathered to address uncertainty regarding its clinical or cost effectiveness (Tureman et al 2010). The approach helps make important contributions by co-creating evidence to inform public health policy and practice.

CHC is a new health technology to treat Dupuytren's contractures. There has been a growing interest to use it. However, its efficacy has been reported to vary in previously published studies. There has been considerable debate in funding CHC injections by the UK's National Health Service. The reason for this has been the weaknesses in the study designs, such as the efficacy measurements employed and the use of multiple injections and also the lack of analysis and reporting of data by disease severity, treatment cycle and joint type in some studies. All these factors combined together made it difficult to establish clinical efficacy and cost-effectiveness with fewer or single injections. Publication 7 and 8 are an example which demonstrates its use in establishing the benefit of CHC injections to inform development of local health policy and inform clinical practise in Herefordshire, UK. Given the uncertainties around the CHC injection, rather than deny coverage for it or grant unlimited coverage, the published works by using CED, attempts to ensure that patients' access is not prevented but is managed in a coordinated way, while also generating additional evidence to reduce any uncertainty about value.

Global experience of CED has been slow to develop despite their potential contribution to decision making. In the UK, similar schemes have been set up

in specialised commissioning within the NHS called commissioning through evaluation (CtE) to support decision making of interventions usually for rare diseases. Due to the small number of patients, it may not always be feasible to undertake large scale randomised control trials. The CtE scheme is aimed to overcome this issue. The CHC study was undertaken prior to the development and setting up of the CtE scheme. The author's experience in undertaking the study had a role supporting the NHS England national Specialised Services team in developing and setting up of the CtE programme in the NHS. He is currently involved in supporting evaluation of CtE studies.

It must also be noted that there are limitations to the use of a CED approach. A decision to use it as an approach to manage uncertainties must be made carefully. It should not be recommended for every new intervention. Such a move could potentially encourage the healthcare industry to move away from undertaking rigorous research in the form of randomised control trials. Furthermore, CED takes away the risk of introducing interventions of low benefit and/or safety from the healthcare industry. Therefore risk sharing approaches, where payments for the treatment are linked to outcomes, may be more advantageous than CED particularly when it relates to high cost or high budget impact interventions.

A limitation of Publications 7 and 8 is the relatively small sample sizes with clinical efficacy results reported at 12 and 24 months of follow-up respectively. The studies lacked a comparator group and the indirect comparisons made with previous published studies should be interpreted with caution. It is also known that late complications from CHC use can and have occurred outside the follow-up period of the initial phase III trials. Therefore, longer-term follow-up of patients is thus essential and further investigation and characterization of the late effects of CHC use is necessary. Furthermore, the cost analysis, which was based on the local information and setting, did not include longer term impacts on quality of life of patients and may not be generalizable. Further well-designed studies are needed to endorse findings, and surgical fasciectomy remains the gold

standard for the treatment of patients with severe Dupuytren's contractures involving multiple joints.

Publication 7 has been cited 3 times since it was published in 2014. Publication 8 has not been cited yet since it was published in 2015. Publication 7 has been included as part of the evidence to develop a NICE technology appraisal guideline which is due to be published in the coming months.

Section 4: Discussion and Implications for Future Research

Section 4.1: Discussion

EIPH is a fundamental concept for public health policy and practice. Despite the many accomplishments of public health, a greater attention to evidence-based approaches is warranted (Brownson et al 2009). The published works included in this thesis present important findings on the use of evidence and barriers and facilitators of its use thereby adding valuable knowledge to the field. It reports research evidence is rarely used in public health policy making. Other types of evidence are given more consideration and are primarily used. A number of barriers and facilitators in four domains (organizations, systems and infrastructure; media engagement and support; access and availability of relevant evidence; and networking and collaboration between researchers and policy makers) were also identified. Together, these findings provide an understanding of evidence-to-policy and practice gaps which is necessary to bridge them. The application of three approaches - the Delphi technique, Population Impact Measure and Coverage with Evidence Development methodologies – to positively address evidence-policy and practice gaps and enable KT facilitating co-creation of evidence to inform public health policy and practice in the areas of SARS and SARS-like diseases, rare diseases, cardiovascular diseases, strokes, cancers and Dupuytren's disease is presented.

Despite being well acknowledged that the use of research evidence in developing public health policy and practice improves outcomes, findings from the thesis show that in real world settings, decisions are mainly based on other types of evidence. There are a limited number of studies that have quantified what and how different types of evidence are used (Orton et al 2011, Amara et al 2004, Ouimet et al 2010, Oxman et al 2009a). A systematic review by Orton et al (2011) with an objective to synthesise evidence on what types of research evidence are used by public health decision makers reported two studies. These studies however focussed on types of research evidence preferred by public health decision makers.

Studies on the actual use of evidence were not included. This is potentially due to the fact that such studies were lacking at the time the review was undertaken. More recently, Zardo and Collie (2014) using a policy content analysis found that research evidence was the least used type of evidence in 128 injury rehabilitation compensation policies from the Victorian state government transport accident compensation authority in Australia. In another study that sought to measure the use of research, the frequency of use and the main purpose for use in comparison to other information types within two public health government agencies through a survey, it was found that internal data and reports were most frequently used sources of evidence while research evidence was the least frequently used source (Zardo and Collie 2015). This study also found that when used, research evidence was used for instrumental purposes more often than for symbolic purposes, which is contrary to findings of previous research. In general, the findings from the limited published literature are in line with those found by the published work in thesis. They provide further validation on what and how different types of evidence are used in physical activity policy making and could potentially be generalised to other health promotion areas given the similarities in policy development across them in terms of stakeholders, policy makers, organisations process etc. The limited studies available also support the need for KT approaches facilitating co-creation of evidence.

A thematic analysis of a recent systematic review of barriers and facilitators of research evidence shows similarities with those found in published work included in the thesis (Orton et al 2011, Oliver at al 2014). The published work confirms that most of what is already known from recent literature on key hindrances in uptake of evidence in policy making from other countries (including low and middle income countries) also holds true at a European level. In addition, it identified some barriers and facilitators (such as political relevance of the policy area) that were specific to the country context and influential in decisions. This highlights heterogeneity in the public health policy making landscape between countries (i.e. heterogeneity in definitions, processes, structures, stakeholders etc.) Such comparative findings have previously not been reported in the published literature.

Publication 2 found multiple barriers accounted for the evidence-to-policy and practice gaps, and many were intrinsic to the stakeholders and their environment or context. For example, organisational constraints, such as lack of time or an inability to access resources, were found to be common barriers to KT. Six published works (Publications 3, 4, 5, 6, 7 and 8) demonstrate the innovative application of three KT approaches (Delphi technique, PIMs and PARs and CED) facilitating co-creation of evidence (research evidence together with other types of evidence) in real world settings with an aim to address the barriers and bridge the evidence-to-policy and practice gaps. All three approaches had previously been reported in literature and applied in different public health areas and settings. This demonstrates their ease of access and their ability to be tailored to specific requirements. In the published works, the three KT approaches were used as single KT approaches in as they were simple to use and did not require as much resources as multifaceted approaches. The impact of their application resulted in changing both knowledge and practice. These experiences of using the three KT approaches are in line with those reported by in a systematic review by LaRocca et al (2012). They suggested that KT approaches that are accessible and can be tailored to the needs and preferences of the users are more successful; they also reported that simple or single KT approaches were shown in some circumstances to be as effective as complex, multifaceted ones when changing practice including tailored and targeted messaging. The difference between the KT strategies considered in the systematic review (LaRocca et al 2012) and those considered in the thesis is that the former facilitated use of research evidence only while the latter facilitated co-creation of evidence. The findings from the thesis demonstrate that the experiences and outcomes of KT facilitating research use only and KT approaches facilitating co-creation are similar.

KT approaches can be (a) driven by researchers, (b) driven by decision-makers or (c) designed to develop partnerships between researchers and organisations to support the use of research evidence in public health decision making (Armstrong et al 2011). The KT approaches used in this

thesis were driven by researchers - the authors of the published works acted as a knowledge broker to link the research with decision makers. Depending on who drives the KT approach, there are practical implications. Resources in various forms such as access to technical information, expertise, collaboration with stakeholders, time etc. will be required. If the necessary resources are not available, these may pose as barriers in their use. It must be noted that no approach will be able to address all the barriers associated with their use due to the many variables associated with their use and the complexity of public health policy making environments. However, aiming to reduce barriers in the use of evidence in the wider context will make their application easier.

Section 4.2: Strengths and Limitations

The thesis includes published works and their findings on a wide range of public health areas and settings at local, national and international levels. Therefore, it makes the findings relevant to a wide audience. The published works also employed a variety of existing and widely reported methodological approaches which increases the reliability and validity of findings. However, their use as KT approaches facilitation co-creation of evidence and also of other approaches has previously not explored. All of these factors add value to findings of the thesis.

While it is advantageous that the published works and their findings were based a wide range of public health areas, settings and administrative levels, it is also a limitation as it was not possible to explore themes that were identified in greater detail. Another limitation of the thesis is that the KT approaches employed in it were researcher initiated. Therefore their use many be limited where individuals with such expertise are not available. Furthermore the KT approaches included in the thesis focussed on disseminating evidence only. It did not include approaches where in evidence was actively sought or those that build partnerships between researchers and decision makers.

Section 4.3: Implications for Future Research

Advances in technology have led to increased adoption of tools and methods aimed at integrating diverse evidence sources to inform decision-making (Hovmand et al 2012, Atkinson et al 2015). While there are many KT approaches and techniques available, the research on evaluation of their use is still in its infancy (Freebairn et al 2016). Rigorous assessment of the value and utility of these methods and tools is required prior to them being more generally adopted to support for evidence-based public health decision making (Freebairn et al 2016). This is particularly necessary given that KT approaches have not demonstrated positive changes (Kiefer et al 2005) and their potential failure may be due to the use of a narrow definition of evidence as research evidence only in them (Kothari et al 2012). More studies need to be undertaken using a boarder definition of evidence which includes other types of evidence and facilitates co-creation and their evaluations reported. Future research should aim to address this and also explore how, when and why different facilitators and barriers come into play during the policymaking process as there is a lack of studies reporting on these factors (Oliver at al 2014).

In general, KT approaches can be categorised as having push, pull and exchange foci (Lavis 2006). Push approaches generally focus on dissemination (for e.g. development and distribution of publications, reports, systematic reviews, evidence summaries etc.). Approaches may support the uptake or reach of these products (Lavis 2006; Nutley 2007). Pull approaches may involve a number of mechanisms including social influence, facilitation and incentives and reinforcements. These may involve training staff in the application of research to decision making, employment of facilitators (also known as knowledge brokers) within decision-making contexts, rapid-response units, and development of project templates that instruct staff to provide rationale for their activities (Lavis 2006, Nutley 2007). Exchange approaches focus on improving the interactions between the researchers and decision-makers. This may include the establishment of networks or formal partnerships to support evidence informed decision making, prioritisation efforts (where decision makers identify their priorities,

turn the questions into researchable questions and promote research into these questions), and the use of knowledge brokers where their role is to facilitate partnerships. Further work is needed to explore pull and exchange approaches as the KT approaches included in this thesis were push approaches.

Characteristics of decision makers were identified as factors that influence use of evidence in the thesis. Based on the experience of using KT approaches, it is considered that interventions to strengthen attitudes and competencies toward KT activities may trigger intention to systematically incorporate the best available evidence into policy making and practice. For policy-makers, it is thought that factors at the individual level that significantly predict research use in certain public health decision-making contexts include research skills and intention to use research findings in the near future (i.e., the next 12 months) (Zardo and Collie 2014). Further understanding of the relevant theoretical and empirical literature; mapping publications for key themes and research gaps of KT competencies, and interventions for enhancing KT competencies, is needed. Mallidou et al (2017) have planned a scoping review on KT competencies. Findings from it may be useful in the development of comprehensive training programs and implementation of research findings and undertake further research where there are gaps.

Section 4.4: Conclusion

A fundamental concept of EIPH is to take into account realities of a specific real-world environment when translating research evidence into policy and practice. This thesis presents an understanding of how evidence is used, barriers and facilitators of its use and potential KT approaches facilitating co-creation of evidence to foster EIPH.

It is essential that approaches supporting the use of research and other types of evidence in public health continue to be developed and evaluated. Usefulness and effectiveness of different KT approaches to facilitate evidence use and reduce its barriers must be documented in the literature so that they can be adopted or modified accordingly. Effective strategies and

interventions along with information of the settings in which they are delivered can then be utilised by public health professionals and policy makers who wish to promote EIDM.

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Appendices

Appendix 1: Bibliography of all published works

i. van de Goor, I., Hämäläinen, R-M., Syed A.M., Lau, C.J., Sandu, P., Spitters, H., Eklund Karlsson, L., Dulf, D., Valente, A., Castellani, T., Aro A.R. (2017) Determinants of evidence use in public health policy making: Results from a study across six EU countries. *Health Policy*, 121(3):273-281

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xiv. Hjarnoe, L., Syed, A.M., Krumkramp, R., Reintjes, R., Aro, A.R. (2006) Community containment in SARS: a Hazard analysis and critical controls point approach. *European Journal of Public Health,* 16(1):186.

Appendix 2: Copies of published works included in thesis

The published works listed in table below are included in full on pages 73 - 143.

Published Work
Publication 1 Hämäläinen, R.M., Aro, A.R., van de Goor, I., Lau, C.J., Jakobsenm M.W., Chereches, R.M., Syed, A.M., REPOPA Consortium.and On behalf of the REPOPA Consortium. (2015) Exploring the use of research evidence in health-enhancing physical activity policies. *Health Research Policy and Systems*. 13:43.
Publication 2 van de Goor, I., Hämälainen, R-M., Syed A.M., Lau, C.J., Sandu, P., Spitters, H., Eklund Karlsson, L., Dulf, D., Valente, A., Castellani, T., Aro A.R. (2017) Determinants of evidence use in public health policy making: Results from a study across six EU countries. *Health Policy*, 121(3):273-281
Publication 3 Syed, A.M., Hjarnoe, L., and Aro, A.R. (2009) The Delphi Technique In Developing International Health Policies: Experience From The SARSControl Project. *The Internet Journal of Health*. 8:2.
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Publication 5 Syed, A.M., Camp, R., Mischorr-Boch, C., Houÿez, F., Aro, A.R. (2015) Policy recommendations for rare disease centres of expertise. *Evaluation and Program Planning*. 20 16;52:78-84
Publication 6 Syed, A.M., Talbot-Smith, A. and Gemmell, I. (2012) The use of epidemiological measures to estimate the effectiveness of planned interventions: Experiences from Herefordshire, UK. *Journal of Epidemiology and Global Health*. 2(3) 111-124.
Publication 7 Syed, A.M., Mcfarlane, J., Chester, T., Powers, D., Sibly, F., Talbot-Smith, A. (2014) Clinical efficacy and cost-effectiveness of Clostridium histolyticum collagenase injections in a subpopulation of Dupuytren's contracture patients. *European Orthopaedics and Traumatology*. 5(3): 311-316
Publication 8 McFarlane, J., Syed, A.M., Sibly, T.F. (2015) A single injection of collagenase clostridium histolyticum for the treatment of moderate Dupuytren's contracture: a 2 year follow-up of 47 patients. *Journal of Hand Surgery (European Volume)*. 41(6):664-5.

Appendix 3: Statements of contributions

Statements of contributions for each included published work undertaken in collaboration with others are provided on pages 144 - 177.

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Hämäläinen, R.M., Aro, A.R., van de Goor, I., Lau, C.J., Jakobsenm M.W., Chereches, R.M., Syed, A.M., REPOPA Consortium.and On behalf of the REPOPA Consortium. (2015) Exploring the use of research evidence in health-enhancing physical activity policies. *Health Research Policy and Systems* 13:43.

Study circumstance: The published work was undertaken as part of the European Commission funded research project "Research into POlicy to enhance Physical Activity (REPOPA)'.The overall aim of REPOPA was to integrate scientific research knowledge, expertise, and real world policy making processes to stimulate evidence-based physical activity policies. The aim of this study was to explore the use of research evidence in health-enhancing physical activity (HEPA) policies, identify when research evidence was used, and indicate which other types of evidence were used in HEPA policy making. 21 HEPA policies implemented at local, regional and national levels in six European countries (Finland, Italy, Romania, UK, The Netherlands and Denmark) were selected for content analysis. Semi-structured interviews were undertaken using a standard topic guide across all six participating countries. The findings were reported in the publication.

Mohamed Ahmed Syed' contribution to the published work: Mohamed Ahmed Syed undertook a lead role in the design, data collection, analysis and reporting of the study as part of the UK REPOPA team and worked in collaboration withother REPOPA consortium partners to produce an overall study report. Riitta-MaijaHämäläinen, took a lead role in drafting the published work in liaison with the co-authors. Mohamed, contributed to country specific sections/information and the overall drafting and revision of the published work.

I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
ARJA R. ARO		16. Feb. 2017

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Hämäläinen, R.M., Aro, A.R., van de Goor, I., Lau, C.J., Jakobsenm M.W., Chereches, R.M., Syed, A.M., REPOPA Consortium.and On behalf of the REPOPA Consortium. (2015) Exploring the use of research evidence in health-enhancing physical activity policies. *Health Research Policy and Systems* 13:43.

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Mohamed Ahmed Syed' contribution to the published work: Mohamed Ahmed Syed undertook a lead role in the design, data collection, analysis and reporting of the study as part of the UK REPOPA team and worked in collaboration with other REPOPA consortium partners to produce an overall study report. Riitta-Maija Hämäläinen, took a lead role in drafting the published work in liaison with the co-authors. Mohamed, contributed to country specific sections/information and the overall drafting and revision of the published work.

I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

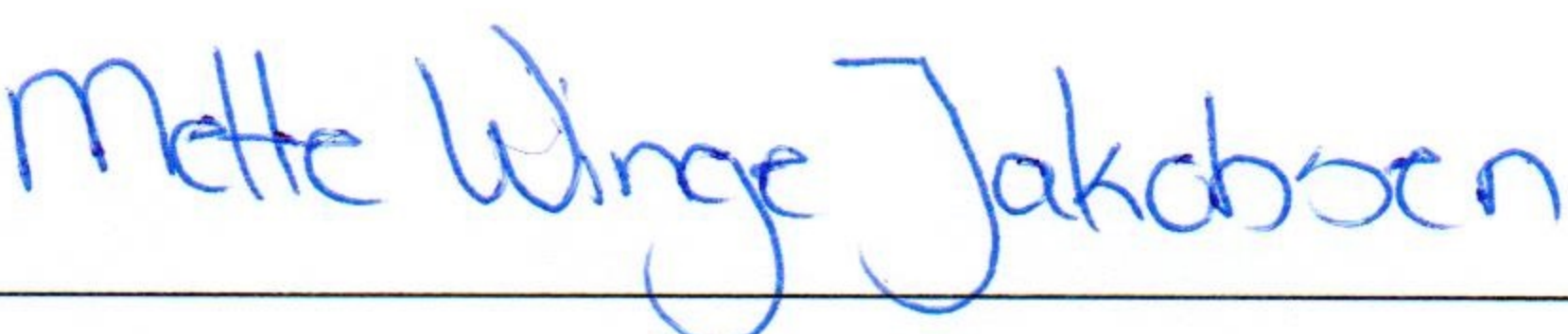| Name	Signature	Date
CATHRINE JUEL LAU		20/2-2017

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Hämäläinen, R.M., Aro, A.R., van de Goor, I., Lau, C.J., Jakobsenm M.W., Chereches, R.M., Syed, A.M., REPOPA Consortium.and On behalf of the REPOPA Consortium. (2015) Exploring the use of research evidence in health-enhancing physical activity policies. *Health Research Policy and Systems* 13:43.

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
Prof. dr. Ien van de Goor		21-02-2017

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Hämäläinen, R.M., Aro, A.R., van de Goor, I., Lau, C.J., Jakobsenm M.W., Chereches, R.M., Syed, A.M., REPOPA Consortium.and On behalf of the REPOPA Consortium. (2015) Exploring the use of research evidence in health-enhancing physical activity policies. *Health Research Policy and Systems* 13:43.

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Mohamed Ahmed Syed' contribution to the published work: Mohamed Ahmed Syed undertook a lead role in the design, data collection, analysis and reporting of the study as part of the UK REPOPA team and worked in collaboration with other REPOPA consortium partners to produce an overall study report. Riitta-Maija Hämäläinen, took a lead role in drafting the published work in liaison with the co-authors. Mohamed, contributed to country specific sections/information and the overall drafting and revision of the published work.

I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

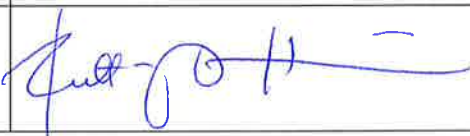| Name	Signature	Date
Mette Winge Jakobsen	*Mette Winge Jakobsen*	15.02.2017

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Hämäläinen, R.M., Aro, A.R., van de Goor, I., Lau, C.J., Jakobsenm M.W., Chereches, R.M., Syed, A.M., REPOPA Consortium.and On behalf of the REPOPA Consortium. (2015) Exploring the use of research evidence in health-enhancing physical activity policies. *Health Research Policy and Systems* 13:43.

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Mohamed Ahmed Syed' contribution to the published work: Mohamed Ahmed Syed undertook a lead role in the design, data collection, analysis and reporting of the study as part of the UK REPOPA team and worked in collaboration with other REPOPA consortium partners to produce an overall study report. Riitta-Maija Hämäläinen, took a lead role in drafting the published work in liaison with the co-authors. Mohamed, contributed to country specific sections/information and the overall drafting and revision of the published work.

I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
Chereceș Răzvan Mircea		17.02.2017

Statement of contribution

Study circumstance: The published work was undertaken as part of the FP7 research funding programme of the European Commission project "Research into POlicy to enhance Physical Activity (REPOPA)'. The overall aim of REPOPA was to integrate scientific research knowledge, expertise, and real world policy making processes to stimulate evidence-based physical activity policies. The sub-study aimed to explore the use of research evidence in health-enhancing physical activity (HEPA) policies, identify when research evidence was used, and indicate which other types of evidence were used in HEPA policy making. 21 HEPA policies implemented at local, regional and national levels in six European countries (Finland, Italy, Romania, England, The Netherlands and Denmark) were selected for content analysis. Semi-structured interviews were conducted for 86 policymakers using a standard topic guide across all six participating countries. The overall findings were reported in the above publication.

Mohamed Ahmed Syed contribution to the published work: Mohamed Ahmed Syed undertook a lead role in England in the design, data collection, analysis and reporting of the study as part of the England REPOPA team and worked in collaboration with other REPOPA consortium partners to produce an overall study report. Riitta-Maija Hämäläinen, took overall lead role in design, data collection, analysis, reporting of the sub-study and drafting the published work in liaison with the co-authors in six EU member states. Mohamed, contributed to country specific sections/information and the overall drafting and revision of the published work.

I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

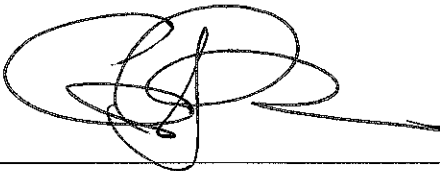| Name	Signature	Date
HÄMÄLÄINEN RIITTA-MAIJA		27.2.2017

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed:van de Goor I., Hämäläinen R-M., Syed A.M., Lau, C.J., Sandu, P., Spitters, H., Karlsson, L.E., Dulf, D., Valente, A., Castellani, T., Aro A.R. (2017) Determinants of evidence use in public health policy making: Results from a study across six EU countries. *Health Policy*pii: S0168-8510(17)30019-2.

Study circumstance: The published work was undertaken as part of the European Commission funded research project "Research into POlicy to enhance Physical Activity (REPOPA)'.The overall aim of REPOPA was to integrate scientific research knowledge, expertise, and real world policy making processes to stimulate evidence-based physical activity policiesThe aim of thispublished work was to further explore barriers and facilitators for the use of research and other evidence in the process of developing HEPA policies identified in semi-structured interviews with key stakeholders in six European Union countries as part of the REPOPA project.21 HEPA policies implemented at local, regional and national levels in six European countries (Finland, Italy, Romania, UK, The Netherlands and Denmark) were selected for content analysis. Semi-structured interviews were undertaken using a standard topic guide across all six participating countries. The findings were reported in the publication.

Mohamed Ahmed Syed' contribution to the published work:Mohamed Ahmed Syed undertook a lead role in the design, data collection, analysis and reporting of the study as part of the UK REPOPA team and worked in collaboration with other REPOPA consortium partners to produce an overall study report.Ien van de Goor, took a lead role in drafting the published work in liaison with the co-authors. Mohamed, contributed to country specific sections/information and the overall drafting and revision of the published work.

I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
ARJA R. ARO		16. Feb. 2017

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: van de Goor I., Hämäläinen R-M., Syed A.M., Lau, C.J., Sandu, P., Spitters, H., Karlsson, L.E., Dulf, D., Valente, A., Castellani, T., Aro A.R. (2017) Determinants of evidence use in public health policy making: Results from a study across six EU countries. *Health Policy* pii: S0168-8510(17)30019-2.

Study circumstance: The published work was undertaken as part of the European Commission funded research project "Research into POlicy to enhance Physical Activity (REPOPA)'. The overall aim of REPOPA was to integrate scientific research knowledge, expertise, and real world policy making processes to stimulate evidence-based physical activity policies The aim of this published work was to further explore barriers and facilitators for the use of research and other evidence in the process of developing HEPA policies identified in semi-structured interviews with key stakeholders in six European Union countries as part of the REPOPA project. 21 HEPA policies implemented at local, regional and national levels in six European countries (Finland, Italy, Romania, UK, The Netherlands and Denmark) were selected for content analysis. Semi-structured interviews were undertaken using a standard topic guide across all six participating countries. The findings were reported in the publication.

Mohamed Ahmed Syed' contribution to the published work: Mohamed Ahmed Syed undertook a lead role in the design, data collection, analysis and reporting of the study as part of the UK REPOPA team and worked in collaboration with other REPOPA consortium partners to produce an overall study report. Ien van de Goor, took a lead role in drafting the published work in liaison with the co-authors. Mohamed, contributed to country specific sections/information and the overall drafting and revision of the published work.

I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

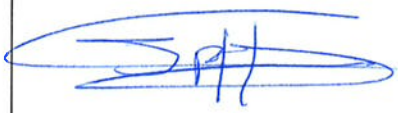| Name	Signature	Date
CATHRINE JOEL LAU		20/2 -2017

Statement of contribution

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
Diana Dulf		20/02/2017

Statement of contribution

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
Hilde Spitters		23 - 02 - 2017

Statement of contribution

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
Prof. dr. Ien van de Goor		21-02-2017

Statement of contribution

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
Leena Eklund Karlsson		16. February, 2017

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed:van de Goor I., Hämälainen R-M., Syed A.M., Lau, C.J., Sandu, P., Spitters, H., Karlsson, L.E., Dulf, D., Valente, A., Castellani, T., Aro A.R. (2017) Determinants of evidence use in public health policy making: Results from a study across six EU countries. *Health Policy*pii: S0168-8510(17)30019-2.

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
PETRU SANDU		16.02.2017

Statement of contribution

Study circumstance: The published work was undertaken as part of the FP7 European Commission funded research project "Research into POlicy to enhance Physical Activity (REPOPA)'. The overall aim of REPOPA was to integrate scientific research knowledge, expertise, and real world policy making processes to stimulate evidence-based physical activity policies. The sub-study aimed to further explore barriers and facilitators for the use of research and other evidence in the process of developing HEPA policies identified in semi-structured interviews with key stakeholders in six European Union countries as part of the REPOPA project. 21 HEPA policies implemented at local, regional and national levels in six European countries (Finland, Italy, Romania, England, The Netherlands and Denmark) were selected for content analysis. Semi-structured interviews were conducted for 86 policymakers using a standard topic guide across all six participating countries. The findings were reported in the publication.

Mohamed Ahmed Syed contribution to the published work: Mohamed Ahmed Syed undertook a lead role in England in the design, data collection, analysis and reporting of the study as part of the England REPOPA team and worked in collaboration with other REPOPA consortium partners to produce an overall study report. Riitta-Maija Hämäläinen, took overall lead role in design, data collection, analysis, reporting of the sub-study and drafting the published work in liaison with the co-authors in six EU member states. Ien van de Goor, took a lead role in drafting the published work in liaison with the co-authors. Mohamed Ahmed Syed contributed to country specific sections/information and the overall drafting and revision of the published work.

I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

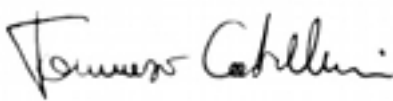| Name	Signature	Date
HÄMÄLÄINEN RIITTA-MAIJA	*[signature]*	27. 2. 2017

Statement of contribution

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
Tommaso Castellani		17.2.2017

Statement of contribution

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
ADRIANA VALENTE	*(signature)*	15-2-2017

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Syed, A.M., Hjamoe, L., and Aro, A.R. (2009) The Delphi Technique In Developing International Health Policies: Experience From The SARSControl Project. *The Internet Journal of Health.* 8:2

Study circumstance: The published work was undertaken as part of the European Commission funded research project called 'SARSControl'. The project's main aim was to develop 'Effective and acceptable strategies for the control of SARS and newly emerging infections in China and Europe'. This study was part of the 'Policy evaluation' work package of the SARSControl project. The aim of the study was to evaluate the practical applicability of the Delphi technique in a real world setting and presents findings based on the criteria identified. The findings of the study are reported in this published work.

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Name	Signature	Date
ARJA R. ARO		16. Feb. 2017

Statement of contribution

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
LuLu HJARNØ		21/2-17

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Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Syed, A.M., Hjarnoe, L., Krumkamp, R., Reintjes, R., Aro. A.R. (2010) Developing policy options for SARS and SARS-like diseases – a Delphi study. *Global Public Health*. 16:1-13.

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Name	Signature	Date
ARJA R ARO		16. Feb. 2017

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
Prof. Dr. Ralf Reintjes		21.02.2017

Statement of contribution

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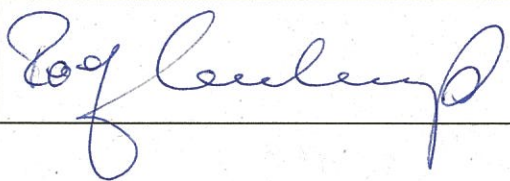| Name	Signature	Date
Lulu Hjarnø	*Center for Maritim Sundhed og Samfund, Niels Bohrs Vej 9-10, DK-6700 Esbjerg, Tlf. 6550 4260 / www.sdu.dk/ist/cmss, SYDDANSKUNIVERSITET.DK*	21/2-17

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
Dr. Ralf Krumkamp		15.02.2017

Statement of contribution

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Study circumstance: The published work was undertaken as part of the European Commission funded research project called 'Patients' Consensus on Preferred Policy Scenarii for Rare Disease (POLKA)'. The main objective of the POLKA project was to facilitate the consultation of the European rare disease community, with the aim of building consensus on preferred public health policy scenarios for rare diseases, including the quality of care available at rare diseaseCentres of Expertise (CoEs), and if that level of quality was sufficient.The Delphi technique was employed to develop policy recommendations to support better provision of healthcare for rare disease patients in Europe. The findings of the study are reported in this published work.

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Name	Signature	Date
ARJA R. ARU		16.Feb.2017

Statement of contribution

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Name	Signature	Date
Christina Mischorr-Boch	*Ellen Mischorr-Boch*	16/2-2017

Statement of contribution

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
François Houÿez POLKA project manager, European Organisation For Rare Diseases		15 February 2017

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Syed, A.M., Camp, R., Mischorr-Boch, C., Houÿez, F., Aro, A.R. (2015) Policy recommendations for rare disease centres of expertise. *Evaluation and Program Planning*. 20 16;52:78-84

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
Rob Camp	*Rob Camp*	17 Feb 2017

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Syed, A.M., Talbot-Smith, A. and Gemmell, I. (2012) The use of epidemiological measures to estimate the effectiveness of planned interventions: Experiences from Herefordshire, UK. *Journal of Epidemiology and Global Health*. 2(3) 111-124.

Study circumstance: Coronary heart diseases, stroke and cancers are the major causes of mortality in the UK and are responsible for significant amounts of morbidity and healthcare costs. This published work examined the proportion of coronary heart diseases, stroke and cancer owing to specific risk factors in Herefordshire, UK. Therefore, this study was undertaken to co-create evidence by estimating the population impact of a number of interventions being implemented to reduce these risk factors, through the National Health Service (NHS) Health Check program and the Herefordshire Health Improvement Plan. The findings of the study are reported in the published work.

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I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
DR ALISON TALBOT-SMITH		21/2/17

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Syed, A.M., Talbot-Smith, A. and Gemmell, I. (2012) The use of epidemiological measures to estimate the effectiveness of planned interventions: Experiences from Herefordshire, UK. *Journal of Epidemiology and Global Health*. 2(3) 111-124.

Study circumstance: Coronary heart diseases, stroke and cancers are the major causes of mortality in the UK and are responsible for significant amounts of morbidity and healthcare costs. This published work examined the proportion of coronary heart diseases, stroke and cancer owing to specific risk factors in Herefordshire, UK. Therefore, this study was undertaken to co-create evidence by estimating the population impact of a number of interventions being implemented to reduce these risk factors, through the National Health Service (NHS) Health Check program and the Herefordshire Health Improvement Plan. The findings of the study are reported in the published work.

Mohamed Ahmed Syed' contribution to the published work: Mohamed Ahmed Syed undertook a lead role in the design, data collection, analysis and reporting of the study. He took a lead role in drafting and revising the published work in liaison with the co-authors.

I agree that Mohamed Ahmed Syed made the aforementioned contribution to the published work.

Name	Signature	Date
Isla Gemmell		16/02/2017

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Syed, A.M., Mcfarlane, J., Chester, T., Powers, D., Sibly, F., Talbot-Smith, A. (2014) Clinical efficacy and cost-effectiveness of Clostridium histolyticum collagenase injections in a subpopulation of Dupuytren's contracture patients. *European Orthopaedics and Traumatology*. 5(3): 311-316.

Study circumstance: There is increasing interest in the use of Clostridium histolyticum collagenase (CHC) injections to treat Dupuytren's contractures. However, the reported efficacy varies between studies and it remains unclear which patients would benefit most from CHC injections. In addition, there is a lack of national guidelines on its use. Therefore, there has been considerable debate in funding CHC injections by the UK's National Health Service. This study used the 'coverage with evidence development' concept to facilitate co-creation of research evidence to inform local policy and practice on CHC injections to treat Dupuytren's contracture. The findings of the study are reported in the published work.

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Name	Signature	Date
DR ALISON TALBOT-SMITH		21/2/17

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Syed, M., McFarlane, J., Chester, T., Powers, D., Sibly, F., Talbot-Smith, A. (2014) Clinical efficacy and cost-effectiveness of Clostridium histolyticum collagenase injections in a subpopulation of Dupuytren's contracture patients. *European Orthopaedics and Traumatology,* 5(3): 311-316.

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Name	Signature	Date
JOHN McFARLANE	J.Mgrle	20/2/17

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Syed, A.M., Mcfarlane, J., Chester, T., Powers, D., Sibly, F., Talbot-Smith, A. (2014) Clinical efficacy and cost-effectiveness of Clostridium histolyticum collagenase injections in a subpopulation of Dupuytren's contracture patients. *European Orthopaedics and Traumatology*. 5(3): 311-316.

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Name	Signature	Date
TONIA CHESTER		15 - 2 . 17.

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: Syed, A.M., Mcfarlane, J., Chester, T., Powers, D., Sibly, F., Talbot-Smith, A. (2014) Clinical efficacy and cost-effectiveness of Clostridium histolyticum collagenase injections in a subpopulation of Dupuytren's contracture patients. *European Orthopaedics and Traumatology.* 5(3): 311-316.

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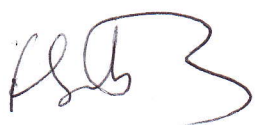| Name	Signature	Date
TF SiBLY		15/ 2/17

Statement of contribution

Publication for consideration as part of PhD by published works for Mohamed Ahmed Syed: McFarlane, J., Syed, A.M., Sibly, T.F. (2015) A single injection of collagenase clostridium histolyticum for the treatment of moderate Dupuytren's contracture: a 2 year follow-up of 47 patients. *Journal of Hand Surgery (European Volume).* 41(6):664-5.

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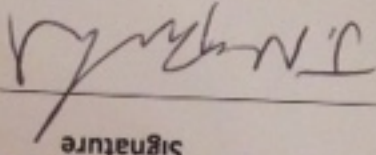| Name	Signature	Date
TF Sibly	*(signature)*	15/2/17

Statement of contribution

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Name	Signature	Date
JOHN MCFARLANE	J. McFarlane	20/2/17