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Setting priorities for conducting and updating systematic reviews

A dissertation including ten research publications and four commentaries

By

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For me, this project is not only a PhD but a collection of research projects to address a research enquiry that emerged from my clinical, research and teaching responsibilities. There were a lot of people who supported me, inspired me and mentored me throughout the process.

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Contents

Setting priorities for conducting and updating systematic reviews	2
AUTHOR'S DECLARATION	5
Abstract.....	9
Executive Summary.....	11
Chapter 1 Critical appraisal	16
What is Research Priority Setting?.....	17
Research priority setting in the context of a systematic review organisation	20
Reducing research waste initiative and health care research funding agencies.....	26
Chapter 2 – Published work - Review of methods to set priorities for systematic reviews.....	30
Chapter 3 – Published work - Drivers in setting priorities for systematic reviews in a systematic review organisation	31
Evaluating the priority setting process in Cochrane	31
Comparing the content of Cochrane with Global Burden of Disease to guide future priority setting processes.....	31
Chapter 4 – Published work - Evaluating the process of allocating funding to research projects in key national funding agencies	33
Chapter 5 – General Discussion/Conclusion	34
Evaluating the process of setting priorities in the Cochrane Collaboration	34
How do national health research funders reduce research waste?.....	61
Next steps:	79
Final note:	79
Appendix 1 Selected research output relevant to this PhD.....	81
Appendix 2 –An overview of reviews on priority setting strategies.....	102
Appendix 3 - An introduction to Research Priority Setting (RPS) for research groups in Cochrane	106
Appendix 4 – Equity guide for developing a priority setting strategy for Cochrane Review Groups	113
References	119

AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Doctoral College Quality SubCommittee

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Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment.

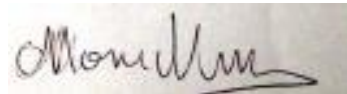
This study was predominantly self-funded. I gratefully acknowledge the funders and organisations which have awarded me or my collaborators small grants to undertake specific topics, they are each cited within the relevant section of the dissertation.

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There were several publications and presentation related to this PhD. They are listed in (Table 1 - My contribution to each publication).

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Table 1 - My contribution to each publication

Publication (the key publications are marked with *)	My contribution	When and where was the study conducted
Nasser M , Welch V, Ueffing E, Crowe S, Oliver S, Carlo R. Evidence in agenda setting: new directions for the Cochrane Collaboration. J Clin Epidemiol. 2013 May;66(5):469-71.	Major. I wrote the first draft, made revisions, and finalised it based on comments of my co-authors.	This is a commentary that I wrote with my colleagues when I was employed in Plymouth University in 2013.
*Nasser M , Welch V, Tugwell P, Ueffing E, Doyle J, Waters E. Ensuring relevance for Cochrane Reviews: evaluating processes and methods for prioritizing topics for Cochrane reviews. J Clin Epidemiol. 2013 May;66(5):474-82.	Major. I led the design and conduct of the project. I collected all data and analysed them. I wrote the first draft and revised and finalised it based on the comments of my collaborators.	I started the project when I was working in Germany in Institute for Quality and Efficiency in Health care in 2008 but finished the project in 2012 when I was in Plymouth University. It was an international survey.
*Nasser M , Ueffing E, Welch V, Tugwell P. An equity lens can ensure an equity-oriented approach to agenda setting and priority setting of Cochrane Reviews. J Clin Epidemiol. 2013 May;66(5):511-21.	Major. I led the design and conduct of the project. I collected all data and analyse them. I wrote the first draft and revised and finalised it based on the comments of my collaborators.	I started the project when I was working in Germany in Institute for Quality and Efficiency in Health care in 2008 but finished the project in 2012 when I was in Plymouth University. It was an international survey.
Nasser M , Karimkhani C, Dellavalle R. Global burden of oral and oropharyngeal diseases in 2010 as reflected in Cochrane Database of Systematic Reviews, BSODR, 14-16 Sep 2015. Cardiff, UK. (Conference presentation)	Major. I designed and conducted the survey and wrote the conference proceedings and addressed the revision.	I was employed in Plymouth University working on the project with them.
*Moher D , Glasziou P, Chalmers I, Nasser M , Bossuyt PM, Korevaar DA, Graham ID, Ravauud P, Boutron I. Increasing value and reducing waste in biomedical research:	Major. This paper has several sections. I led the section on the	I was employed in Plymouth University working on the project with

who's listening? Lancet. 2015 Sep 25. pii: S0140-6736(15)00307-4.	funders. I led the design, conduct of the project, writing the first draft and revising and finalising the paper.	them. It is an international survey.
* Nasser M , Clarke M, Chalmers I, Brurberg KG, Nykvist H, Lund H, Glasziou P. What are funders doing to minimise waste in research? Lancet. 2017 Mar 11;389(10073):1006-1007.	Major. This paper has several sections. I led the section on the funders. I led the design, conduct of the project, writing the first draft and revising and finalising the paper.	I was employed in Plymouth University working on the project with them. It is an international survey.
Nasser M , Welch V. Prioritization of systematic reviews leads prioritization of research gaps and needs. J Clin Epidemiol. 2013 May;66(5):522-3.	Major. This is a commentary. I took the lead in writing the paper, revising and finalising it.	I was employed in Plymouth University working on the article.
Pooler J, Nasser M . Challenges in conducting priority setting exercises for Cochrane entities. Cochrane Methods Supplement 2013. ISSN: 2044-4702. http://www.cochranelibrary.com/dotAsset/bcc67133-fbf0-47a4-8190-1e0c3a70ac2d.pdf	Moderate. I designed the project and conducted the survey and has done the initial analysis. My co-author wrote the paper and did some additional analysis on the data.	I was employed in Plymouth University when I conducted the survey which was international
Bhaumik S, Rana S, Karimkhani C, Welch V, Armstrong R, Pottie K, Dellavalle R, Dhakal P, Oliver S, Francis DK, Nasser M, Crowe S, Aksut B, Amico RD. Ethics and equity in research priority-setting: stakeholder engagement and the needs of disadvantaged groups. Indian J Med Ethics. 2015 Apr-Jun;12(2):110-3.	Minor. I was involved in planning the workshop that underpinned this article and was involved in revising the article.	This is a commentary. The workshop was organised in India as part of the Cochrane Colloquium in Hyderabad, India in 2014.
Karimkhani C, Boyers LN, Nasser M , Dellavalle R. Mapping research prioritization by The Cochrane Collaboration to Global Burden of Disease 2010 data. Cochrane Methods. Issue September 2014. Available at: http://www.cochranelibrary.com/dotAsset/8df3b5a2-217a-41fd-ac77-9d8d05487970.pdf	Minor. I was involved in developing the methodology and making revision and comments on the article.	I was employed in Plymouth University working on the project with them.

<p>Pederson H, Okland T, Boyers LN, Karimkhani C, Rosenfeld RM, Nasser M, Yoong SL, Wolfenden L, Kyu HH, Serina PT, Coggeshall M, Dellavalle RP. Identifying otolaryngology systematic review research gaps: comparing Global Burden of Disease 2010 results with Cochrane Database of Systematic Review content. JAMA Otolaryngol Head Neck Surg. 2015 Jan;141(1):67-72.</p>	<p>Minor. I was involved in developing the methodology and making revision and comments on the article.</p>	<p>The lead author is based in USA but I was employed in Plymouth University working on the project with them.</p>
<p>Karimkhani C, Boyers LN, Prescott L, Welch V, Delamere FM, Nasser M, Zaveri A, Hay RJ, Vos T, Murray CJ, Margolis DJ, Hilton J, Macle hose H, Williams HC, Dellavalle RP. Global Burden of Skin Disease as Reflected in Cochrane Database of Systematic Reviews. JAMA Dermatol. 2014 Sep;150(9):945-51.</p>	<p>Minor. I was involved in developing the methodology and making revision and comments on the article.</p>	<p>The lead author is based in USA but I was employed in Plymouth University working on the project with them.</p>
<p>Bhaumik S, Karimkhani C, Czaja CA, Williams HC, Rani M, Nasser M, Boyers LN, Dmitruk S, Dellavalle RP. Identifying gaps in research prioritization: The global burden of neglected tropical diseases as reflected in the Cochrane database of systematic reviews. J Family Med Prim Care. 2015 Oct-Dec;4(4):507-13.</p>	<p>Minor. I was involved in developing the methodology and making revisions and comments on the article.</p>	<p>The lead author is based in India but I was employed in Plymouth University working on the project with them.</p>
<p>Karimkhani C, Trikha R, Aksut B, Jones T, Boyers LN, Schlichte M, Pederson H, Okland T, DiGuisseppi C, Nasser M, Naghavi M, Vos T, Yoong SL, Wolfenden L, Murray CJ, Dellavalle RP. Identifying gaps for research prioritisation: Global burden of external causes of injury as reflected in the Cochrane Database of Systematic Reviews. Injury. 2016 May; 47(5): 1151–7.</p>	<p>Minor. I was involved in developing the methodology and making revisions and comments on the article.</p>	<p>The lead author is based in USA but I was employed in Plymouth University working on the project with them.</p>

Abstract

Systematic reviews - appraisal and synthesis of all primary research - are increasingly being used to inform policy and practice in health care. Therefore, it is important to understand how the key questions in systematic reviews are identified and prioritised and whether they are relevant to policy makers, practitioners and members of the public. Research priority setting (RPS) is usually defined as any interpersonal activity that leads to the selection of topics and/or choices of key questions to investigate¹. Diverse approaches to setting research priorities are used in different countries, regions and organisations. There is no consensus in the literature on the most effective processes with which to set these priorities. However, these decisions define the quality and implications of the evidence, and syntheses of it, available to patients, public and policy makers to help them make informed decisions.

My initial scoping work, was to design and conduct a survey across an influential international systematic review organisation (Cochrane Collaboration²) on how they set priorities for their reviews. We identified 13 structured approaches to setting priorities. As part of the project, we developed an evaluation framework that demonstrated whether the priority setting processes meet the values and principles of the Cochrane Collaboration. Subsequently, we developed an equity lens for research priority setting exercises to inform the design of research priority setting processes to ensure that they consider the priorities of disadvantaged groups along with advantaged groups. We used the equity lens to do a second evaluation on the priority setting processes in the Cochrane Collaboration. Both evaluation frameworks demonstrated that the Cochrane Collaboration requires better designed priority setting approaches and must be more transparent in reporting those processes.

The evaluation of research priority setting exercises in the Cochrane Collaboration, along with the wider literature, demonstrates that research priority setting exercises cannot be evaluated in isolation from organisational cultures, values and context. Therefore, the next step of the project focused on a specific stakeholder group (major research funders) with significant influence on research, including support for systematic reviews. We selected 11 national research agencies in the UK, Netherlands, France, Norway, Denmark, Germany, Australia, Canada, and the USA. We devised and used a checklist based on Chalmers and Glasziou's "avoidable research waste" framework (and evaluated the processes and policies of these agencies using this checklist). As

¹ There is no currently agreed definition for research priority setting. This is the definition that we developed in a discussion with experts in research priority setting in the Cochrane priority setting methods group

² The organisation was originally called Cochrane Collaboration (and still is its legal name) but it was later rebranded (January 2015) as Cochrane. I used the term Cochrane Collaboration throughout this document

previous evaluations had demonstrated, this second evaluation found a lack of transparency in the process of setting priorities for research and other related organisational and policy issues.

Increased funding is needed for methodological research to evaluate research practices and to monitor how funding research projects is done and reported.

My evaluation of funding agencies and the Cochrane Collaboration found a similar lack of transparency and accountability in the context of conflicting values among stakeholders that decreases accountability and scrutiny of researchers and their institutions. However, the projects have led to organisational and policy changes in the two key stakeholder groups (the Cochrane Collaboration and selected funding agencies). Officials of national health research funding agencies have approached me to collaborate with them to address the issues raised by my work on reducing research waste. This led to the establishment of Funders Forum - the Ensuring Value in Research (EViR) Funders' Collaboration and Development Forum - to enable agencies in various countries to exchange their experience in addressing issues and creating work groups to address them. The Forum is chaired by individuals from three major research funders: NIHR (UK), ZonMW (Netherlands) and Patient-Centered Outcomes Research Institute (PCORI; USA). The Forum organises several meetings to establish common principles, standards and work plans to achieve the common objective around reducing research waste and adding value for research for a national research funder.

Executive Summary³

This summary is an overview of the research projects and subsequent publications which comprise this dissertation. It identifies the stakeholders who participated in these projects, and it summarizes the history, objectives, methodology, results, and implications for policy and practice of each project.

Research priority setting is generally a group activity that leads to decisions about topics and key questions to investigate in research projects, so we need to understand how, why and by whom such priority setting decisions are made. My projects document the characteristics and limitations of the research priority setting processes in selected key organisations, and how research priority setting relates to the allocation of resources in these organisations. The projects demonstrated that lack of transparency and accountability was a key problem across most of these organisations. Conflicting views, values and principles among those involved in these processes is a significant cause of this problem. My principal recommendation is that organisations that set priorities for systematic reviews should improve how they integrate the diversity of these views and values in their processes and structures.

The projects which were the basis of each publication in this dissertation involved two groups of stakeholders: 1) members of formally organized research groups within the Cochrane Collaboration; and 2) officials in public national agencies funding health research in Europe, North America, and Australia. This first group of projects evaluated the processes for allocating resources to particular topics of research in the Cochrane Collaboration; the second group assessed analogous processes in research agencies in 11 countries. In studying both groups, I considered financial and/or nonfinancial resources allocated to research topics and projects.

The Cochrane Collaboration groups were an appropriate set of stakeholders. The work of Cochrane groups and the overall organisation has been increasingly influential in decisions about policy and practice for patient care and public health around the world. It also has an important role in the history of systematic reviews. Priorities set by members of the Cochrane Collaboration define what new and updated systematic reviews are available to inform decision making by policy makers, clinicians and, increasingly, by patients.

We also selected major funding agencies in particular countries because, in addition to determining what systematic reviews will be available, these agencies also fund primary research, which provide the data for new and updated systematic reviews. We selected agencies in Europe, Australia and

³ The structure of the PhD in the Plymouth University guidelines for PhD by published work does not require an executive summary. However, I added one to facilitate navigating through the different sections of the dissertation.

North America as a diverse range of major funders. We decided not to include funders based in developing countries in this project as their social, economic and cultural context is different.

The dissertation has five chapters. Chapter 1 summarizes a growing literature about the history of systematic reviews as a product of evidence-based health research; the state of the methodology for research priority setting when the projects in this dissertation began; and the history of each project. Chapter 2-4 presents the research publications which are the subjects of this dissertation. These include four key publications (1-4) based on the major research projects in which I was involved, nine related publications (5-13) grounded in my research, and one conference presentation (14). Chapter 5 summarises the methods, findings, and practical results and implications of these publications. There are four appendices: appendix 1 explains selected research output relevant to this project, appendix 2 is an overview of reviews on research priority setting strategies and appendix 3 is an introduction to research priority setting for research groups in the Cochrane Collaboration. Finally, appendix 4 outlines a guide for using the equity lens to develop priority setting exercises for Cochrane Review Groups.

With regard specifically to the published works, Chapter 2 starts with two commentaries that set the context for the publications in Chapter 3. The first commentary provides an overview of the Cochrane Collaboration and its history, a summary of methods used in research priority setting, and limitations and gaps in the literature that led my colleagues and me to generate recommendations for the Collaboration and other organisations (15). The chapter then presents case studies from inside and outside the Cochrane Collaboration on incorporating the views of disadvantaged groups in the process of research priority setting and setting a research agenda for public health interventions. These exposed differences between issues raised by patients and clinicians than those than prioritized by research (8, 16).

Chapter 3 includes my work describing and evaluating the research priority setting processes in the Cochrane Collaboration. The chapter has two sub-sections: (a) evaluating the priority setting process in the Cochrane Collaboration and (b) assessing the results of priority setting by the Cochrane Collaboration in the context of priorities identified by the authors of the Global Burden of Disease. The projects included in part (a) were initiated with a small research grant from the Cochrane Collaboration, and a small grant from Plymouth University enabled me to organise a priority setting meeting in Plymouth (17). The first project started in 2008 and involved designing a survey and conceptual framework to evaluate the research priority setting processes in the Cochrane Collaboration. I adapted this conceptual framework to take account of the principles and values of the Cochrane Collaboration (2). As part of the first project, I organised several workshops and meetings to discuss its results. Participants in these workshops and meetings suggested more

detailed guidance on how priority setting processes within Cochrane could be designed to reduce health inequalities. Prompted by this suggestion, my next project (1) developed a tool to select, interpret and use data that could inform efforts to reduce inequality in health care. I called this tool an “equity lens” because it provides a more systematic approach to prioritising topics with a view to reducing inequity in health. The development of the lens was based on consultation workshops, literature reviews, and the experience of using two previously developed tools (18, 19).

Since the start of the project in 2008, there has been a sharp increase in the number of studies discussing or exploring the issue of priority setting for systematic reviews in Cochrane and other organisations across the world. This increase is likely a result of the struggle that many organisations that conduct or sponsor systematic reviews face because of increased demand for reviews to inform decisions in health care. The increasing volume of published primary clinical research also intensifies the challenge of keeping systematic reviews up to date. The proliferation of reviews and primary research led me to participate in designing and conducting a survey (9) about the challenges that Cochrane groups face in conducting priority setting exercises. Problems highlighted by the results of this survey included “balancing workload”, “allocating time to conduct or implement priority setting exercises”, “resource allocation”, “translating priorities into research questions appropriate for Cochrane Reviews”, and “engaging with stakeholders”.

Section b in chapter 3 presents a series of papers which emerged from a project titled “Mapping Cochrane to the Global Burden of Disease” (7, 10-14). Some Cochrane groups had considered the burden of disease in their priority setting process (or thought they should). However, no high-quality data were available to analyse how well the Cochrane Library took account of the global burden of disease. I am not suggesting that global burden of disease should be the only factor to inform the research priority setting process, but rather that, if data about the burden are used in setting priorities, it should be data of high quality. I was involved in mapping the following topic areas: skin diseases (10), otolaryngeal diseases (13), injuries (11), neglected tropical diseases (7), and oral health (14). Here are some examples of the gaps that we identified: edentulous diseases had a higher percentage of total 2010 Disability-Adjusted Life Years (DALY) compared to periodontal diseases, but they are less frequently addressed in the Cochrane Database of Systematic Reviews (11 versus 13 reviews)(14). Similarly, skin diseases including acne vulgaris, bacterial skin diseases, urticaria, pruritus, scabies, cellulitis, and alopecia areata were underrepresented in the Cochrane Database of Systematic Reviews compared to corresponding disability-adjusted life years (DALY) (10). My role in most of the Global Burden of disease projects was limited but it demonstrates the whole picture of my research in this field.

In chapter 4, I focused on major funders of health research, another major group of stakeholders. These funders prioritise and then finance systematic reviews and/or primary studies that could inform future new or updated systematic reviews. This research sought overall evaluation of the structures and processes of research priority setting and then funding processes (3, 20) by 11 national research agencies in the UK, Netherlands, France, Norway, Denmark, Germany, Australia, Canada and the USA. We devised and used a checklist based on the Avoidable Research Waste framework (21-27). The final section of this chapter is a commentary that addresses a key issue for funding agencies: how systematic reviews could inform future research (6). The commentary also provides further information of whether and how the prioritisation of primary research and prioritisation of systematic reviews are correlated.

These projects have led to organisational and policy changes in the two key stakeholder groups (the Cochrane Collaboration and selected funding agencies). The results of my research stimulated the development of a new Methods Group within the Cochrane Collaboration and formed the basis for guidance for research groups within the Cochrane Collaboration, thus impacting over 100 such groups around the world. The Collaboration leadership recognized the importance of this research by awarding us the Bill Silverman Prize in 2012. Dame Sally Davies (Chief Medical Officer of NHS England) praised our work at the UK and Ireland Cochrane Contributors meeting in March 2013. She highlighted the work as a key development that ensures that Cochrane Reviews are relevant to the needs of the NHS. Moreover, research groups inside and outside the Cochrane Collaboration have used my publications to inform their own research priority setting processes. Officials of national health research funding agencies have approached me to collaborate with them to address the issues raised by my work on reducing research waste. For instance, the National Institute for Health Research (NIHR) invited me to several meetings with other funders to address the issues that the project has raised. In May 2016, ZonMW (a key health research funder in The Netherlands) and the French Ministry of Health attended a funders' meeting as part of the NIHR 10-year anniversary in London. This meeting led to the establishment of a Funders Forum to enable agencies in various countries to exchange their experience in addressing issues and creating work groups to address them. The Forum had its first meeting on 27 January 2017 in London. It was chaired by individuals from three major research funders: NIHR (UK), ZonMW (Netherlands) and Patient-Centered Outcomes Research Institute (PCORI; USA).

As I have noted above, a key problem across most of these organisations is a lack of transparency and accountability that obscures the extent to which their priority setting processes achieve their goals and targets. A good example is the current situation in the Cochrane Collaboration. Following publications by me and others and the work of the Cochrane Priority Setting Methods Group, the

governing board of the Cochrane Collaboration announced a policy requiring all review groups to set priorities for topics of systematic reviews. However, it became clear over time that these groups have different agendas and goals and opinions about what is best for the Cochrane Collaboration overall. I am currently helping to organise a leaders' meeting to address these issues. My evaluation of funding agencies found a similar lack of clarity, transparency and accountability in the context of conflicting values among stakeholders.

Chapter 1 Critical appraisal

This chapter starts with a brief history of systematic reviews followed by a description of the concept of research priority setting and a categorization of processes for conducting it. Next, I describe events and discussions that led to each project reported in the publications in this dissertation, including a review of the literature available when these projects were designed and implemented. I summarize the findings of each project and their implications in chapter 5.

In 1753, James Lind described a critical and chronological view of what had been published on scurvy before designing and conducting a new clinical trial – an early example of a systematic review. In 1904, Karl Pearson used statistical techniques to synthesize the data across clinical trials to introduce scientific rigour to evidence synthesis. Pearson used the methods presented by George Biddell Airy in his textbook to statistically summarise the results from different studies that has been previously used in astronomy (28),(29, 30). Karl Pearson used these methods to analyse data comparing infection and mortality among soldiers who had volunteered for inoculation against typhoid fever in various places across the British Empire compared to other soldiers who had not volunteered. As part of this evaluation, he was specifically thorough in evaluating the consistency and irregularity across individual results and keen to discover clues for future research based on this. In the early 1970s, there were examples of collaborative overviews where researchers shared their data to reduce waste and enhance progress. Towards the end of the 1970s, there was a call for evidence by Archie Cochrane “It is surely a great criticism of our profession that we have no organised a critical summary, by speciality or sub-speciality, adapted periodically, of all relevant randomised controlled trials”. A few years later, the international Cochrane Collaboration was established in 1992. The Cochrane Collaboration set itself a goal to help people make well-informed decisions about healthcare by preparing, maintaining and promoting the accessibility of systematic reviews of effects of health care interventions. During the following years, most researchers and organisations around the world began to conduct systematic reviews. These systematic reviews are increasingly used to inform healthcare, health services and policy making decisions (30).

International discourse about using systematic reviews to inform policy and practice for health care, public health, and clinical practice started in the 1980s with consensus development conferences in the UK and US. Systematic reviews were reported in a wide variety of fields, but particularly in cancer, cardiovascular disease, and care during pregnancy, childbirth and early infancy (30). Since then, systematic reviews have increasingly become central in conversations that shape policy. These conversations take account of the effectiveness of drug and non-drug clinical interventions, including interventions that address care processes and service configurations, education, poverty, the socioeconomic determinants of health, and environmental influences on health (31). As

systematic reviews have increasingly informed policy and practice, it has become more important that the key questions they address are relevant to policy makers, practitioners and the public.

In a growing number of countries including the United Kingdom, Germany, and the USA, systematic reviews are informing policy decisions about reimbursing drugs, shaping clinical guidelines, and organizing health programmes (32). Many of these reviews are commissioned by policy making organisations, which vary in the extent to which they engage with other health care stakeholders (e.g. patients and clinicians) in setting priorities.

What is Research Priority Setting?

Research priority setting (RPS) is usually defined as any interpersonal activity that leads to the selection of topics and/or choices of key questions to investigate⁴. Diverse approaches to setting research priorities are used internationally. There is no consensus in the literature on the most effective processes with which to set these priorities. We provided an overview of different steps involved in research priority setting exercises in one of our publications (1). A refined version of it is available in Figure 1 - Steps in involving the preparation, conduct and implementation of research priority setting exercises. I further evaluated the critical reviews on research priority setting that are available in **Appendix 2** –An overview of reviews on priority setting strategies.

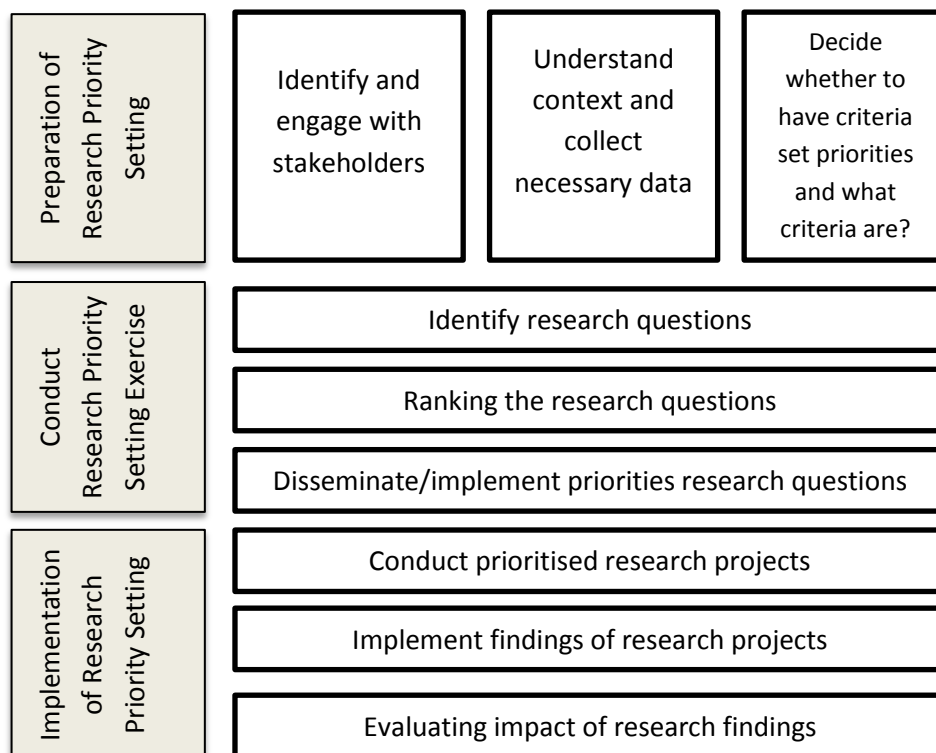


Figure 1 - Steps in involving the preparation, conduct and implementation of research priority setting exercises

⁴ There is no currently agreed definition for research priority setting. This is the definition that we developed in a discussion with experts in research priority setting in the Cochrane priority setting methods group

Policy makers for research, particularly organisations, categorize RPS in different ways. Some research managers categorise RPS exercises as retrospective and/or future-oriented, focusing on current uncertainties or problems existing in society with the long-range goal of benefitting policy and practice in the future. Other managers categorise RPS mainly as the application of technical or interpretive/consultative methods to identify data and encourage stakeholder involvement in participating in reviews and/or using findings from them to inform policy and practice (33, 34). However, research priority setting exercises do not always clearly belong to one category. For instance, research priority setting exercises that emphasize involving stakeholders still use data to inform the decision-making process. In those that are predominately data driven (e.g. that emphasize the value of information analysis), people make value-driven assumptions in interpreting the data to inform the decision making.

People who study or conduct research prioritisation frequently fail to report in adequate detail how the value judgements of individual stakeholders affect the interpretation and use of data in the process. For example, the US National Academy of Medicine Committee on Health Care Technology recommends collecting or estimating “*data for the prevalence of specific conditions, the unit cost of the relevant technology, various uses of the technology, the burden of illness addressed by the technology, and the potential of the results of technology assessments to affect health outcomes and costs*” (35). The difficulty with this approach is that the collection, analysis and presentation of data are buried under layers of assumptions and value judgements that may not account fully for the values and perceptions of different stakeholders affected by the process. This variation can justify different decisions about collecting or analysing data. For example, different approaches to defining the burden of illness can lead to different decisions on research priorities (33, 36).

Beyond the methods used in the research priority setting exercises, the social and political environment surrounding these exercises and the skills and experience of the individuals involved in the process affect their performance. RPS invariably occurs in particular contexts, i.e. the political, organisational, financial and legal environments. Moreover, most of the skills required to conduct these exercises are broadly technical, such as managing information. However, interpersonal skills, including effective communication, relationship building with stakeholders, coordinating and chairing discussions, and the ability to analyse political situations in order to decide on appropriate strategies and tactics, are also crucial (5, 37, 38).

Here is an example of the complexity introduced by the organisational and political environment: in 2008, my colleagues and I attempted to find reviews and studies that present evidence about what makes a research priority setting exercise successful. It soon became clear to us that “success” is a vague phrase and its definition varies among the organisations and particular stakeholders involved in a research priority setting process (1, 2, 15).

Similarly, regarding building relationships with stakeholders, the James Lind Alliance (JLA) has raised issues about how to ensure inclusion of groups in the priority setting process and about the importance of facilitators in managing political conflict among different stakeholders. The JLA also raised issues about particular groups “not being involved” in research priority setting processes. For example, the JLA decided to do priority setting with patients and clinicians, involving researchers only as observers and policy makers as they already have substantial influence on research agendas(39). The issue of inclusion/exclusion of different groups has also arisen in other situations. For instance, a review of priority setting exercises in the Zambia engaged the issue of whether the involvement of global donors could skew research priorities away from local priorities (40).

In summary, the complexity of setting RPS methods and processes within their contexts presents a challenge to understanding and evaluating them. Organisational knowledge accrued from facilitating priority setting exercises in different locations and the experiential knowledge of individual participants in these processes are central to understanding and judging them.

Reviewing previous priority setting exercises has identified several uncertainties regarding the best methods for setting health research priorities and the need for more guidance on the process of setting research priorities in health care (15, 41). Research priority setting can be technical (e.g., using economic analysis) or interpretive (e.g., with stakeholder involvement). Montorzi et al. further categorized research priority setting exercises as those focusing on existing data sets like burden of disease and others that focus on what questions would be important for future research (foresighting approaches) such as horizon scanning (34). One issue that was widely discussed in the critical reviews was stakeholder involvement: who to involve in the process (should participants be funders, health professionals, researchers, or patients?) and how to involve them (42, 43). There have been concerns that social, political and power relations can inhibit certain stakeholders to engage productively in the process. Some strategies suggested to improve the stakeholder engagement process include using systematic approaches (e.g. Delphi consensus) and managing conflicts of interests in a more transparent way (44-48). Transparency was an issue that regularly arose in these reviews, such as transparency in reporting the criteria of priority setting or the quality and availability of data used to inform decision making (42, 45). Because I recognised that the published literature is limited by the publication choices of researchers, authors and editors,

we had discussions and workshops to identify other issues not covered in the current literature. These issues have been incorporated in the evaluation framework that was developed for Cochrane groups (1, 2, 15).

Research priority setting in the context of a systematic review organisation

Systematic reviews have been used to assist decision making by patients, clinicians, and policy makers. Some reviews are directly commissioned by policy making organisations, which may or may not engage with other stakeholders, such as patients and clinicians. Other systematic reviews are commissioned and/or conducted by research organisations that claim to be independent of policy makers.

The Cochrane Collaboration

The Cochrane Collaboration (www.cochrane.org) is one of the best-known and most influential research organisations in health care. It is a network of independent researchers, professionals, patients and carers who work together to produce and maintain systematic reviews that inform decision making in health care. Despite its reputation and impact, in 2008 (when the project to study research priority setting began), its leaders had scant formal knowledge about how internal decisions were made about which questions are most worth addressing through Cochrane Reviews and when reviews should be updated. The Cochrane Collaboration employs staff to assist the volunteers in these groups. The Cochrane Policy Manual also highlights the qualifications and characteristics of authors:

“Whilst enthusiasm and time are the first essential qualities in an author, each needs to combine knowledge about the topic in which s/he is interested with a willingness to apply methodological rigour to the review process. This combination of qualities rarely exists within a single individual. More often, it will be necessary to arrange author partnerships, to try to ensure that content and methodological expertise is both applied in preparing reviews. Such partnerships are generally preferable to working alone, even when both partners possess both types of expertise, to ensure the reproducibility of the judgements that are necessary in preparing reviews. One author will sometimes miss something that the other will pick up. It is also very likely that they will complement each other in various ways, and it is often more fun to work with someone else⁵.”

My conversations with members of the Collaboration demonstrated that author teams don't always meet the published criteria. Researchers who have been involved with the Cochrane Collaboration since its inception told me that the model in the policy manual was grounded in the assumption that clinicians would voluntarily bring their questions and uncertainties to the

⁵ This is an extract from a Cochrane Collaboration organisational manual that was decommissioned in December 2016 (after the study was conducted). There will be an updated version available in future. However, the old manual is no longer available.

Cochrane Collaboration and that its central staff would help them address these concerns. As a member of the Collaboration since 2006 (in several volunteer leadership or executive roles) and a trustee from 2011 (my term as a trustee will end in 2017), I observed that Cochrane groups are strongly committed to the central values and principles of the Collaboration which include building on the enthusiasm of individuals, collaboration and enabling wide participation(49). When I joined the Collaboration, Cochrane groups were following an unwritten policy (driven by the principles of the Collaboration) to help and engage with any volunteer reviewer in conducting systematic reviews. These volunteer reviewers might have limited knowledge of systematic reviews, difficulty writing scientific articles or difficulty in communicating and writing in English. The review groups might reject a request to do a review if the question was already addressed by a review in the Cochrane Library or seemed inappropriate. However, there were wide variations in how these decisions were made. I have heard and seen that review groups struggled with workload but were worried that rejecting an author violates the fundamental values of the collaboration to be inclusive and collaborative. Moreover, Cochrane groups have a variety of funding sources that include government agencies, universities, hospital trusts, charities, and personal donations. Consequently, they are required (sometimes implicitly, sometimes explicitly) to take account of the priorities of their funders as well as the values and expectations of the larger Cochrane Collaboration.

These tensions led, in October 2011, to approval by the Cochrane Board of Trustees of a policy requiring minimum competence of authors of reviews(50). This policy stimulated a gradual cultural change in which Cochrane Review Groups asserted greater leadership in making decisions about which topics are relevant and should have priority in their field and evaluating the competencies of the author team.

In 2007, the Collaboration's Board of Trustees established the Prioritisation Fund, a one-off call for proposals to suggest mechanisms for increasing the relevance of Cochrane Reviews (another principle of the Collaboration). A year later, the US Cochrane Centre organized a conference on priority setting in systematic reviews (51). I was part of a team led by Peter Tugwell of Canada that received a grant from Cochrane to examine priorities of low and middle income countries for review topics (I was at that time the coordinator of the Cochrane Developing Countries Network, a position I left at the end of 2008)⁶. As coordinator, I led a survey in 2008 (2) of the processes for setting priorities for Cochrane Reviews. To conduct the survey, I contacted two key types of Cochrane groups: the Review Groups, which are the central editorial units for different areas of

⁶ Afterwards, it became a Cochrane field (i.e. a thematic network) and was later eliminated. The initiative was replaced by a wider one called Global Evidence Synthesis that Cochrane is a partner of it.

health problem which decide topics for Cochrane Reviews; and Fields/Networks, which support review groups to include cross-cutting themes (such as children or the elderly) in their portfolios.

Evaluation of priority setting processes in Cochrane:

To conduct the survey and evaluate responses, we needed a framework to evaluate the priority setting processes in the Cochrane Collaboration. In 2008, there were no frameworks to evaluate success or accountability in research priority setting exercises. We looked at models and frameworks used in setting health priorities in the health sector and consulted experts in the field of health research priority setting. In 1997, Norman Daniels of Harvard University had raised questions about the fairness and legitimacy of decisions about which health services are prioritised and funded. Daniels proposed a framework called Accountability of Reasonableness to address these issues (2, 52). This framework has been widely used in evaluating health service priority setting processes in various geographical settings (53-56). We selected it as one of the models to inform our evaluation.

In 2009, Shannon Sibbald conducted Delphi exercises with scholars in the field of priority setting as well as decision makers from health systems in five countries and interviews with patients/health system users, and a focus group of public policy makers to develop a conceptual framework for evaluating “success” in priority setting (57). This framework had some overlap with the Accountability for Reasonableness framework. We discussed how these frameworks related to the values and principles of the Collaboration and developed criteria to evaluate processes in the Collaboration (2).

At several stages of the project, we discussed emerging results with Cochrane contributors to learn whether we missed any priority setting exercises (or misinterpreted them), whether we missed key elements in evaluating the priority setting processes, and sought feedback on how to address the issues identified in responses to the survey. We then presented the results of the survey in a workshop at the annual Cochrane Colloquium in 2008, using only Daniels’ Accountability of Reasonableness framework. The workshop demonstrated that many Cochrane groups were unfamiliar with the literature on methods for setting priorities(58). This recognition led to an exploratory meeting at the next colloquium about whether to establish a new methods group on priority setting within Cochrane. Leaders of several Cochrane groups, authors and external partners who attended the meeting identified challenges that the proposed methods group could address (58). These challenges included “dealing with health inequalities in developing and conducting priority setting”.

Equity Lens for setting priorities in research

After several workshops/discussion forums about the Cochrane survey results, my colleagues and I recognized a need to improve the process of agenda setting and priority setting for Cochrane Reviews to ensure transparency and inclusiveness and to consider health equity. That is, we wished to identify and prioritise systematic reviews of interventions that could potentially reduce inequity by addressing the effectiveness of interventions that are particularly relevant to disadvantaged groups.

The need to consider inequity in setting priorities for systematic reviews and primary research has been considered outside the Cochrane Collaboration. The Child Health and Nutrition Research Initiative (CHNRI) expressed concerns that allocation of investment in certain research topics can increase health inequity (59). In 2005, a group at the South African Cochrane Centre conducted a study that identified that systematic reviews more often address health problems that are priorities in high-income countries (HICs), while neglecting problems in low- and middle-income countries (LMICs) (60, 61). A paper by Ortiz in 2007 (62) described the Cochrane Developing Countries Initiative, which Zulma Ortiz and I co-chaired, and criticized the lack of relevance of Cochrane Reviews to developing countries. The Cochrane Developing Countries Network has since evolved into the Global Evidence Synthesis initiative (63) hosted by the American University of Beirut with a central focus on capacity building for research synthesis worldwide. Several efforts have been initiated to develop equity-oriented priority setting strategies (62, 64). For example, a recent paper highlighted the importance of increasing non-elite stakeholders' participation in promoting health equity in national health research priority setting (65). There is still considerable room for improvement, however, particularly considering the limited resources available in low and middle-income countries.

As an international organisation, the Cochrane Collaboration is committed to ensuring that questions relevant to disadvantaged groups or issues relevant to reducing health inequality are addressed in systematic reviews. To address this issue, I conducted a review of the literature about current tools and conceptual frameworks for exploring equity in setting priorities for research, and we facilitated discussion sessions on this topic. This work resulted in a new tool (called the Equity Lens for Research Priority Setting). This tool has been piloted in evaluating priority setting processes within Cochrane (1) and in shaping suggestions and recommendations for improvement (8).

Challenges that the Cochrane Collaboration faces in setting priorities

Since the start of my project in 2008, there has been a sharp increase in the number of studies discussing or exploring the issue of priority setting of systematic reviews in the Cochrane

Collaboration and other organisations across the world. The increase is mainly a response to the struggle faced by many organisations that fund and conduct systematic reviews because of increased demand for systematic reviews to inform decisions in health care. In addition, the increasing volume of published primary clinical research intensifies the challenge of keeping systematic reviews up to date. Two issues constrain the development and implementation of priorities: (a) many, perhaps most, systematic reviews (and the research studies that are the data for reviews) are not conducted, driven or shaped by systematic prioritisation exercises involving policy makers, practitioners and patients; and (b) systematic reviewers may change questions derived from priority setting exercises by stakeholders before conducting reviews.

Following my study evaluating priority setting processes in the Cochrane Collaboration, increasing numbers of Cochrane groups conducted priority setting exercises. I did a survey of the challenges the groups faced in conducting these exercises (9). The response rate was low but the results were consistent with my informal discussions with the facilitators of other groups like the James Lind Alliance (an organisation that conducts research priority setting exercises with patients, carers and clinicians). Five broad themes emerged across the responses: (a) achieving balance in workload and time allocation across different reviews; (b) securing adequate time to conduct or implement priority setting exercises; (c) allocating resources to priority setting exercises and their results; (d) translating priorities into research questions appropriate for Cochrane Reviews; and (e) engaging with stakeholders.

Stakeholder engagement is the most commonly reported of these challenges in conducting priority setting exercises. The issues involved in stakeholder engagement include their understanding the concept of research prioritisation; the needs of particular categories of stakeholder; equitable involvement of the range of stakeholder groups; the composition of stakeholder groups (who is involved in these groups and what their background is); and maintaining engagement.

One of the greatest challenges was how to translate a question from the priority setting exercise to an answerable question in systematic reviews. This problem might have derived from changes in how Cochrane groups set priorities. Historically, topics for Cochrane Reviews were suggested by a volunteer author who used a standard template for setting key questions. Systematic review methods guidance/handbooks describe this template with the acronym PICO: Population, Intervention, Comparison and Outcome (66). Issues around setting and context are conventionally considered under Population and timing (how the intervention is implemented or when the outcome is measured) is considered under Intervention, Comparison and Outcome. The questions developed using the PICO template, however, are not necessarily compatible with how stakeholders conceptualize their priorities and questions. When reviewers attempt to translate

priorities for systematic review topics into a key question for a particular review, they can, inadvertently or not, modify the problem that made the review a priority. The problem of translating research priorities into answerable questions for systematic reviews has been increasingly recognized by systematic review organisations because they have to work with policy makers and other stakeholders. The selection of the key question for a review in these organisations is usually the product of negotiations between reviewers and stakeholders. This might be one reason that sometimes a similar policy priority e.g. effectiveness of HPV vaccination might lead to a variety of key questions generated by PICO analysis in different systematic reviews conducted by different national organisations. Policy makers might suggest that a new systematic review needs to have high priority because existing reviews do not address the key policy questions that they want to address (this might be policy makers wanting a review that clearly focuses on issues in their country). Sometimes, the structure of priority setting for a review or a key question might be solely driven by the policy agenda. For example, if care of the elderly becomes a strategic priority, policy makers might insist on a review focusing on this population even if reviewers or clinical trialists do not agree that these groups respond to the intervention differently from the average adult.

The problems in the prioritisation, production and publication of systematic reviews

The publication of systematic reviews and meta-analyses has increased rapidly in recent years. Unfortunately, this increased production of systematic reviews causes problems e.g. conflicting findings in systematic reviews in the literature or selective use of data retrospectively to fit the expectations of the editors and reviewers. Moreover, many published reviews do not add significantly to the literature and thus waste resources. For example, a systematic review might be repeated to ensure that it reaches a more favourable conclusion and become a marketing tool by the pharmaceutical industry (31, 67-70).

Despite issues about the production and publication of systematic reviews, they increasingly inform policy makers and clinicians. More policy makers and clinicians have acquired knowledge and skills to understand the methods and uses of systematic reviews. Because of increased use of systematic reviews, the integrity of processes to prioritize and conduct them is critical. To ensure the process is not corrupted and biased, several policy-level initiatives should be established. Examples of these initiatives are: (a) policy makers being more involved in setting priorities for the topics and key questions that systematic reviews address; (b) organisations that train health professionals ensuring that appraisal and interpretation of systematic reviews is covered in the educational curriculum; (c) funding only primary research supported by reference to systematic reviews of existing evidence (31).

I have demonstrated that the process of prioritizing systematic reviews cannot be independent of processes for addressing other organisational and structural issues. Therefore, the next study in which I participated focused on research funding agencies. I evaluated their priority setting process and the wider issue of how their processes relate to a recently published framework to “reduce research waste”.

Reducing research waste initiative and health care research funding agencies

In January 2014, the Lancet published a series of articles on increasing value and reducing waste in biomedical research (22-24, 26). The series pointed out potential sources of waste related to five main questions:

- (i) Are the questions addressed relevant to users of research?
- (ii) Is the research design, conduct and analysis appropriate?
- (iii) Is research regulation and management efficient?
- (iv) Are full reports of the research accessible?
- (v) Are the reports of research usable and unbiased?

The Lancet series began by addressing the waste of resources resulting from decisions about what research to conduct. Research waste was defined in two ways in this series: 1) when the needs of potential users of research evidence are ignored; and 2) when what is already known or being researched is overlooked (71).

Before designing and implementing the project, I had several discussions with researchers around the world during workshops and panel discussions about what influences their decisions on selecting research questions. Two examples are a research priority setting workshop at Modena University (Italy) in 2013 and a panel discussion at the International Evidence Based Health-care Society conference in Kish (Iran) in 2016.

(A) In 2013, during a workshop on research priority setting that I led at Modena University (as part of a MSc programme), I asked the participants how they select the research projects that they conduct. Some said that they make decisions based on funding availability, while others highlighted that they are following research agendas set by their supervisors. Some also said that they researched topics relevant for patient care.

(B) In December 2016, there was a discussion panel on reducing research waste at the International Evidence based Health-care Society conference in Kish (Iran). An issue raised was that a substantial number of research funders and managers invest heavily in funding stem cell research and biotechnology. These investments produce publications in high impact factor journals without addressing fundamental public health problems in Iran. The research managers conduct these types of research to increase the reputation of

universities in Iran and to obtain more international acceptance for Iranian science and scientists.

These two examples of the complexity of decisions about priorities demonstrate that decisions on setting priorities are related to wider issues of social, political, culture, and organisational structures. They highlight the importance of understanding the role of each stakeholder in the research system along with the internal complexity of each organisation. This can help us to understand the drivers of setting priorities.

Therefore, I accord attention in the articles that comprise this dissertation to national and international health-related research funders. Research funders have a lot of control over decisions about priorities, especially in countries where researchers must apply for funding and reappointment or promotion are dependent on being awarded grants. Although research funders are my focus in this project, I recognise that many researchers are employed by universities and that universities influence research priorities by funding salaries for both faculty and staff and providing space. However, the role of universities in setting priorities is beyond the scope of the current project.

For the publications included in this dissertation, I evaluated the work of research funders, examining different aspects of their efforts to reduce research waste rather than focusing on priority setting. Focusing on reducing waste increased the interest of funding agencies in the project and their responsiveness to the questions put to them. Of 11 national research funding agencies, of varying sizes, in Europe, North America and Australia, all but one responded to our questions. Table 2 provides an overview of the funding available of some of the funding agencies that we looked at in our project, based on a publication by Viergever et al (72).

The results of this project were published and presented in several journals and forums. I published the summary and preliminary results of an assessment of the policies and processes of six research funders as part of a Lancet paper (3). The full data are published in another Lancet publication (20). I presented the initial results of my study at the Evidence Based Research Network Conference in Bergen, Norway in December 2014, and further results at the REWARD/EQUATOR conference in Edinburgh, Scotland in October 2015. The National Institute for Health Research (NIHR) invited me in November 2015 to present the results in a meeting with ZonMW (a key health research funder in The Netherlands) and the French Ministry of Health to discuss how we can address the issues that the project had raised. The project was also presented at the Cochrane Colloquium (October 2015) in Vienna, both as an oral presentation and as a special session I led on using systematic reviews to inform future research. Both events generated much interest and prompted me to look in depth at how research funders are (or should be) using systematic reviews in the process of informing

primary research. I was subsequently invited to present the data at an event celebrating NIHR's 10-year anniversary in London in May 2016, which engaged major funders nationally and internationally. Discussions during this meeting led to the proposal of a forum for funders. This forum is addressing some of the issues raised by our evaluation. The Funder's Forum is enabling funding agencies to share their experiences addressing issues and create working groups to address them. The Forum had its first meeting on 27 January 2017 in London and it was chaired by individuals from three major research funders: NIHR (UK), ZonMW (Netherlands) and Patient-Centered Outcomes Research Institute (PCORI – USA). The second meeting was organised in Amsterdam on 1 June 2017 hosted by ZonMW in Utrecht (Netherlands). The third meeting was in Washington (USA) hosted by PCROI in Nov 2017.

Table 2 - Annual health research expenditures of selected major public and philanthropic funders of health research – reproduced partially from Viergever 2016 (72)

Public and philanthropic health research funding organisations	Country	Type of funding organisation	Year for which funding data were collected	Total health research expenditures (in million 2013 US \$)
National Institutes of Health (NIH)	USA	Public	2013	26,081.3
UK Medical Research Council (MRC)	UK	Public	2013	1,321.5
Canadian Institutes of Health Research (CIHR)	Canada	Public	2012	883.6
Australian National Health and Medical Research Council (NHMRC)	Australia	Public	2013	777.6
Deutsche Forschungsgemeinschaft / German Research Foundation (DFG)	Germany	Public	2012	630.6
UK Department of Health / National Institute for Health Research (NIHR)	UK	Public	2012	491.2
ZonMw / Netherlands Organisation for Health Research and Development	Netherlands	Public	2012	172.7

The next three chapters are published papers of the projects that I have outlined in Chapter One. Chapter Two is a review of methods to set priorities for systematic reviews. Chapter Three addresses drivers in setting priorities for systematic reviews in a systematic review organisation. This chapter has two sections: 1) evaluating the priority setting processes in the Cochrane Collaboration; and 2) comparing the content of the Cochrane Database of Systematic Reviews with the Global Burden of Disease to guide future priority setting processes. Chapter Four is an evaluation of the process of allocating funding to research projects in key national funding agencies. Finally, Chapter Five provides a summary of the projects.

Chapters 2-4 have been removed due to copy right restrictions

Chapter 2 – Published work - Review of methods to set priorities for systematic reviews

- a) **Nasser M**, Welch V, Ueffing E, Crowe S, Oliver S, Carlo R. Evidence in agenda setting: new directions for the Cochrane Collaboration. J Clin Epidemiol. 2013 May;66(5):469-71.
DOI: 10.1016/j.jclinepi.2012.08.006
- b) Bhaumik S, Rana S, Karimkhani C, Welch V, Armstrong R, Pottie K, Dellavalle R, Dhakal P, Oliver S, Francis DK, **Nasser M**, Crowe S, Aksut B, Amico RD. Ethics and equity in research priority-setting: stakeholder engagement and the needs of disadvantaged groups. Indian J Med Ethics. 2015 Mar 16;-(-):1-4.
DOI: 10.20529/IJME.2015.030
PEARL: <https://pearl.plymouth.ac.uk/handle/10026.1/9524>

Chapter 3 – Published work - Drivers in setting priorities for systematic reviews in a systematic review organisation

Evaluating the priority setting process in Cochrane

- a) **Nasser M**, Welch V, Tugwell P, Ueffing E, Doyle J, Waters E. Ensuring relevance for Cochrane reviews: evaluating processes and methods for prioritizing topics for Cochrane reviews. *J Clin Epidemiol*. 2013 May;66(5):474-82.
DOI: [10.1016/j.jclinepi.2012.01.001](https://doi.org/10.1016/j.jclinepi.2012.01.001)
- b) **Nasser M**, Ueffing E, Welch V, Tugwell P. An equity lens can ensure an equity-oriented approach to agenda setting and priority setting of Cochrane Reviews. *J Clin Epidemiol*. 2013 May;66(5):511-21.
DOI: [10.1016/j.jclinepi.2012.11.013](https://doi.org/10.1016/j.jclinepi.2012.11.013)
- c) Pooler J, **Nasser M**. Challenges in conducting priority-setting exercises for Cochrane entities. *Cochrane Methods Supplement* 2013. ISSN: 2044-4702.
Available at: <http://www.cochranelibrary.com/dotAsset/bcc67133-fbf0-47a4-8190-1e0c3a70ac2d.pdf>

Comparing the content of Cochrane with Global Burden of Disease to guide future priority setting processes

- d) Karimkhani C, Boyers LN, **Nasser M**, Dellavalle R. Mapping research prioritization by The Cochrane Collaboration to Global Burden of Disease 2010 data. *Cochrane Methods*. Issue September 2014.
Available at: <http://www.cochranelibrary.com/dotAsset/8df3b5a2-217a-41fd-ac77-9d8d05487970.pdf>
- e) Pederson H, Okland T, Boyers LN, Karimkhani C, Rosenfeld RM, **Nasser M**, Yoong SL, Wolfenden L, Kyu HH, Serina PT, Coggeshall M, Dellavalle RP. Identifying otolaryngology systematic review research gaps: comparing Global Burden of Disease 2010 results with Cochrane Database of Systematic Review content. *JAMA Otolaryngol Head Neck Surg*. 2015 Jan;141(1):67-72.
DOI: 10.1001/jamaoto.2014.2700
- f) Karimkhani C, Boyers LN, Prescott L, Welch V, Delamere FM, **Nasser M**, Zaveri A, Hay RJ, Vos T, Murray CJ, Margolis DJ, Hilton J, MacLehose H, Williams HC, Dellavalle RP. Global burden of skin disease as reflected in Cochrane Database of Systematic Reviews. *JAMA Dermatol*. 2014 Sep;150(9):945-51.
DOI: [10.1001/jamadermatol.2014.709](https://doi.org/10.1001/jamadermatol.2014.709)
- g) Bhaumik S, Karimkhani C, Czaja CA, Williams HC, Rani M, **Nasser M**, Boyers LN, Dmitruk S, Dellavalle RP. Identifying gaps in research prioritization: The global burden of neglected tropical diseases as reflected in the Cochrane database of systematic reviews. *J Family Med Prim Care*. 2015 Oct-Dec;4(4):507-13.
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DOI: [10.1016/j.injury.2015.12.019](https://doi.org/10.1016/j.injury.2015.12.019)

PEARL: <https://pearl.plymouth.ac.uk/handle/10026.1/9159>

- i) **Nasser M**, Karimkhani C, Dellavalle R. Global burden of oral and oropharyngeal diseases in 2010 as reflected in Cochrane Database of Systematic Reviews, BSODR, 14-16 Sep 2015. Cardiff, UK. (Conference presentation)

Chapter 4 – Published work - Evaluating the process of allocating funding to research projects in key national funding agencies

- a) Moher D, Glasziou P, Chalmers I, Nasser M, Bossuyt PM, Korevaar DA, Graham ID, Ravaut P, Boutron I. Increasing value and reducing waste in biomedical research: who's listening? Lancet. 2016 Apr 9;387(10027):1573-86.
DOI: [https://doi.org/10.1016/S0140-6736\(15\)00307-4](https://doi.org/10.1016/S0140-6736(15)00307-4)
PEARL: <https://pearl.plymouth.ac.uk/handle/10026.1/4917>
- b) Nasser M, Clarke M, Chalmers I, Brurberg KG, Nykvist H, Lund H, Glasziou P. What are funders doing to minimise waste in research? Lancet. 2017 Mar 11;389(10073):1006-1007.
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PEARL: <https://pearl.plymouth.ac.uk/handle/10026.1/9158>
- c) Nasser M, Welch V. Prioritization of systematic reviews leads prioritization of research gaps and needs. J Clin Epidemiol. 2013 May;66(5):522-3. (related editorial)
DOI: [10.1016/j.jclinepi.2012.09.007](https://doi.org/10.1016/j.jclinepi.2012.09.007)

Chapter 5 – General Discussion/Conclusion

This chapter covers the methods and results of each project included in this dissertation, describing the wider impact that these publications have had on practices within the research community. I apologize for repeating myself, which I do in some sections to remind readers about what was written in Chapter 1, usually at greater length.

Evaluating the process of setting priorities in the Cochrane Collaboration

Colleagues and I received a small grant in 2008 to study research priority setting processes in the Cochrane Collaboration. We began by searching for reviews of research priority setting processes (Appendix 2 –An overview of reviews on priority setting strategies). I documented a summary of the key issues raised in these reviews in the research priority setting section in Chapter 1, where I also described the values, principles and history of the Cochrane Collaboration.

Developing an evaluation framework and evaluating priority setting in the Cochrane Collaboration

Following the review of literature and the description of the context of the Cochrane Collaboration, I worked with my collaborators to develop a framework to evaluate research priority setting in the Cochrane Collaboration and in other organisations that conduct systematic reviews. We were particularly eager to ensure that the different elements of the framework related to the Cochrane Collaboration’s principles and values.

In 2008/2009, tools were available to evaluate decisions about setting priorities in health care but not for health care research specifically (2). Two conceptual frameworks informed the evaluation of health priority setting: the Sibbald et al., 2009 conceptual framework for successful priority setting, which considers values (57, 73); and the “Accountability for Reasonableness” framework, which addresses equity and fairness (74). We adapted these tools for research priority setting, incorporating the Cochrane Collaboration’s values and objectives with the results of published critical reviews of priority setting (15). Our tailored evaluation framework incorporated a checklist with nine themes that characterized “good” research priority setting exercises (10). Our framework also added more detailed instructions for judging how it could be applied by systematic review organisations. We used our evaluation framework to evaluate the Cochrane Collaboration processes as part of a survey across the Cochrane review groups and fields (Table 3; Table 4). Our evaluation focused on the process of research priority setting rather than outcome because we did not have sufficient data for a meaningful outcome evaluation.

Table 3 - The four conditions of “Accountability for Reasonableness”: reproduced from Martin 2003(74)

Relevance	<i>Rationales for priority setting decisions must rest on reasoning (evidence and principles) that “fair-minded” people can agree is relevant in the context. “Fair-minded” people seek to cooperate according to terms they can justify to each other; which narrows, though does not eliminate, the scope of controversy, which is then further narrowed by specifying that reasons must be relevant to the specific priority setting context.”</i>
Publicity	<i>“Priority setting decisions and their rationales must be publicly accessible. Justice cannot abide secrets where people’s well-being is concerned.”</i>
Appeals	<i>“There must be a mechanism for challenge, including the opportunity for revising decisions in light of considerations that stakeholders may raise.”</i>
Enforcement	<i>“There is either voluntary or public regulation of the process to ensure that the first three conditions are met.”</i>

Table 4 - Sibbald et al. (2009) (73) framework for a successful priority setting: process elements* as mapped to the Cochrane Collaboration. Reproduced from Nasser, M., et al. (2)

Process element	How it relates to Cochrane
Stakeholder engagement	The organisation, which in this study is the Collaboration, needs to identify the relevant internal and external stakeholders and ensure that these stakeholders are effectively involved in the priority setting through partnership and empowerment. <i>“Enabling wide participation”</i> is one of the principles of the Collaboration, and <i>“relevance”</i> cannot be achieved without knowing the preferences and interests of all stakeholders.
Use of explicit process	The Collaboration needs to ensure that the priority setting process is transparent to all stakeholders to enhance trust and confidence of the stakeholders in the process and the product. To achieve <i>“collaboration”</i> and <i>“wider participation”</i> in Cochrane and avoid duplication of effort, building trust and confidence is crucial.
Information management	This refers to the information that is collected and selected to make an informed decision during the priority setting possible. To ensure <i>relevance</i> , we need to have access to sufficient information and data on the need of the community, health status, current policies, and so forth.
Consideration of values and context	As part of the goal to <i>enable wider participation</i> , Cochrane encourages increasing <i>diversity</i> . To ensure true involvement of individuals from different culture and backgrounds, their values need to be considered.
Revision or appeal mechanism	This refers to a formal mechanism for reviewing decisions. This ensures the quality of the final decision (which is one of the principles of the Collaboration) and provides an opportunity to identify failures and errors or contribute additional information in the process.
<i>* This table provides an overview of process elements, not outcome elements. Data on the outcome of the priority setting process of the Collaboration was not available so we could not evaluate it.</i>	

The survey had a high response rate and provides insight into the prioritisation process of the Collaboration (2). I did not include methods groups (which focus on developing methods for

conducting systematic reviews) or Cochrane centres (which focus on training and capacity building and coordinating Cochrane activities in particular countries). Instead, I contacted the 66 Cochrane groups (Table 8) which focus on different health problem topic areas. Of the 66 Cochrane groups contacted, 52 responded (78%). Of the 52 respondents, 29 (56%) had a process to inform the selection or prioritisation of topics for Cochrane Reviews. Fifteen Cochrane groups had a transparent and structured approach, but two of these were joint initiatives between Cochrane groups. The remainder did not report a priority setting process with identifiable steps or structure for decision-making. Therefore, there were 13 structured prioritisation projects. With only two exceptions, these prioritisation processes were being used to identify new topics for Cochrane Reviews. One group focused instead on prioritisation of already published Cochrane Reviews to develop a dissemination strategy, and another focused on prioritising existing Cochrane Reviews which needed to be updated.

Table 5, Table 6 and Table 7 provide a summary of the priority setting methods for all the Cochrane groups and their evaluation. Table 8 outlines the Cochrane groups that responded to the survey and did not use a prioritisation process in 2008. Our evaluation focused on the process of research priority setting rather than its outcome because we did not have access to sufficient data to do a meaningful outcome evaluation.

Table 5 - Priority setting in Cochrane Groups in 2008 (part 1): Methods, Tools, Criteria, and Inclusiveness

Cochrane Groups (if the information is publicly available, they were named, otherwise they were anonymised and named as group1, group2 and so on)	Methods, tools, criteria: How to do priority setting	Inclusiveness (Who is involved)
Bone, Joint and Muscle Trauma Group (75)	<p>Approach 1 – (jointly with the Health of Older People Field) Feedback from the members of both groups on priority topics on the general area of hip fracture and rehabilitation for future Cochrane Reviews, summary table was prepared and the register of the CRG was searched for trials. After a selection procedure which included the establishment of pre-specific criteria, the project group agreed on a priority topic for a new Cochrane Review.</p> <p>Approach 2 – The information specialist searched the specialized register to identify topic areas in which there are trials without Cochrane Reviews.</p>	<p>Approach 1 - Editorial Board of Bone, Joint and Muscle Trauma group and members of the Health of Older People field.</p> <p>Approach 2 - NA</p>
Cochrane Consumer Network (76)	<p>An online survey was developed. All Review Group review titles (from the Cochrane Library 2007, Issue 3) were listed as health topics and divided into broad categories such as prevention, treatment, and rehabilitation (English and Spanish). A Communication Strategy was developed. Eleven criteria for setting priorities were selected as part of a workshop held at the Dublin Cochrane Colloquium in 2006. The criteria were piloted by the Cochrane Consumer Network (CCNet) Geographical Centres Advisory Group.</p>	<p>The survey was aimed at consumers and patients.</p> <p>522 valid responses were received. 21.3% were male, 73.2% were female. 5.5% did not respond. 13.4% of respondents were aged less than 30 years; 52.5% were 30 to 55 years; and 28.4% were older than 55 years. North America 37%; South America 4%; UK 13%; Scandinavia 0.3%; Continental Europe 6%; Eastern Europe 0.3%; Middle East 8%; Africa 4%; Asia 5%; Australia and New Zealand 18%. Caregiver 2.3%; consumer (advocate) 26.6%; patient 19.7%; health professional 20.5%; researcher 14.2%; other (including journalist, communicator) (9.2%); or did not provide an answer to this question (7.4%).</p>

<p>Effective Practice and Organisation of Care Group (only Australian satellite) (77)</p>	<p>The project involved a survey of senior policy makers to identify priority policy issues that can be informed by EPOC systematic reviews along with content analysis of annual reports of Commonwealth, States and Territories. They also conducted interviews held over two months (June/July 2008) with approx. 40 policy makers. Finally, there was a Delphi process to achieve consensus and ranking of topic priorities.</p>	<p>Policy makers, National Institute of Clinical Studies (NICS), The National Health and Medical Research Council (NHMRC), Australian Cochrane Centre (ACC)</p>
<p>Eyes and Vision Group (78, 79)</p>	<p>They started with the “evidence gap” project and screening the guidelines of eyes and vision, selecting American Academy of Ophthalmology (AAO) guideline on glaucoma, extracting research questions with the existing evidence, undertaking a search of the existing (or planned) systematic reviews and clinical trials in the Cochrane Library, circulating the research questions and related evidence to a larger group including editors, guideline developers and consumers to rank the topic, aggregated data presented to an international expert panel to obtain consensus, evaluate the programme.</p>	<p>Editors, Guideline Developers, Consumers</p>
<p>Incontinence Group (80)</p>	<p>Participating organisations consulted memberships to identify “uncertainties” affecting treatment decisions. “Uncertainties” were also identified in published research recommendations.</p> <p>Prioritisation involved two phases: 1) shortlisting of “uncertainties” by organisations; 2) patient-clinician prioritisation using established consensus methods.</p> <p>Prioritised “uncertainties” were verified by checking any available relevant up-to-date published systematic reviews.</p>	<p>United Kingdom clinician and patient organisations whose remit includes urinary incontinence were invited to participate; 8 patient and 13 clinician organisations responded.</p>
<p>Cancer Network (81)</p>	<p>The network identifies national cancer priorities based on incidence and mortality and categorizing reviews in the field of prevention, treatment, supportive and palliative care, diagnosis, screening for each cancer priority and identifying the gaps in the library.</p>	<p>It did not involve individuals in priorities; priorities are based on mortality and incidence data</p>

Musculoskeletal Group (82)	<p>The following steps were used:</p> <p>(1) Conduct an initial assessment of the current Global evidence mapping method (83) by comparing it to other priority setting research approaches.</p> <p>(2) Through expert consultation, identify new decision factors and processes that can be incorporated into the method to improve its results.</p> <p>(3) Create a new version of the GEM methodology.</p> <p>(4) Conduct a pilot exercise in collaboration with the Cochrane Musculoskeletal Group to set priorities in the Osteoarthritis area. A minimum of 60 stakeholders representing the different groups will be engaged throughout the pilot exercise. (82)</p>	A minimum of 60 stakeholders representing different groups: Clinician, researchers, patients/consumers, policy makers/decision-makers
Public Health Review Group (84)	<p>Terms of reference (TOR) for taskforce members were sent to the ten members involved in the priority setting of topics and there was a first teleconference identifying background and proposed phases of the project. The existing reviews of health promotion and public health topics were identified and presented to the taskforce members, so they knew what had already been covered. Finally, the briefing for 3rd teleconference includes criteria options for prioritising topics and a proposed framework. With this guidance, the Taskforce set about putting forth suggested topics.</p>	Only Policy makers
Group 1	<p>Surveys of consumers, editors and reviewers of the review group are conducted and then discussed by the editorial board. Possible titles are put online. Titles are also suggested through the process of restructuring of the register of the CRG.</p>	Members of Cochrane entity (consumers, editor and authors)
Group 2	<p>There were two steps used to conduct the priority setting exercise:</p> <p>1) Identifying clinically relevant areas with sufficient number of RCTs. Searching the Trial register of the group and grouping the trials on areas with a high yield of RCT and , CCTs, generating a list of reviews, excluding non-clinically important topics, circulating between editors of the CRGS, finalizing the review title.</p> <p>2) Ongoing project, to search the national research register, categorize results in the six groups that are the scope of the review group, generate a list of areas that are in the scope but no RCTs,</p>	Editors

	circulating between editors.	
Group 3	Prioritisation of titles relevant to abortion with the global stakeholders and request of reviews from World Health Organisation (WHO) and Family Health International (FHI).	Global Organisations e.g. World Health Organisation, Family International Health, United Nations
Group 4	A request was made widely to group members and a wider group of partner organisations to suggest large number of reviews. Afterwards, in a meeting of twenty people from all over the UK including health professionals, researchers and consumers, 20 titles were selected. Funding covers the cost for a support group to train new reviewers to od the priority reviews.	As the funding source was the department health of the UK, it only included individuals from the UK but included a wide range of individuals This included the following partners: Cancer Networks, British Gynaecological Cancer Society (BGCS), The British Society for Colposcopy and Cervical Pathology (BSCCP), Royal College of Obstetricians and Gynaecologists (RCOG), The National Forum of Gynaecological Oncology Nurses (NFGON), Ovacome (The ovarian cancer support charity), Jo's Trust (Jo's Cervical Cancer Trust), The National Institute for Health and Care Excellence (NICE), Centre for reviews and dissemination (CRD), The National Cancer Research Institute (NCRI) and NHS programme Directors
Group 5	Reviews needed updating were circulated ranked for 1,2,3. The editors ranked according to their knowledge of new trials in the area and the current clinical importance in neonatal surgery.	Members of the group
Group 6	The topics lists are regularly circulated amongst) staff and stakeholders. Moreover, the information specialist (trial search coordinator) looked for trials in the register not covered by the Cochrane Review Group.	Involving different stakeholders in the field of neuromuscular health including the editorial board and European neuromuscular partners, secretary of state for health, the chief medical officer at the department of health and staff at the National Institute for Health and Care Excellence (NICE)

Group 7	The prioritised reviews in an annual editorial board meeting with editors from developed and developing countries and consumer panel coordinator. In addition to this, NICE helps the review group to prioritise reviews that are relevant to their guidelines.	Editors, Consumers
Group 8	Every 6-12 months, the group compiles suggestions from Group members and circulates the suggested list, asking members to prioritise it. The top five titles are posted on the website and reviews are undertaken wherever possible.	Members of the group
Group 9	Priority setting is part of the editorial process. The Group had these strategic objectives: to increase the proportion of high impact reviews, editorial base efficiency and the group's profile. A high impact review: is likely to generate consideration interest in the international public health community; has the potential to change policy or treatments with substantive impact on the UN Millennium Development Goals; is frequently cited in the scientific literature; is of considerable interest; is likely to capture high levels of press coverage; and should have two or more potential trials.	Editors

Table 6 - Priority setting in Cochrane Groups in 2008 (part 2): mapped to the Accountability for Reasonableness Framework (74)

Cochrane Groups (if the information is publicly available, they were named, otherwise they were anonymised and named as group1, group2 and so on)	Relevance	Publicity	Appeals	Enforcement
Bone, Joint and Muscle Trauma Group	<p>Approach 1 – To identify priority review relevant to hip fracture and rehabilitation in elderly people based on the views of experts and the existing trials</p> <p>Approach 2 – topics that are not covered by the group but have trials</p>	<p>Approach 1 – A commissioning brief for producing the priority review was developed and sent to potential review team authors who had expressed an interest in becoming involved in the review in the feedback we received from members of the Field and BJMT Group. The project was published in specialist journals, websites, newsletters or societies</p> <p>Approach 2 – not reported</p>	No	No
Cochrane Consumer Network	To prioritise existing Cochrane Reviews for consumers and the public in low and high-income countries as a way of promoting evidence-based health care and the Cochrane Library - for use by individuals (with their healthcare providers), patient support groups and organisations and to encourage the implementation and use of Cochrane Reviews by the public.	A Communication Strategy was developed to inform people about the survey and invite them to participate, reviews identified will be assessed as to how they can be applied by consumers (using specific questions); the content of the review conclusions and plain language summary; how up to date the reviews are; any gaps in 'knowledge'. This assessment will be made available to authors and review groups with an offer of input from Cochran consumer network when the review is updated.	No	No

Effective Practice and Organisation of Care (EPOC) Group	Identify and help produce EPOC reviews that are relevant to the Australasian region. Involvement of end users in priority setting of the satellite – identify research questions of relevance.	The survey intends not only to capture the views of policy makers but also to increase policy makers awareness of the work of EPOC and their sense of ownership. Dissemination of survey results to policy makers - awareness of satellite priorities and reviews in progress. Encourage policy makers to be involved in the review team. Work with Australasian Cochrane Centre to produce policy summaries of the completed reviews and dissemination of review results.	There is no mechanism of Appeal designed but the interested policy makers are intended to be involved in the peer review process which provides a potential opportunity of Appeal	No
Eyes and Vision Group	The process aims to identify topics that are identified as clinical relevant in guidelines, identified as priorities by clinicians and consumers taking into consideration the existing systematic reviews and clinical trials.	The list of clinical questions would be published on the group website and if accepted also on DUETS website.	No	Yes, the website provides the opportunity for everybody to contribute in developing a priority list
Incontinence Group (80)	Identifying treatment uncertainties for both patients and clinicians that are not addressed by systematic reviews.	UK Database of Uncertainties about the Effects of Treatments (UK DUETs) database and reported to funding agencies	No	No
Cancer Network	Identifying gaps in the management and diagnosis of cancers that affect or kill most of the people.	Presented to local authorities and in colloquium.	No	No
Musculoskeletal Group	The prioritisation process intends to identify priorities from different groups and incorporate health equity and the social determinants of health into the analysis.	The results will be presented in two conferences and the results will be published in BMC health services. Furthermore, results will be posted to the CMSG website.	Yes	Yes
Public Health Review Group	Priority of policy makers and those involved in public health policy.	The list was published on the website and presented in conference.	No but authors could further refine the topics or change it when	No

			they overtake it.	
Group 1	Priorities and interests of members. Topics with clinical trials conducted on that topic	The list was published on the website.	No	The process can be initiated by authors and other members
Group 2	The rationale is to undertake reviews on areas clinically relevant with adequate number of available trials	The project was presented as a poster and the titles were sent for call of proposals.	No	No
Group 3	Topics that are relevant to global organisations or a priority in developing countries (e.g. abortion).	The list was published on the website.	No	NO
Group 4	Selecting reviews based on views of stakeholders from different relevant organisations and the relevancy of the topics to improving patient outcome and importance to NHS and includes a wide range of topics.	The titles were made available through the cancer networks and NHS Gynaecological Cancer Networks and presented in meetings.	Not for the prioritisation program but the stakeholders act as peer reviewers of the reviews.	No
Group 5	The titles are prioritized by knowledge of editors on clinical importance and knowledge of new trials. This is reasonable but not sufficient.	The list was published on the website	No	No
Group 6	It is reasonable as it covers the priority of stakeholders and the gaps in the primary research.	No	No	No
Group 7	Identify priority topics that editors from developed and developing countries and consumer agree upon and identifying national priorities to develop guidance in the UK.	No	No	No

Group 8	Identifying the most relevant question in the view of members of CRG.	The list was published on the website	It is every 6-12 months updated so people could suggest other priorities.	Individuals can suggest titles regularly and they are asked to prioritise them regularly.
Group 9	The editorial intends to identify high impact reviews with the potential to be delivered in an acceptable period.	No	No	The CRG is attempting to identify a good author team that would be able to implement the prioritized topic.

Table 7 -Priority setting in Cochrane Groups in 2008 – further information on characteristics of the priority setting exercises (part 3)

Cochrane Groups (if the information is publicly available, they were named, otherwise they were anonymised and named as group1, group2 and so on)	Evaluation of the existing evidence coverage	Criteria for priority setting	Communication, dissemination and feedback of information	Investigator or curiosity driven research	Implementation, monitoring and evaluation, sustainability
Bone, Joint and Muscle Trauma Group	Search of the register of CRG	1) There must be no current Cochrane Review on this topic. 2) It must fall under the BJMT group scope. 3) There should be at least 2 fully published trials. 4) The topic must have been identified as a priority by the feedback.	The members and contributors of the CRG would be informed about the list of topics	The members of the entity could suggest questions that could be a potential also curiosity driven	Dissemination of findings through specialist journals, websites, newsletters or societies
Cochrane Consumer Network	It is based on the existing systematic reviews.	Title of the review clearly conveys its meaning, Health and wellbeing; Clear benefits; Harms	A Communication Strategy was developed to inform people about the survey and invite them to participate.	No	"Reviews identified will be assessed as to how they can be applied by consumers (using specific questions); the content of the review conclusions and plain language summary; how up to date the reviews

		weighed against benefits, Prioritised in healthcare system; Newsworthy, Topic can be addressed with randomised controlled trials; Relevant or familiar healthcare setting (higher response for health professionals as compared with patients); Intervention is available to use; Cost of the intervention needs to be weighed against the benefits.			are; any gaps in 'knowledge'. This assessment will be made available to authors and review groups with an offer of input from CCNet when the review is updated. - This work is to help identify what can assist consumers to make informed healthcare decisions, promote (access to) Cochrane Reviews and CCNet. What we do not want is for people to be disappointed once they go to the actual review”.
Effective Practice and Organisation of Care Group (only the Australian satellite has a specific strategy)	Content Analysis of Annual Reports of Commonwealth, States and Territories.	Priority policy issues of Australia, the themes of EPOC review group. Professional, Financial, Organisational and regulatory interventions.	Dissemination of survey results to policy makers, work with Australian Cochrane Centre to produce policy summaries of the completed reviews and dissemination of review results.	No	The Satellite intends to prepare the Cochrane Reviews, encourage policy makers to be involved and prepare policy summaries.

Eyes and Vision Group	Search for clinical trials and systematic reviews.	1) Clinical relevance 2) Priority of those who rate the topics 3) Availability of evidence	Presentation in congresses, informing on website and if possible on DUETs, - Obtain feedback from CEVG Editors as to utility of project; -Obtain feedback from others conducting systematic reviews in eyes and vision (e.g., AAO) as to utility of project.	Individuals could have suggested titles based on their perception on clinical importance and priority	In Phase III of the Project, we will evaluate the prioritizing process using the following measures: -Estimate approximate length of time to complete each step of prioritizing project; -Assess the number of clinical questions for which there are reviews completed and an indication of whether they are up-to-date; the number of questions with at least one controlled trial but no review; number of clinical questions with no apparent relevant controlled trials
Incontinence Group (James Lind Alliance partnership project)	The researchers evaluated whether the identified uncertainties were addressed by a Cochrane Review on one side and on the other side, they have identified some of the uncertainties through the ongoing Cochrane Reviews and protocols	Individuals were asked to identify and rank the ten uncertainties that they would most like to see prioritised for research. The ranked responses from all organisations were then collated in a single database and scored by ranking and other factors for example being submitted more than once by different organisations.	The findings of the James Lind Alliance partnership (JLA) will be used by the Group to prioritise new and updating Cochrane Reviews. It will be published and formally reported to research organisations such as the NHS Health technology assessment (HTA) Programme and the Medical Research Council (MRC).	No	A concurrent qualitative evaluation will be conducted alongside the JLA Working Partnership to ensure that the strengths and limitations are identified and reported(85). Funds have been identified and a very able researcher with a background in social anthropology appointed to undertake the study.

Cancer Network	Mapping available Cochrane Reviews on the topic	Highest incidence and mortality rate Do not have already a Cochrane Review	Presented to local authorities and in colloquium	No	No
Musculoskeletal Group	A scoping literature with stakeholder consultation would be undertaken to identify osteoarthritis research topics. The scoping will produce an evidence map, which will be used to frame subsequent stages.	The following 5 dimensions are being considered to prioritise topics: Clinical, Importance, Novelty, controversy, Equity, Social Determinants Based on the responses, the questions are ranked into 2 broad categories - high or low priority for example if clinical importance, equity along with either novelty or controversy is high or moderate, the topic is high priority.	Results of the priority setting exercise will be posted to the entity website.	The experts and stakeholders could suggest further titles based on their personal interest	Yes, results will not only be published on the website but will also be presented at the 2010 World Congress on Osteoarthritis to enable changes in the osteoarthritis community.
Public Health Review Group	Search for Cochrane and non-Cochrane systematic reviews on the topic.	(1) Burden of disease, magnitude of problem, urgency; (2) Importance to developing countries; (3) Avoidance of duplication; (4) Opportunity for action.	Presented on website and conferences.	No	The field has changed to a CRG to address the need for conducting these reviews.

Group 1	Searching the register	They did not use any criteria to make decision beyond looking	They did not have these steps	They did not consider this	They did not have these steps.
Group 2	Searching for Clinical Trials	1. clinical relevance 2. Number of RCT/CCTs available	It was presented as a poster	No	The titles were used as call of proposals.
Group 3	No	Priority of global agencies	No	No	They would try to work with active author teams for important and urgent topics.
Group 4	Searching the register	1) Improving patient outcomes 2) Importance to NHS priorities 3) Achievability and resources required 4) Impact on efficacy and efficiency	The titles were put available through the cancer networks and NHS Gynaecological Cancer Networks and presented in meetings. The stakeholders were also involved in peer reviewing the reviews.	Individuals can suggest clinically relevant reviews	The reviews were undertaken by authors teams and the group team funded an information specialist and statistician to support reviewers in undertaking the review
Group 5	No	Clinical importance, knowledge of clinical trials	Putting on the website	Yes, individuals can suggest and rank titles	No
Group 6	NO	Priority of editors and priorities of international organisations	No	Yes, individuals can suggest titles that they consider clinically important	No
Group 7	No	Interest of those who rate the priorities, National Institute for Health and Care Excellences (NICE) priorities	No	Yes, the editors and consumers can suggest titles that they consider interesting	No

Group 8	No	Interest and priorities of those who rates	They are published on the website and members can regularly provide further feedback	Yes, individuals can suggest titles based on their interest	The author teams can request to undertake the titles and some are taken by the CRG
Group 9	There should be at least 2 trials available for the review topic, no further evaluation of evidence coverage	High impact review (1-4): 1) likely to generate considerable interest in the international public health community 2) the potential to change policy or treatments with substantive impact on the United Nations Millennium Development Goals (MDG), 3) frequently cited in the scientific literature, is of considerable interest and likely to capture 4) high levels of press coverage 5) the review should have two or more potential trials.	No	No	The author team would be appraised along with the title registration form. This would be done if the author team has demonstrable topic expertise (published peer reviewed articles in the topic), completed at least 1 Cochrane Review or equivalent, contact author has time to dedicate to review (3 to 6 months for review with >3 trials). The CRG would help in building teams, helps finding financial support e.g. salary, author meeting, build in deliverables to contract and the CRG actively manages the review team by checking on progress, dialogue, conference calls.

Table 8 - List of Cochrane groups in December 2008

Type of entity	List of Cochrane groups in December 2008	
Cochrane Review Groups	<ol style="list-style-type: none"> 1. Acute Respiratory Infections Group 2. Airways Group 3. Anaesthesia Group 4. Back Group 5. Bone, Joint and Muscle Trauma Group 6. Breast Cancer Group 7. Childhood Cancer Group 8. Colorectal Cancer Group 9. Consumers and Communication Group Cystic 10. Cystic Fibrosis and Genetic Disorders Group 11. Dementia and Cognitive Improvement Group 12. Depression, Anxiety and Neurosis Group 13. Developmental, Psychosocial and Learning Problems Group 14. Drugs and Alcohol Group 15. Ear, Nose and Throat Disorders Group 16. Effective Practice and Organisation of Care Group 17. Epilepsy Group 18. Eyes and Vision Group 19. Fertility Regulation Group 20. Gynaecological Cancer Group 21. HIV/AIDS Group 22. Haematological Malignancies Group 23. Heart Group 24. Hepato-Biliary Group 25. Hypertension Group 26. Incontinence Group 	<ol style="list-style-type: none"> 27. Stroke Group 28. Tobacco Addiction Group 29. Upper Gastrointestinal and Pancreatic Diseases Group 30. Wounds Group 31. Infectious Diseases Group 32. Inflammatory Bowel Disease and Functional Bowel Disorders Group 33. Injuries Group 34. Lung Cancer Group 35. Menstrual Disorders and Subfertility Group 36. Metabolic and Endocrine Disorders Group 37. Methodology Review Group 38. Movement Disorders Group 39. Multiple Sclerosis Group 40. Musculoskeletal Group 41. Neonatal Group 42. Neuromuscular Disease Group 43. Oral Health Group 44. Pain, Palliative and Supportive Care Group 45. Peripheral Vascular Diseases Group 46. Pregnancy and Childbirth Group 47. Prostatic Diseases and Urologic Cancers Group 48. Public Health Group 49. Renal Group 50. Schizophrenia Group 51. Sexually Transmitted Diseases Group 52. Skin Group
Cochrane Fields and Networks	<ol style="list-style-type: none"> 1. Behavioral Medicine Field 2. Cancer Network 3. Child Health Field 4. Complementary Medicine Field 5. Consumer Network 6. Developing Countries Network 7. Health Care of Older People Field 	<ol style="list-style-type: none"> 8. Health Equity Field 9. Neurological Network 10. Occupational Health Field 11. Prehospital and Emergency Health Field 12. Primary Health Care Field 13. Rehabilitation and Related Therapies Field 14. Vaccines Field

The results of our study showed that priority setting strategies across the Cochrane Collaboration are fragmented. There have been attempts to address these issues but there is more work required. For example, the sources and definitions of topic relevance for reviews vary significantly among groups. Most Cochrane Review Groups consider patients' views probably the most important category for rationalizing priorities. However, in practice, they took different approaches to this, as outlined in Table 5 and Table 6. None of the groups had a formal appeal mechanism as part of the process of prioritisation beyond the revision and feedback features of the Cochrane Library. To address these issues, Cochrane requires better designed priority setting processes and more transparency about who is involved, how these individuals are involved and what data/information is used to inform the decision-making process. Better designed priority setting approaches can improve the relevancy of Cochrane Reviews published in the Cochrane Library and thus increase the impact of its reviews on health and related outcomes.

Cochrane needs to develop supportive policies to encourage priority setting and provide necessary resources and methodological guidance. After publication of the above project, there have been attempts to improve priority setting in the Cochrane Collaboration. The Cochrane editorial unit asked all Cochrane groups to develop a priority setting process and report back to the unit.

Consequently, there are now more Cochrane groups attempting to incorporate our published work along with other methodological research to inform their priority setting processes. However, the Cochrane Collaboration is still not reporting transparently how these priority setting processes are conducted. This limits the ability of external stakeholders to challenge the current processes or provide suggestions how to improve them. In conversations that I had with some of these stakeholders, there has been concern that, despite the attempt to engage with a wider stakeholder group in Cochrane, priority setting is still inward looking and does not address the needs of some key users of the Cochrane Library. The Priority Setting Methods Group provides some methods guidance (Appendix 3 - An introduction to Research Priority Setting (RPS) for research groups in Cochrane. However, further methodological research is needed. We need comparative studies of the effectiveness of different methods and processes for research priority setting. In addition, further research on the most appropriate approaches for taking account of context (e.g., cultural factors, political structures, and so forth) is critical.

Some Cochrane groups have either used burden of disease as a criterion in the ranking process of systematic review topics or they have used the global burden of disease data as background information to inform their decision making. The next project - Global Burden of Disease- Cochrane Collaboration project - assessed the extent to which the burden of disease influenced which

Cochrane reviews ended up in the Cochrane Library, and it also provided better quality data to inform future research priority setting exercises.

Comparing The Cochrane Library to the Global Burden of Disease data

The design of a priority setting exercise might focus on using certain data, information or views of certain stakeholders to meet its objectives. For example, several review groups and the central editorial unit considered Global Burden of Disease as one of the important criteria or indicators to inform their decision making. This was either officially highlighted as a criterion or was mentioned by the editors or stakeholders as a criterion that they consider during the consensus process. To see how much these issues influenced the content of the Cochrane Library, we undertook a mapping of Cochrane Reviews in relation to the Global Burden of Disease. I was involved in the projects looking at skin diseases (10), otolaryngeal diseases (13), injuries (11), neglected tropical diseases(7), and oral health (14). For most of these, I contributed to the methodology, the data analysis, and writing the article. I played a larger role as lead for the oral health project, for which I collected, analyzed the data and prepared the final report. The oral health project was presented at a conference. The comparison of the published Cochrane reviews with the ranking of diseases based on disability-adjusted life years (DALYs) prepared by the Global Burden of Disease project are available in

Table 9. There are other mapping projects finished and ongoing beyond this project for eyes and vision (86), heart disease, cancer, infectious disease, and renal and urologic diseases, but I am not involved in these.

Table 9 - The mapping of the Cochrane Library compared to the Global Burden of Disease (GBD) using the ranking of diseases based on the disability-adjusted life years (DALYs)

Disease area	Results
Oral Health	The conditions were ranked in decreasing order based on their disability-adjusted life years (DALYs) - esophageal cancer, edentulism, dental caries, periodontal disease, mouth cancer, cancer of other parts of the pharynx and oropharynx, nasopharynx cancer, cleft lip and cleft palate. All conditions are represented with at least one systematic review and one protocol in the library. Edentulism had higher % total 2010 DALY compared to periodontal diseases but has been less represented in the Cochrane Library (11 versus 13 reviews) and in terms of the total number of clinical trials included within the reviews (87 versus 101 trials)(14).
Skin Diseases	All 15 skin conditions were represented by at least 1 systematic review in CDSR; 69% of systematic reviews and 67% of protocols by the CSG covered the 15 skin conditions. Overall, the number of published reviews/protocols was well matched with disability metrics for 5 of the 15 studied skin diseases, while 3 skin diseases were overrepresented, and 7 were underrepresented. Comparing the number of reviews/protocols and their DALY measurement, dermatitis, melanoma, nonmelanoma skin cancer, viral skin diseases, and fungal skin diseases were well matched. Decubitus ulcer, psoriasis, and leprosy demonstrated review/protocol overrepresentation when matched with

	corresponding DALYs. In comparison, acne vulgaris, bacterial skin diseases, urticaria, pruritus, scabies, cellulitis, and alopecia areata were underrepresented in CDSR when matched with corresponding DALYs (10).
Otolaryngology diseases	All 10 otolaryngologic conditions were represented by at least 1 systematic review in CDSR. The number of reviews and protocols in CDSR was well matched with GBD 2010 disability metrics for only 1 disease, mouth cancer. Upper respiratory infections, otitis media, thyroid cancer, and cleft lip and cleft palate were overrepresented in CDSR, and esophageal cancer, "other hearing loss," nasopharynx cancer, larynx cancer, and "cancer of other part of pharynx and oropharynx" were underrepresented. The representation of otolaryngologic conditions in CDSR correlates poorly with DALY metrics (13).
External causes of injury	Eleven of the 12 causes were represented by at least one systematic review or protocol in CDSR; the category collective violence and legal intervention had no representation in CDSR. Correlation testing revealed a strong positive correlation that was statistically significant. Representation of road injury; interpersonal violence; fire, heat, and hot substances; mechanical forces; poisonings, adverse effect of medical treatment, and animal contact was well aligned with respect to DALY. Representation of falls was greater compared to DALY, while self-harm, exposure to forces of nature, and other transport injury representation was lower compared to DALY. CDSR representation of external causes of injury strongly correlates with disease burden. The number of systematic reviews and protocols was well aligned for seven out of 12 causes of injury (11).
Neglected tropical diseases	Overall, there was poor correlation between CDSR representation and DALYs. Yellow fever, echinococcosis, onchocerciasis, and schistosomiasis representation was well-aligned with DALY. Leprosy, trachoma, dengue, leishmaniasis, and Chagas disease representation was greater, while cysticercosis, human African trypanosomiasis, ascariasis, lymphatic filariasis, and hookworm representation was lower than DALY. Three of the 18 neglected tropical diseases (NTDs) had reviews/protocols of diagnostic test accuracy. Our results indicate the need for increased prioritisation of systematic reviews on NTDs, particularly diagnostic test accuracy reviews (7).

Equity in setting priorities for topics of Cochrane Reviews

In the next step of the project, we developed a tool that can be used to evaluate and inform the development of equity-oriented research priority setting within and outside the Cochrane Collaboration. In developing this tool, we attempted to evaluate how well the Cochrane Collaboration addresses questions from both advantaged and disadvantaged groups relevant to reducing health inequalities.

The tool ("equity lens") looks first at the process of setting priorities and whether (a) the priority setting process provided opportunities to incorporate the views of stakeholders from less advantageous background or (b) the individuals involved in the priority setting process have collected and used data reflecting health inequalities. Afterwards, we assessed whether using the tool resulted in research priorities relevant to disadvantaged groups or to reducing health inequity. Moreover, the tool evaluates whether the dissemination and implementation of the results reaches the right people. To situate the tool, we selected a definition of health equity: 'absence of

systematic differences in health, both between and within countries that are judged to be avoidable by reasonable action” (87).

Development of the lens occurred at a consultation workshop, through literature reviews and by using two previously developed tools: (1) an equity tool for evaluating clinical guidelines (18) and (2) the PROGRESS-PLUS mnemonic that describes a range of disadvantaged groups. PROGRESS-PLUS is an extension of Evans’ and Brown’s framework PROGRESS (Place of residence, Race/ethnicity, Occupation, Gender, Religion, Education, Socioeconomic status, and Social capital), with “PLUS” representing additional dimensions such as age, sexual orientation, and disability (1). Table 10 - Equity lens for agenda setting and research priority setting is an overview of the equity lens for research priority setting that I have developed for this project.

We used the equity lens to evaluate the priority setting of 15 Cochrane Groups. In the 2008 survey of Cochrane groups, 29 groups reported that they had processes to inform their topic selection. Some groups had only limited and unclear approaches. For example, one Group used certain information to feed into their process but they did not report a process for making the decision. The evaluation using the equity lens focused on the 15 groups with more structured and transparent approaches, as outlined in Tables 5, 6, and 7. Due to the limited data collected by the review groups, we were only able to evaluate some of the processes (e.g. who is involved in the process), not the outcomes (e.g. whether the topics prioritised were relevant to disadvantaged groups). It was clear that very few Cochrane groups have explicit strategies addressing the need of different socio-demographic groups. The process of developing the equity lens demonstrated that there is a wide variety of approaches to integrate these issues into the process. However, there is limited evidence to show whether it makes a difference in the finally selected priorities.

Table 10 - Equity lens for agenda setting and research priority setting (1)

The questions focusing on the design and conduct of research priority setting exercises (process section)
1. Are different stakeholders who might be affected by the choice of research (review) topics involved in the prioritisation process (different age, sex, sexual orientation, disability, ethnicity, and religion, place of residence, occupation, education, socioeconomic status, and social capital groups)? In which steps are they involved?
2. Does the prioritisation project consider reducing inequity as part of its objectives?
3. Are the selected methods and tools to identify, prioritize, implement, disseminate, and communicate research topics understandable, transparent and relevant for different stakeholders (different age, sex, sexual orientation, disability, ethnicity, religion, place of residence, occupation, education, socioeconomic status, and social capital groups)?
4. Are specific strategies considered to minimize the barriers to reach disadvantaged or less accessible populations?

5. In the stage of situation analysis (evaluating the current health research coverage, identifying gaps, evaluating healthcare needs, etc.), does the analysis consider the differences in the prevalence, severity and urgency of health problems along with potential differences in the impact or value of the health care interventions assessed across different subgroups (age, sex, sexual orientation, disability, ethnicity, religion, place of residence, occupation, education, socioeconomic status, and social capital)?
6. Do the criteria for prioritisation consider the potential differences in the severity and urgency of health problems in disadvantaged populations or less accessible groups as opposed to the health problems in privileged populations?
7. Do the criteria for prioritisation consider the potential differences in the impact of a health care intervention in disadvantaged populations as opposed to the health problems in privileged populations?
8. Do the criteria for prioritisation consider that different population groups might have different values and preferences?
9. Are different stakeholder groups (representing age, sex, sexual orientation, disability, ethnicity, and religion, place of residence, occupation, education, socioeconomic status, and social capital groups) provided with an opportunity to provide feedback and appeal the process and results of the prioritisation process?
The questions related to the results of the research priority setting exercise and the following implementation of them (section)
1. Did the prioritisation result in more research topics (in this case Cochrane reviews) that are relevant to disadvantaged groups?
2. Did the dissemination and implementation strategy increase the likelihood that funders and research institutes become aware of the prioritised research topics and consider them as part of their research agenda or strategic planning?
3. Did the dissemination and implementation strategy increase the likelihood that the prioritised research topics that are relevant to disadvantaged groups get funded and conducted?
4. Did the dissemination and implementation strategy increase the likelihood that researchers who work with disadvantaged groups conduct or get involved in the prioritised research projects (in this case the research project is a Cochrane systematic review review)?
5. Did the dissemination and implementation strategy increase the likelihood that disadvantaged groups or decision makers or practitioners who work with disadvantaged groups get involved in the prioritised research topics?
6. Does the dissemination and implementation strategy increase the likelihood that policy makers and decisions makers who work with disadvantaged groups use the result of the prioritised research topics?
7. Did the results of the prioritised research topics changed policies, legislation or clinical practice in favour of disadvantaged groups?
8. Did the appeal and enforcement strategy increase the likelihood that disadvantaged groups or decision makers, researchers and practitioners who work with disadvantaged group had provided feedback and comments on the prioritisation process or results?

Table 11 - Using the equity lens for priority setting processes in 15 Cochrane groups(1)

Equity Lens	The strategies taken by the Cochrane Groups to address the question from the equity lens
<p>1. Are different stakeholders who might be affected by the choice of research (review) topics involved in the prioritisation process (different age, sex, sexual orientation, disability, ethnicity, and religion, place of residence, occupation, education, socioeconomic status, and social capital groups)? In which steps are they involved?</p>	<ul style="list-style-type: none"> • 1 group targeted consumers, 2 groups targeted policy makers, 1 group targeted both clinicians and patients, • 1 group involved stakeholders from different countries, different ethnic backgrounds, and both genders, • 1 group involved diverse stakeholders by providing the survey in English and Spanish • 1 group collaborated with a group focussed on a particular demographic to ensure that they are appropriately represented.
<p>2. Does the prioritisation project consider reducing inequity as part of its objectives?</p>	<ul style="list-style-type: none"> • 1 group (only) specifically aimed to introduce health equity and the social determinants of health into the prioritisation process. • 2 groups emphasized that they would try to include the priorities of individuals based in LMICs (among others).
<p>3. Are the selected methods and tools to identify prioritize, implement, disseminate, and communicate research topics understandable, transparent and relevant for different stakeholders (different age, sex, sexual orientation, disability, ethnicity, religion, place of residence, occupation, education, socioeconomic status, and social capital groups)?</p> <p>4. Are specific strategies considered to minimize the barriers to reach disadvantaged or less accessible populations?</p>	<ul style="list-style-type: none"> • 2 projects used online surveys a) one survey was provided only in English; b) the second one was available in both English and Spanish. • 1 project, which aimed to involve patients and clinicians, made specific attempts to ensure that the provided information was understandable for both groups.
<p>5. In the stage of situation analysis (evaluating the current health research coverage, identifying gaps, evaluating healthcare needs, etc.), does the analysis consider the differences in the prevalence, severity and urgency of health problems along with potential differences in the impact or value of the health care interventions assessed across different subgroups (age, sex, sexual orientation, disability, ethnicity, religion, place of residence, occupation,</p>	<ul style="list-style-type: none"> • 1 project searched for evidence and categorized the identified studies from the search according to stages of the condition, consequences of ill health, and social determinants potentially affecting the condition. • 1 project used the WHO Health Report 2002 (18, 19) as a basis for categorizing the identified literature that can demonstrate the differences in severity and prevalence between Low and Middle-Income countries (LMIC) and High-Income countries (HICs).

education, socioeconomic status, and social capital)?	
6. Do the criteria for prioritisation consider the potential differences in the severity and urgency of health problems in disadvantaged populations or less accessible groups as opposed to the health problems in privileged populations?	<ul style="list-style-type: none"> • 1 group, the priority setting group considered five dimensions in setting priority research topics. Two of them were relevant to this question. In the below ones, depending on how the panel interpreted these criteria, this might have led to the inclusion of priority questions that addressed question 6. • 1 group considered burden of disease, magnitude of problem, and urgency as criteria. • 2 groups considered the priorities of a health care system as one of the criteria.
7. Do the criteria for prioritisation consider the potential differences in the impact of a health care intervention in disadvantaged populations as opposed to the health problems in privileged populations?	<ul style="list-style-type: none"> • 1 group considered a criterion that partially addresses this question: potential impact of the intervention on changing policy or treatment especially in areas of the United Nations Millennium Development Goals (MDGs).
8. Do the criteria for prioritisation consider that different population groups might have different values and preferences?	<ul style="list-style-type: none"> • None of the processes considered values and preferences.
9. Are different stakeholder groups (representing age, sex, sexual orientation, disability, ethnicity, and religion, place of residence, occupation, education, socioeconomic status, and social capital groups) provided with an opportunity to provide feedback and appeal the process and results of the prioritisation process?	None of the processes ensured that different socio-demographic groups had the opportunity to provide feedback and appeal the results

The impact of the priority setting projects

The Collaboration has recognized the importance of our priority setting research projects in several ways. For instance, these projects were the basis for developing a new Methods Group within the Cochrane Collaboration. The Cochrane Priority Setting Methods Group was launched in 2011. This Group connects researchers working on priority setting methodology with Cochrane groups and disseminates the latest research on priority setting to Cochrane reviewers. It translates the research on priority setting processes mentioned above into policy guidance, checklists and guidance documents for research groups within the Cochrane Collaboration. The policy guidance is directed at all Cochrane groups (> 100 groups) around the world and several groups have developed better ways of prioritising topics for Cochrane Reviews⁷. The Methods Group organized and conducted workshops to communicate key issues that had emerged, to raise awareness, and to increase public engagement in research. I worked with other groups to integrate the results of the projects in other training programmes e.g. online training resources on research priority setting for Cochrane Canada and the Pan American Health Organisations (PAHO), training session for the UK-based Cochrane Review Groups at the 2013 UK and Ireland Cochrane Contributors Meeting, and training resources for the Yorkshire and Humber Research Design Service (part of the NHS).

The importance of our priority setting research was recognized by the Collaboration in awarding us the Bill Silverman Prize in 2012 and by Dame Sally Davies at the UK and Ireland Cochrane Contributors meeting in March 2013. Dame Sally highlighted our work as a key development in the Cochrane Collaboration to ensure that its reviews are relevant to the needs of the NHS. It was also used to inform the development of a research priority setting process for systematic reviews on consumer and communication topics at La Trobe University in Australia (88).

The priority setting projects shaped a research impact story in the last Research Excellence Framework (REF) 2014 exercise as part of Plymouth University's submission entitled "Advancing methods for prioritising health research"⁸. The REF panel has provided the following feedback about this impact story: "Some of the case studies were considered to be of very considerable impact in terms of their reach and significance, especially in relation to genetic counselling competencies and prioritising health research".

Since the start of my priority setting research in 2008, there has been a sharp increase in the number of studies discussing or exploring the issue of priority setting of systematic reviews in the Cochrane Collaboration and other organisations across the world. This may be due to the struggle that many systematic review organisations (national and international) face with the increased

⁷ https://methods.cochrane.org/prioritysetting/resources/priority_setting-cochrane-groups-examples

⁸ <http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=4645>

demand for systematic reviews to inform decisions in health care. The increase in the conduct of primary clinical research also leads to challenges in keeping systematic reviews up to date. Due to the diversity of the aim and scope of these organisations, I decided for the next part of the project to focus on a specific group of organisations involved in deciding what systematic reviews and primary research get funded: national health research funders.

How do national health research funders reduce research waste?

As seen in the first set of the publications in this dissertation (1, 2, 15), research priority setting cannot be evaluated in isolation from the organisational cultures, values, context, etc. in which they occur. Internal organisational factors and external drivers affect how priority setting processes are planned and what is expected to happen as a result. Accordingly, I broadened the scope of my second evaluation to include characteristics of structures and processes of the research funding agencies that can influence the process of setting priorities, the outcomes of priority setting or the implementation of the outcomes. The framework used for this project was based on a framework developed by Iain Chalmers and Paul Glasziou in 2009 (21) and further expanded in a Lancet series (22-27) focusing on avoidable waste in the production and reporting of research. We adapted the overall framework into a checklist to evaluate the work of public research funders based on publicly available information (Table 12). The objective of the project was to explore how funders (a) promote and monitor waste-reducing measures in the research that they support, and (b) support methodological research (research on research) and research infrastructure.

Table 12 - adaptation of the reduce research waste framework into an evaluation framework for research funders

<p>Decisions on which research proposals are priorities</p> <ul style="list-style-type: none"> • How do funders set their overall research agenda and commissioned research projects? • Do they report an overall vision or principle for the organisation? Does this include a balance between basic, applied and translational work? • Do they require applicants for funds to do additional primary research to refer to systematic reviews of existing evidence showing why the proposed research is justified? • Do they report a process to set their research agenda? What is the balance? (General details on the process, level of transparency, the people involved in the process (6 Ps - public, patient, provider, press, policy-maker, private sector + Researcher), criteria for making decisions, the process that the decisions are made, the scoring structure for boards and panels) • Do they engage with stakeholders in setting this research agenda? Does this include the end users of research (e.g. clinicians, patients, policy makers, as well as other researchers)? • Do they have certain pieces of information (e.g. prioritised agenda by other public agencies) that they use to inform these decisions? • How do funders make decisions to fund between the individual proposals submitted to them? • Do they report a process to make these decisions? • Do they engage with stakeholders to make these decisions? Does this include users of research? • Do they have certain pieces of information that they require in proposals to justify new primary research? Does this include systematic reviews or preparations of systematic reviews? How is this checked and monitored? Does the funder support such systematic reviews?
<p>Requirements in conduct of the research proposal and reporting it</p> <ul style="list-style-type: none"> • Does the funder require registration of research? If yes, which types? • What is the funder’s policy on public access to protocols for completed or ongoing research? • What is the funder’s policy on public access to data from completed research? • Does the funder promote use of relevant reporting guidelines (CONSORT, ARRIVE, STROBE, PRISMA, etc)? • What assistance, rewards, or incentives does the funder use to encourage: (i) publication of research? (ii) dissemination of research? (iii) re-use of data by other researchers?
<p>Policies of funders to wider support researchers, research organisations and research infrastructure</p> <ul style="list-style-type: none"> • What support is provided for training of, or assistance for, researchers in research methods? • What support does the funder provide for good research infrastructure (non-equipment), such as: research networks, study registries, data repositories, and open access? • Does the funder monitor their research output and impact? • Do they provide funding for others do undertake “research on research” or methods to improve research production such as reporting guidelines?

We selected 11 national research funding agencies in order to include large and small funders, some of them with a wide research agenda addressing diverse topics and others with a more focused research agenda. These were:

- the National Institute for Health Research (NIHR - England);

- the Medical Research Council (MRC - UK);
- the National Health and Medical Research Council (NHMRC - Australia);
- the Canadian Institutes of Health Research (CIHR – Canada);
- the National Institutes of Health (NIH – USA);
- Deutsche Forschung Gesellschaft/ German Research Foundation (DFG – Germany);
- French Ministry of Health; l’Agence Nationale de la Recherche (ANR – France);
- Nederlandse organisatie voor gezondheidsonderzoek en zorrinnovatie/ The Netherlands Organisation for Health Research and Development (ZonMw - Netherlands);
- Danske Regioner / Danish Regions (DR – Denmark); and
- the Regional Health Authorities in Norway (RHA – Norway).

I searched for information addressing our questions by:

- a. Browsing funding agency websites and following links providing information about the organisations, funding opportunities, information and guidance for reviewers, researchers and members of the public.
- b. Identifying, downloading and reviewing any handbooks for applicants and reviewers for grant committees, or documents on objectives and strategies. This included any regulations and guidelines issued by the funding agencies on their funding allocation process, but we did not look systematically at legislation and other central government policy documents from which regulations and guidelines derive, unless this was raised by the funding agencies when we contacted them.
- c. Searching websites, handbooks and other documents using the following specific terms: systematic review, meta-analysis, reporting guidelines, trial registry, CONSORT, PRISMA, STROBE, SPIRIT and ARRIVE (acronyms for reporting guidelines). I also used these terms together with the names of the funding agencies and scanned the first 20-30 results.

As background information on the funding agencies, I examined the composition of project grant committees and the affiliations of members, broadly categorized into academics and clinicians, policy makers, industry, and members of the public. I looked at the composition of the committees but did not explore their authority. My collaborator looked at the website of the Danish and Norwegian funding agencies as they were not available in English. A research collaborator double checked the data that I extracted. We contacted all funders to verify the data. All except for the Danish funders responded.

We published the initial results in *The Lancet*. Our paper included data from other projects looking at compliance to reduce research waste frameworks conducted by medical editors, universities, academics, etc. (3). The full results have been published subsequently in *The Lancet* (4). In the next

sections, I provide details beyond the published data in the Lancet reports. I explain why I did not include these data in the final publication. Moreover, I collected additional data through opportunistic sourcing – conversations with key individuals who develop and implement policies in funding agencies. We used this information to interpret and contextualise the data from the survey. Opportunistic sourcing is a recognised methodology in policy sciences, investigative and interpretative journalism to acquire human and documentary primary sources (89).

Summary of the context and characteristics of funding agencies

Of the 11 research funding agencies, DFG (Germany) and ANR (France) had the broadest research agendas, which included research unrelated to health. DFG funds research in any field of science, including engineering, life sciences and natural sciences and the humanities, including social sciences. ANR funds research on climate, energy and urbanisation. All the other funders focus on health research. Some - NIHR and the French ministry of health, for example - mainly fund applied and clinical research. At the beginning of the study, I intended to categorise the research focus/agenda/vision of each funding agency as applied research (clinical and public health), basic sciences, or translational research. After data collection, I realised that my attempt to categorise research foci could be misleading. There was a mismatch between my interpretations of the words and terms used to describe the visions and research agendas of funding agencies (as outlined by them) and the perceptions of researchers working in those countries and applying to those funding agencies. For example, the overall vision and agenda of a funding agency can be focused on improving people’s health but the researchers would highlight that the same agency can disproportionately focus on allocating funding to basic science. This is in line with the overall conclusion of this dissertation about the lack of transparency in the processes used by funding agencies and research organisations (Figure 2).

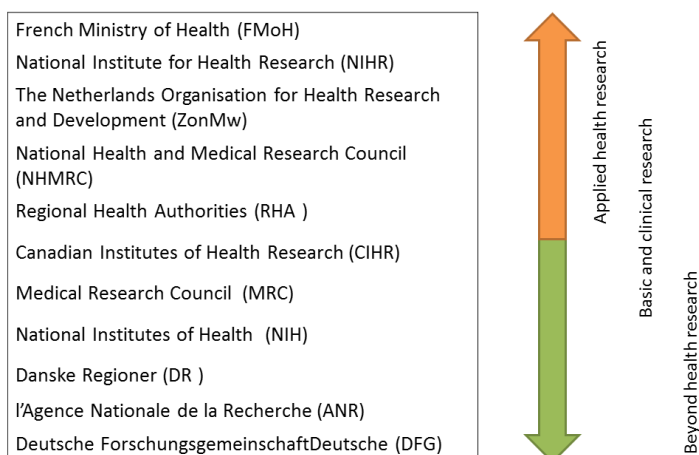


Figure 2 - Overview of the focus of the research agenda of research funders

Evaluating the research agenda and structure of these funding agencies provided an insight on individuals and organisations that influence and shape them. National and international policies and events can influence the decisions made in these organisations. Some examples are as follows:

- **The UK MRC** works in partnership with nine government departments, research councils and charities to lead an initiative aimed at supporting informatics research, infrastructure and scientists.
- **The English NIHR** invested in two national priorities identified by policy makers in the UK: dementia (the Prime Minister's Dementia Challenge) and antimicrobial resistance (identified by the Chief Medical Officer).
- **The US National Institutes of Health (NIH)**, a part of the U.S. Department of Health and Human Services, is the principal US medical research funding agency. NIH is strategically responsive to Congressional legislation that adjusts NIH's programmes to meet changing research needs. When I conducted the study, NIH had a operating budget of \$30.15 billion, an increase of \$1 billion (program level) over the fiscal year 2013. NIH has 27 Institutes and Centers, each with a specific research agenda, often focusing on particular diseases or body systems. NIH leadership plays an active role in shaping the agency's research planning, activities, and outlook (Table 13).
- When this study was conducted, **Australia's NHMRC's** priority actions were set out in the NHMRC Strategic Plan 2013-15 tabled in the Australian Parliament on 18 January 2013. These included: *“(a) create new knowledge through support of discovery research; (b) Accelerate research translation and build Australia's future capability for research and translation; (c) Set high standards in ethics in health care and research; and (d) Work with partners – States and Territories, health bodies, health industries and community and consumer groups”*. NHMRC's work is underpinned by the principles of “fairness, transparency, independence, appropriateness and balance, research community participation, confidentiality, impartiality, quality and excellence” (Table 14). The members of the council of the NHMRC include the chairs of each of its principal committees, the chief medical officer, head offices of commonwealth and state/territory, along with individuals with specific expertise and experiences e.g. health needs of aboriginal people, expertise in consumer issues, business and nursing professions. The committees are the research committee, the Australian health ethics committee, the human genetics advisory committee, the health care committee and the prevention and community health committee.
- **The Dutch ZonMW's** main commissioners are the ministry of health, welfare and sport and the Netherlands Organisations for Scientific Research, so its focus is on projects related to

improving health and health care in The Netherlands. The organisation not only focuses on conduct of health research but also on implementing research findings. In a meeting, a senior member of ZonMW provided an example in which the funder decided to fund a replication of a clinical trial in The Netherlands despite available results of other clinical trials in other countries. They decided to fund this trial as it had important implications for subsequent implementation of the results in The Netherlands.

Table 13 - the list of NIH institutes and centres

NIH Institutes	<ol style="list-style-type: none"> 1. National Cancer Institute (NCI) — NCI 2. National Eye Institute (NEI) 3. National Heart, Lung, and Blood Institute (NHLBI) 4. National Human Genome Research Institute (NHGRI) 5. National Institute on Aging (NIA) 6. National Institute on Alcohol Abuse and Alcoholism (NIAAA) 7. National Institute of Allergy and Infectious Diseases (NIAID) 8. National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) 9. National Institute of Biomedical Imaging and Bioengineering (NIBIB) 10. Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) 11. National Institute on Deafness and Other Communication Disorders (NIDCD) — Est. 1988 12. National Institute of Dental and Craniofacial Research (NIDCR) — Est. 1948 13. National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) 14. National Institute on Drug Abuse (NIDA) 15. National Institute of Environmental Health Sciences (NIEHS) 16. National Institute of General Medical Sciences (NIGMS) 17. National Institute of Mental Health (NIMH) 18. National Institute on Minority Health and Health Disparities (NIMHD) 19. National Institute of Neurological Disorders and Stroke (NINDS) 20. National Institute of Nursing Research (NINR) — Est. 1986 21. National Library of Medicine (NLM) — Est. 1956
NIH centres	<ol style="list-style-type: none"> 1. Center for Information Technology (CIT) 2. Center for Scientific Review (CSR) 3. Fogarty International Center (FIC) 4. National Center for Complementary and Alternative Medicine (NCCAM) 5. National Center for Advancing Translational Sciences (NCATS) 6. NIH Clinical Center (CC) — Est. in 1953

Table 14 - Processes to set the research agenda for the funding agency (high level decisions rather than for individual grant submissions)

NIHR (UK)	<p><i>Investigator initiated research</i> – decisions are made by a panel of stakeholders including researchers, policy makers and patient representatives; applications must meet minimum criteria e.g. involving patients in developing research proposals.</p> <p><i>Priority driven research (themed calls)</i> – This can be driven by policy makers priorities. NETSCC (NIHR Evaluation, Trials and Studies Coordinating Centre) builds partnerships with external organisations and has an open online web form for the submission of potential research questions. They also support the James Lind Alliance Programme of Priority setting partnerships that engage with clinicians and patients to priorities. An advisory board is involved to identify overlapping topics.</p> <p>NIHR introduced an “adding value to research” framework to meet the targets of the “reducing research waste” initiative. Both programmes are monitored against these criteria.</p>
MRC (UK)	<p>The overall strategic plan guides the specific objectives and goals for each funding panel. The strategy board, the research boards and the four overview groups (public health, global health, and translation and research careers) are heavily involved in setting the research objectives.</p>
CIHR (Canada)	<p><i>Investigator Initiated research</i> - must be of internationally accepted standards of scientific excellence and improve health for Canadians.</p> <p><i>Priority driven research (themed calls)</i> - is designed to respond to Canada’s strategic health-related research priorities developed by their Governing Council and Science Council, by evaluating government priorities, emerging needs, trends and important knowledge deficits in the Canadian health research landscape.</p>
DFG (Germany)	<p>The DFG is the self-governing organisation for science and research in Germany. It serves all branches of science and the humanities. In a multi-layered decision-making process, proposals are evaluated by voluntary reviewers according to scientific criteria; and then assessed by chosen members of the Review Board, with the final decision taken by each Grants Committee which consists of researchers, representatives of federal and state governments, and the Donors’ Association for the Promotion of Sciences and the Humanities. Any eligible researcher may submit a funding proposal at any time and on any research topic. As the DFG does not specify a topic for proposals, but, instead, reacts to proposals on any topic, it promotes research primarily in “response mode”, thereby complementing the agenda driven and programme oriented funding by the ministry of research and education (BMBF) in Germany.</p>
NHMRC (Australia)	<p>Has an overall strategic vision and health care, preventive and community health and genetic committees to advise them along with principles of: Fairness, Transparency, independence, Appropriateness and balance, Research community participation, Confidentiality, Impartiality, Quality and excellence. It is mostly concerned with investigator initiated research.</p>
ZonMw (Netherlands)	<p>The main commissioning organisations of ZonMw are the Ministry of Health, Welfare, Sport, and the Netherlands Organisations for Scientific Research. ZonMw involves several stakeholders to define the programmes and agenda for allocating research funding. Programmes have different perspectives: simulating scientific quality, developing certain scientific fields, developing and researching innovations in health care, development and research for specific target groups, coordinating large-scale introduction of proven valuable innovations. Prioritised Research Agendas of professional associations as well as those of social organisations and movements (like gender and health) are used in some programmes to help judge the relevance of the proposals.</p>
NIH (USA)	<p>The U.S. congress sets NIH institutes and centers funding levels and directs NIH attention to areas of research interest or emphasis. The NIH Division of Coordination, Planning and Strategic Initiatives in the NIH Office of the Director identifies important areas of scientific opportunity, rising public health challenges, and gaps in knowledge that deserve special emphasis. Trans-NIH planning for the Common Fund involves broad stakeholder input from multiple scientific and public inputs. The mission of each NIH Institutes and centres generally</p>

	<p>focuses on a different disease, organ, or stage of life. The individual ICs set their own research priorities considering the following factors, IC mission, available funding, scientific needs and opportunities, gaps in funded research, burden of disease, and public health need, such as an emerging threat. Priorities are partially driven by the research community with their investigator initiated proposals. Each of the NIH institutes and centers update their strategic plans regularly and make them publicly available on the RePORT portal. NIH funding strategies are updated and made public annually through the website.</p>
FoH (France)	<p>The general research agenda and scope of the institute is set by the policy makers according to a national health strategy which supports further investment in primary care research. There are seven general programmes that accept funding applications:</p> <ol style="list-style-type: none"> 1. National clinical hospital research programme, PHRC-N ; 2. National clinical research in oncology, PHRC-K ; 3. Inter-Regional Programme hospital clinical research, PHRC-I; 4. National Health economics research programme, PRME-N ; 5. The medico-economic research program in oncology, PRME-K; 6. Research Program on the performance of the healthcare system, PREPS; 7. The nurse and paramedic Research Hospital Program, PHRI. <p>They use consensus processes to reach grant funding decisions.</p>
ANR (France)	<p>ANR has a work programme with four interlinked components, each with a specific budget and governance- (major societal challenges, at the frontiers of research, building the European research and France international attractiveness, economic impact of research and competitiveness). They work across the European Horizon 2020 framework programme. There are both targeted calls (mostly collaborative), and a general call for proposals with a two-stage selection process.</p>
DR (Denmark)	<p>The five regions are responsible for allocating resources within their geographical areas. They seem to engage with policy makers and are guided by the priorities of the ministry of health. They suggest the following ways in which resources can be allocated: (a) First-come-first-served (b) Preadmission evaluation with or without explicit criteria for choosing between projects (c) Co-funding (d) Quota system with or without criteria for choosing between projects.</p>
RHA (Norway)	<p>Each RHA has established a research strategy (available on the website) based on regulations and initiatives from the national health authorities with some local or regional adaptations. For example, the central RHA has six research programs: (a) Patient centered clinical research; (b) Translational research; (c) Medical technology (e.g. imaging); (d) Informational and communicational technology; (e) HUNT (population study), biobanks, and registries; and (f) Health services research. The regional liaison committees involve representatives from the RHA, universities in the region, and clinicians, policy makers, researchers and some patients. There are also initiatives to increase collaboration between different regions, for example by the involvement of the Norwegian Research Council.</p>

The selection of funding agencies was intended to demonstrate diversity of public national research funding agencies in developed countries. In two instances, I selected two funding agencies in the same country (UK and France). In both cases, one funding agency has a predominately basic science focus and the other one an applied research focus. In both cases (and others), I could not identify a national strategy describing how this funding organisation coordinates their research agenda and priorities with other organisations in their country. In a conversation with a staff member of one of the funding agencies, I was told that funding agencies in the UK meet or communicate with each other to ensure some coordination between their work. There are no details publicly available on how this collaboration works. Regarding the UK, there is an overall diagram that is intended to demonstrate the research pathway and the position of two major

health-related funders (Figure 3). The research pathway assumes that research starts with a new idea from basic scientists. Ideas which are successful in the lab move forward to applied research. MRC mostly funds basic science research although it also funds some clinical trials and public health projects. NIHR supports applied research as the next step of development. This theoretical pathway is an inadequate representation of research processes. Basic science research ideas sometimes arise from applied research projects and occasionally from issues raised by members of public. Based on the dominant model, it can be seen that priorities in applied research tend to be driven by priorities in basic science research. However, basic scientists are not aware of, or involved in, major clinical and public health issues to drive priorities.



Figure 3 - The research pathway to outline the work of NIHR and MRC (ref: <http://www.nihr.ac.uk/documents/about->) NIHR/Briefing-Documents/1.1-The-National-Institute-for-Health-Research.pdf

The structure of funding programmes in NIHR

As part of a separate project, I have data on NIHR funding mechanisms which were not covered in the published papers. The project focused on engaging with policy makers regarding the prioritisation of systematic reviews. I interviewed several people in the UK, including Professor Tom Walley, director of the NIHR Health Technology Assessment and Efficacy and Mechanism Evaluation programmes, on how funding to prioritise systematic reviews is decided and allocated. There are underlying principles that drive the work of NIHR e.g. ensuring patient benefit and reducing research waste. NIHR is closely related to the National Health Service (NHS) in the UK. There is a specific focus in their funding programme looking at projects that potentially could lead to improved patient health within five years. NIHR also introduced an ‘adds-value’ framework in research. Adding value in research ensures that NIHR-funded research answers questions relevant

to stakeholders; uses appropriate designs and methods; is delivered efficiently, provides full results accessible in publications; and produces reports that are complete, unbiased and usable.

NIHR has a range of programmes focusing on different research topics, including health services and delivery research, invention for innovation, health technology assessment (HTA) and public health research. All the programmes have the same underlying principle: commissioning research which meets the information needs of healthcare and public health professionals, practitioners, policy makers, patients and the public. All of the research proposals require a systematic review before publication and need patient involvement before submission.

The key funding for systematic reviews on health care topics in the UK comes from NIHR, predominately through the systematic review and health technology assessment (HTA) programme. However, other programmes - e.g. health services research and research for patient benefit - might also fund systematic reviews. The decisions on the funding of a programme of systematic reviews are made mainly by the director. In part, this is through block funding to the Cochrane Collaboration. Although the NIHR director may be engaged in the process, the Cochrane Collaboration makes independent decisions on prioritising topics. As Cochrane is an organisation containing diverse groups, it has a diverse range of approaches to prioritising topics (and in some cases, it is very vague how decisions are made). In addition to the central funding to the Cochrane Collaboration, NIHR provides incentive funding for Cochrane Reviews that directly benefit the NHS in England. The committee making those decisions includes patient representatives and individuals with experience in policy and systematic reviews.

The HTA programme has a diverse approach to setting priorities for systematic reviews. There is a HTA prioritisation panel but other individuals and organisations can affect the decisions:

- The *HTA prioritisation panel* operates a complex process starting with the identification of topics, the involvement of a panel of NHS experts, and comparisons with other resources allocated in the NHS. The group includes NHS managers, patient representatives, commissioners and advisers but the final decisions are always taken by the director.
- The existence of the *National Institute of Clinical and social care Excellence (NICE)* has a clear role in shaping the decisions made by funding agencies. Some projects commissioned through the health technology assessment programme have been selected to fill gaps and to inform NICE policy decisions
- *Policy makers and managers* in the NHS can suggest topics. In certain situations, NIHR can respond quickly to a policy request if an urgent decision is needed. For example, in 2009, the 'flu' pandemic led to a systematic review being commissioned to be completed in three

months in order to inform NHS managers. Commissions like these can come from higher or lower level policy makers

The HTA programme also accepts applications in a responsive format – researchers can submit grants on any topics (as long as they are relevant to patients). However, these applications tend to be more complicated to review, with economic analyses, Individual patient data analyses, or realist reviews (a model of research synthesis that is designed to address questions on complex social and health care interventions and programmes. It is an explanatory analysis what works, in what circumstances, in what respects and how (90)). In addition to the HTA programme, the health services research programme can also commission (or be responsive to) systematic review projects. In all these cases, conflict of interest can be an issue. Individuals might not report conflicts of interest and they may have academic/intellectual conflicts of interest on a specific topic. They may thus advocate for their “pet” research topic and not consider sufficiently systematically the existing evidence on the need (or lack of need) of a new research project.

Results of the survey of research funders

The key results of the survey are outlined in Chapter 4.

The fundamental issue that these studies (and the previous studies) identified was the lack of transparency in the process of setting priorities for research and other related organisational and policy issues. Lack of transparency or misleading information can negatively affect public trust in scientific organisations (and consequently science itself). Public viewpoints drive politicians, their views and actions. Politicians have a key role in continuing the support of funding agencies.

Several research funding agencies have promising strategies (or plan to have them) to address key aspects of the “Reduce research waste” framework (21). However, there are many gaps in their efforts and substantial uncertainty about how to reduce waste. In the agencies we studied, grant committees were dominated by academics and clinicians. NIHR and ZonMW had the most extensive involvement of members of the public. There is no international agreement or consistency in policies and procedures intended to reduce research waste and increase the efficient allocation of scarce resources for research on questions that are important to the public and practitioners. The process to set a research agenda involves many stakeholders in complex interactions but these processes are difficult to monitor and consequently difficult to capture. An example of data collected from funders is available in Table 15.

I did not find any studies evaluating the impact of decisions about strategic objectives, setting priorities and designing the infrastructures of research funding agencies on the selection and composition of research topics. This may be important because research priority setting exercises involving patients and clinicians have shown that the priorities of patients and clinicians can differ

from those of researchers: patients and clinicians want more evaluation of educational interventions, physical and psychological therapies, and service development, while most clinical trials are conducted on drugs, vaccines, and biologics (16, 31, 91). In another example, a research priority setting process focusing on burn survivors found that patients' priorities were control of itching and oedema in scars and donor sites, but these were not reflected in researchers' priorities (92). One of the key researchers (funders) mentioned that they also struggled to get any researcher to conduct research on "itching and oedema in scars and donor sites" despite availability of funding. It is unclear from our survey how extensively funders monitor waste-reducing policies. A staff member of one of the funding agencies raised the issue of the lack of resources to monitor compliance with the "Reduce research waste" framework (21). It is unclear why these funding agencies do not allocate funding in ways that would ensure an accountable process for funding research. It seems that, in most countries, the processes of governance do not hold funding agencies accountable for measuring whether and how they address the questions raised by the "Reduce research waste" framework. We suggest that at least two aspects of monitoring would be worth considering: (a) how well researchers following the protocols and methods needed to conduct research that will deliver the research quality envisaged in the funding application and (b) how should any changes of the funding be managed to ensure high quality research and sustainability?

There were several meetings at which the results of the projects were presented to funding agencies. One of the issues that was raised and discussed was the need to compare the regulation, policies and processes to prepare and submit grant applications. There was a recognition that some steps are unnecessarily burdensome and waste resources for researchers and funders. This has also been raised in previous studies and anecdotes (23). Further discussion and evaluation of processes across the funding agencies and sharing experiences could help to inform the design and implementation of better processes and policies across these organisations.

There are several academic initiatives aiming to improve the quality of research and reduce research waste. These initiatives have made more progress in some disciplines than in others. Conducting systematic reviews to improve practice and research or introducing reporting guidelines to improve reporting of research articles was first introduced for clinical research. These initiatives have been extended to other areas e.g. animal research. However, the latter are at earlier stages and are less developed and need further work to reach similar standards to those in clinical research(93-95). This explains some of the differences across funding agencies that focus primarily on applied research and those that focus on a broader range of scientific disciplines.

Table 15 - Overview of research funder’s performance against criteria of the Reduce Research Waste framework (see guidance at the bottom of each column regarding on the colouring of each column)

	Does the funder promote the use of relevant <u>reporting guidelines</u>?	Do they have any targeted programmes to <u>support, prioritise and/or fund systematic reviews</u>?	Are applicants who seek <u>support for new research required to refer to systematic reviews of existing evidence</u>?	Does the funder provide targeted/ prioritised funding to undertake <u>“research on research”</u>?*
NIHR	YES. NIHR clearly recommends the use of reporting guidelines available on the EQUATOR network website.	YES. "There are commissioned and researcher led programmes that fund systematic reviews amongst a wider portfolio of research." NIHR also funds several UK-based Cochrane Review Groups.	YES. Only funds research that is supported by a systematic review of existing evidence. For commissioned calls, the review is done by the funder.	YES. The NIHR/MRC Methodology Research Programme explicitly includes “research on research” as part of its remit, and has funded guideline initiatives such as EQUATOR and COMET in the past.
MRC	YES. The ARRIVE guideline is clearly mentioned. CONSORT is mentioned briefly in good practice guidelines.	NO.	PARTIAL. The global Health Clinical Trial Programme requires systematic reviews.	

CIHR	YES. They refer to the CONSORT guidelines.	YES. CIHR has a knowledge synthesis programme which funds systematic reviews.	PARTIAL. Encourages (but does not require) a systematic review to be included in proposals for clinical trials.	NO. However, they have funded research on research through other funding schemes and provided data and funding to other organisations, such as the Rand Corporation, to undertake “research on research”. **
DFG	YES. DFG recommends the use of CONSORT, PRISMA and STARD.	NO.	PARTIAL. Only for clinical trials	NO.
NHMRC	PARTIAL. Guidelines are not clearly mentioned as required for project grants but there is one programme grant in which CONSORT was required in the grant application.	NO.	NO.	NO.
ZonMw	YES.	PARTIAL.	PARTIAL.	NO.

	The animal research project departments recommend the use of ARRIVE guidelines.	They do not have a programme that structurally provides grants for systematic reviews. However, in several programmes commissioning one or more reviews is often a first step in selecting and prioritizing topics and research questions. Also, they occasionally ask for a systematic review on a specified subject as part of a broader research programme.	Only for clinical trials	They are developing a funding programme for research on research focusing on “research integrity” that will be opened in 2017.
NIH	YES. A comprehensive list of reporting guidelines is recommended to researchers.	NO. Programmes to support systematic reviews are more in line with the mission of the Agency for Healthcare Research and Quality (AHRQ).	NO.	NO. However, they have internal staff working on research on research.
PHRC	NO.	NO. They have no specific programme for systematic reviews. However, they do accept systematic reviews in their	NO.	YES. They fund the Cochrane Centre in France that has an extensive focus on “research on

		process.		research". They had a budget line for this item until 2015 but it is not clear whether it will continue.
ANR	NO.	NO.	NO.	NO. The generic call contains a dedicated line for research methods in the Life, Health and Wellbeing challenge.
DR	NO.	NO.	NO.	Unclear
RHA	NO.	NO.	NO.	NO.
	Green – If several reporting guidelines are required, Yellow – if one of the reporting guidelines are required (or encouraged), Red – If not recommended White – if unclear	Green – they have a programme, Yellow – they have sometimes programme targeting systematic reviews Red – no targeted programme. White - Unclear	Green - if SR for all proposals Yellow - If SR only for clinical trials Red - if no rules White – if unclear	Green – they have a dedicated research on research funding programme; Yellow – they have either an internal research on research programme or they have funded research

				on research projects through other funding schemes; Red – they have no programme, White – Unclear
<p><i>Note:</i></p> <p>* <i>This refers to “research on research”, or methods to improve research production such as reporting guidelines. We did not include those open funding calls which don’t target or specifically encourage “research on research”. Some of these funders have funded methodology research in the past (e.g. ZonMw and NIH). However, they did not have a prioritised or targeted research scheme for that and “research on research” projects had to compete with other research projects. Some of these funders (e.g. NIHR and NIH) also have internal departments or research groups that engage with research on research.</i></p> <p>** Examples of projects where CIHR was involved include: http://www.rand.org/randeurope/research/projects/mental-health-retrosight.html http://www.rand.org/pubs/monographs/MG1079.html</p>				

Funding for methodological research

There is a need for more funding for methodological research in healthcare research. In the research community, methodological research (or meta-research)⁹ (96) has been central to the evaluation and analysis of research practices to identify how these practices affect the availability, quality and usability of research. Publication bias is a good example of the importance of this form of research (97). Methodological research showing that publication bias is a problem led to changes of policies and actions to address this issue. There is still a lot to be done about publication bias but methodological research was (and still is) key to identifying the problem, planning interventions to address it and monitoring the effect of those interventions.

Funding for methodological research is very limited. As Table 15 demonstrates, the only funders with a dedicated methodological research funding programme are NIHR and MRC. ZonMw is planning a methodological research programme on research integrity. Some funding agencies undertake methodological research as part of their internal work e.g. NIHR and NIH. Other funding agencies are supporting research groups that prioritise methodological research e.g. the French ministry of health supporting the French Cochrane Centre. Beyond our survey, there is also limited

⁹ Meta-research, or the scientific study of research practices, aims to characterize existing standards and ultimately improve the quality and reliability of scientific research (<http://collections.plos.org/meta-research-reproducibility>)

funding available from other agencies that support methodological research. For example, in the UK, in addition to the MRC, the Chief Scientist's Office in Scotland and the Cochrane Methodological Innovation Fund (the Cochrane Collaboration) have funded methodological research.

An issue to consider is whether methodological research should be conducted by internal staff of funding agencies to inform their practices or should be an external funding programme to which independent researchers can apply. I believe that both are necessary. It is important that funding agencies monitor their internal practices and identify approaches to improving them. However, it is crucial to enable independent researchers to identify and raise questions that affect the wider research community. Independent researchers should also be encouraged to conduct methodological research on the performance of funding agencies independent from the funding agencies themselves.

Impact of the projects on funders' research:

I presented the results of this project at several research conferences and meetings. This helped to engage research funders and to establish a Funders' Forum. The initial results of the study were first presented at the inaugural meeting of the Evidence-Based Research Network in Bergen, Norway, in December 2014. Further results were presented at the REWARD conference in Edinburgh, Scotland in October 2015.

Several funding agencies have shown interest in the results of the project. The National Institute for Health Research (NIHR) invited me to present the results at a meeting in November 2015 along with ZonMW (the main funder of healthcare research in The Netherlands) and the French Ministry of Health, and then to discuss how issues raised by the project could be addressed. The project was also presented in the Cochrane Colloquium (October 2016) in Vienna, both as a panel and as a special session which I led on using systematic reviews to inform future research. Both events evoked considerable interest, which resulted in broad agreement that it would be useful to conduct a research project to examine how research funders are using - and should use - systematic reviews in the process of informing primary research. I was invited afterwards, to present the data at a conference to celebrate NIHR's 10th anniversary in London in May 2016. The discussions during this meeting led to the idea of establishing a funders' forum to address some issues raised by the evaluation (in which I have a key role). The Funders' Forum aims to enable funding agencies to exchange experiences in addressing issues and create working groups to address them. The Forum had its first meeting on 27 January 2017 in London. It is co-convened by individuals from three major research funders: NIHR (UK), ZonMW (Netherlands) and Patient-

Centered Outcomes Research Institute (PCORI; USA). The forum was officially launched as part of the 5th International Conference on Research Integrity in The Hague in May 2017. The next meeting will be later in 2017 hosted by PCORI in Washington. The forum is called “Ensuring Value in Research (EViR) Funders’ collaboration and Development Forum”.

Next steps:

I am working with colleagues on the following research projects as next steps following from the projects that comprise this dissertation. Some projects are at the design stage, while others are at the data collection stage:

Research Priority Setting

- 1) Conducting informal interviews with individuals working on priority setting across the Cochrane Collaboration to identify the barriers and facilitators to implementing more structured approaches to setting priorities for Cochrane Reviews (design stage)
- 2) Conducting a systematic review of qualitative and quantitative studies that describe or evaluate research priority setting projects (data collection stage)

Funding agencies

- 3) Evaluating a wider range of funding agencies including international funders and funding agencies based in developing countries (data collection stage)
- 4) Developing a conceptual framework for how systematic reviews can be used to inform future research in a funding agency (design stage)
- 5) Evaluating the REF 2014 impact stories that focus on clinical trials on whether the underlying research met some key criteria of the reduce research waste framework (design stage)

Final note:

Previous studies have shown that robust analysis of what has worked in research can be beneficial to inform the allocation of future research funding. Better ways of evaluating the impact of research and funding organisations can inform decisions on prioritisation and allocation of funding. Although several funding agencies have taken the initiative to evaluate their work, little is being done to identify and compare methods and approaches to the evaluation of research impact (98). A key problem across most of these organisations is a lack of transparency and accountability, which obscures the extent to which their priority setting processes achieve their goals and targets. A good example is the current situation in the Cochrane Collaboration. Following publications by myself and others and the work of the Cochrane Priority Setting Methods Group, the governing board of the Cochrane Collaboration announced a policy requiring all review groups to set priorities for topics of systematic reviews. However, it soon became clear that these groups have different

goals and opinions about what is best for the Cochrane Collaboration as a whole. I am helping to organise a meeting of leaders of Cochrane Review Groups to address these issues. My evaluation of funding agencies found a similar lack of transparency and accountability in the context of conflicting values among stakeholders that decreases the possibility of accountability and scrutiny by researchers and their institutions.

Research priority setting is almost always a group activity that leads to decisions about topics and key questions to investigate and to fund. These decisions define the quality and implications of the evidence, and syntheses of it, that become available to patients, public health professionals and policy makers to help them make better-informed decisions. It is important that we understand how, why and by whom such priority setting decisions are made. My projects and the publications they have generated document the characteristics and limitations of the research priority setting process in selected key organisations and how research priority setting is related to the allocation of resources in these organisations. My research projects demonstrated that a key problem across most of these organisations was a lack of transparency and accountability about whether priority setting processes are achieving the goals and targets of the organisations. Conversations with several of the stakeholders about the results of this project revealed that conflicting views among those involved in these processes are a significant cause of this problem. These individuals have different views, values and principles. My recommendation is that organisations that set priorities for systematic reviews improve how they integrate the diversity of these views and values within their processes and structures.

Regular collection of data is required to monitor whether funding agencies achieve the objectives of reducing research waste and enhancing value. It is important that the evaluation is external to the organisation to ensure that it is valid and independent. However, it is also necessary to have a collaboration with the funders as the internal staff have access to internal data and information that external researchers don't have. The members of EViR forum have developed a set of guiding principles based on the different dimensions of reduce research waste framework. I am currently working with them in developing ways to measure the performance of the organisations in achieving these principles. My recommendation will be that all stakeholders in the research system identify measurements to monitor their performances in reducing research waste and regularly collect these data to inform their future work.

Appendix 1 Selected research output relevant to this PhD

• MAJOR HONOURS & DISTINCTIONS

Honour/distinction	Date awarded
2 nd place, British Dental Editors Forum (BDEF); Young Dental Communicator Award 2014 from the <i>British Dental Journal</i> for evidence summary publications in British Dental Journal based on a priority setting exercise	2014
Bill Silverman Prize awarded by Cochrane for the JCE priority setting papers	2012

• POSTGRADUATE SUPERVISION relevant to projects related to this PhD

Student/staff	Degree and title of thesis	Start date	Completion date (or proposed completion date)
Anastasios Plessas (Director of studies)	ResM, Impact of stress on the practice of dentistry The topic was selected as part of a research priority setting exercise with a systematic review followed by primary studies	Oct 2015	2018
Zoe Allen (third supervisor)	PhD, Exploring the referral interface between general dental practice and salaried dental services The topic was selected as part of a need identified by clinicians with a systematic review followed by primary studies	Jan 2013	2018
Agatha Haines (second supervisor)	PhD, Ideas exchange: Understanding the human object – www.cognovo.eu The project amongst other issue explored how the concept of human object affects what research questions that researchers ask.	April 2014	2018
Dr. Jaysan Charlesford	Postdoctoral fellow, Impact of a community and patient-centred dental school on the existence and gradient of oral health inequalities in Devon and Cornwall The project was identified as priorities by local decision makers and the project explores the mismatches between scientific expectations and members of public	May 2017	Nov 2019

• RESEARCH ACTIVITY

a) Summary of current research

a) Summary of current research

- **Conducting meta-research on how research funders contribute to reducing research waste**
- Meta-research is an evolving scientific discipline that aims to evaluate and improve research practices. I lead the work around funding agencies as part of the wider Reduce Research Waste initiative (REWARD – www.researchwaste.net). The REWARD initiative is an international collaboration with academics from around the world e.g. Stanford University (USA), Toronto University (Canada), Bond University (Australia), University of Edinburgh (Scotland). For the funding project, I work with ZonMW (a key health care research funder in Netherlands), National Institute for Health Research (NIHR) (a key health care research funder in UK), French ministry of Health, James Lind Alliance (UK), Queen's University Belfast (Northern Ireland), Bond University (Australia), Norwegian Institute of Public Health (Norway), Bergen University College (Norway) and University of Southern Denmark (Denmark). I have published the results of this project in Lancet (impact factor 2015 is 46.119). The project already had clear outputs and impact on the work of other organisations and will be part of a new impact story for REF 2020.
- **Oral Health Inequalities** - Measuring the impact of the Peninsula Dental Social Enterprise (PSDE) and the Dental School on oral health inequalities in Devon and Cornwall. I received funding from PDSE to conduct this project. The project involves working with local policy makers and academics but also international collaborators from Ottawa University, Canada.
- **Cochrane Priority Setting Methods Group** (<http://priority.cochrane.org>): I conduct methodological and implementation research as part of an international collaboration of researchers and stakeholders with an interest in research priority setting methodology. This also included an interdisciplinary project as part of the larger Cognovo project (www.cognovo.eu) with colleagues from the arts, humanities and cognitive science. The project looked at how the interactive design approach to biomedicine can raise new ways to approach research questions that to address clinical problems. The Cochrane Priority Setting Methods group is an international collaboration led by me between Plymouth University, John Hopkins University (USA), Cambridge University (UK), UCL (UK), Ottawa University (Canada), Bihar Monitoring and Evaluation Project (India), Modena University (Italy), Melbourne University (Australia). The Journal of Clinical Epidemiology agreed to devote a special issue to research priority setting to publish my work along with my research collaborators. The results of this project were part of a REF impact story that was submitted in 2014 and praised by the REF panel for its reach and significance. There are organisations around the world that use the publications to implement new approaches to set priorities in their organisation.
- **Conducting and implementing systematic reviews on the effectiveness of healthcare interventions and develop methods in this field** - (e.g. rehabilitation of astronauts as part of the newly established *aerospace medicine systematic review group*, local consensus process for implementing guidelines, updating the mandibular fracture review, updating the community-based interventions for promoting child oral health review), developing new methods on how to conduct systematic reviews (e.g. developing methods on the use of systematic reviews to inform future research, comparing the Cochrane Library with the Global Burden of Disease). These projects are part of international collaborations with Norwegian Knowledge Centre (Norway), University of Melbourne (Australia), UCL (UK), Northumbria University (UK), European Space Agency (Germany), University of Colorado (USA), University of Washington (USA) and the Royal Dental Hospital of Melbourne (Australia). I have published these projects in well-known academic journals e.g. the BMJ (impact factor 2015- 19.697), the Cochrane Library (impact factor 2015- 6.035) and JAMA dermatology (impact factor 2015 - 5.097). I am also on the Steering group of “the Global Health Trials Methodology Research Agenda: a priority setting exercise” project. The

a) Summary of current research

project intends to identify priorities on trial methodology. The other steering group members are based in University of Birmingham (UK), University of Oxford (UK), University of Bristol (UK), Queen’s University of Belfast (Northern Ireland), South African Medical Research Council (South Africa), Cochrane Innovations (UK), University of College London (UK), University of Liverpool (UK), Tianjin University of Traditional Chinese Medicine (China).

- **Interdisciplinary research to address priority research questions** – I worked with academics from different fields to address questions that were prioritized as part of a process of stakeholder engagement. One such project, as mentioned above, was methodological research on how research priorities are set. Others were priority questions identified through consultation with dentists: environmental sustainability in dental practices working with experts in this field in the faculty of health; and, in collaboration with psychologists, looking at the impact of fear and anxiety on dentists’ performance.

b) Summary of research in the previous three years

- My work on research priority setting, interdisciplinary research to address priority research questions, and systematic reviews has been a key theme in my research over the past 10 years. Specific highlights from the past three years are:
- **Conducting methodological research on research priority setting** – as part of the Cochrane Priority Setting Methods Group, I conduct meta-research or evaluation projects in this field. A major focus was to evaluate priority setting tools to improve attention to equity in this process.
- **Conducting systematic reviews on the effectiveness of healthcare interventions** (mandibular fractures, approaches to oral health promotion, bonded amalgam for dental restorations, understanding differential attainment across medical training pathways)
- **Conducting research on the methodology of systematic reviews:** e.g. developing methods for dealing with conflicting systematic reviews, and to evaluate the quality and reporting of epidemiological studies

d) Relevant research grants and contracts

Dates	Award holder(s)	Funding body	Title	Value
2016-2019	Mona Nasser (PI), David Moles (Col)	Peninsula Dental Social Enterprise (PDSE)	Impact of a community and patient-centred dental school on the existence and gradient of oral health inequalities in Devon and Cornwall	£92,922
2016-2017	David Moles (PI), and other co-investigators, (Mona Nasser – Col)	Dental Education and Training limited	Developing sustainability in dental practice and education through an action research approach	£8,000
2015-2018	Tom Thompson (PI) And other co-investigators (Mona Nasser – Col)	National Institute for Health Research (NIHR)	A systematic review of physical activity for alcohol and substance use disorders: evidence synthesis with stakeholder engagement to formulate practical recommendations	£149,946
2015	Sam de Regan	General	Understanding differential attainment across	£34,837

	de Bere (PI) and other co-investigators (Mona Nasser – Col)	Medical Council (GMC)	medical training pathways	
2014-2015	Elizabeth Kay (PI) and other co-investigators (Mona Nasser – Col)	National Institute for Health and Care Excellence (NICE)	Production of an evidence review of approaches for conveying oral health promotion messages by dental teams	£54,628
2014-2019	Stuart Logan (PI) and other co-investigators, (Mona Nasser – Collaborator)	National Institute for Health Research (NIHR)	Peninsula Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) – Theme Evidence synthesis for policy and practice	£10 million
2014	Janet Richardson (PI) and other co-investigators (Mona Nasser – col)	Institute for Sustainability Solutions Research (ISSR) small collaborative award (ISSR has been re-structured as Sustainable Earth Institute)	How can dentistry be sustainable? an explorative study	£9,790
2013-2017	Sue Denham (PI) and other co-investigators (Mona Nasser – Col)	EU FP7 Marie Curie Initial Training Network (FP7-PEOPLE-2013-ITN-IDP 604764)	Cognovo: Cognitive Innovation	€4.1m
2012	David Moles (PI) and other co-investigators (Mona Nasser – collaborator)	NHS North Devon	A mixed-method study to investigate the referral behaviours and attitudes of NHS general dental practitioners in making referrals from primary dental care to specialist surgical services for the extraction of teeth in North Devon	£5,989
2011-2012	Mona Nasser (PI)	International Research, Networking and Collaboration, Round 3 scheme – Plymouth University	Developing a research programme for empirical studies on health research priority setting methodology	£9,574

2008- 2011 I worked in the German Institute for Quality and Efficiency in Health care (IQWiG) – the German version of National Institute of Clinical Excellence (NICE). As it was a government research institute, we were not allowed to apply for external research grants and we were a funder of systematic reviews in Germany.				
2007-2008	Peter Tugwell (PI), and other co-investigators. Mona Nasser (CI)	The Cochrane Collaboration Prioritisation Fund	Prioritising Cochrane review topics to reduce the know-do gap in low- and middle-income countries	£17,000
2004-2005	Zohreh Ahangari (PI), Mahvash Oskoi (CI), Mona Nasser (CI)	Iranian Centre for Dental research, Shahid Beheshti University of Medical Sciences (Tehran, Iran)	Antimicrobial Activity of Mineral Trioxide Aggregate (MTA), Portland cement and Calcium Hydroxide against five oral microorganisms.	The funding awarded was two million Iranian Toman, equivalent at that time to about £1,400

PUBLICATIONS

Books - Short Works

Green LW, **Nasser M**. Chapter 15: Further Dissemination and Implementation Research: The Need for Attention to External validity. In: Brownson RC, Colditz GA, Proctor EK (eds). Dissemination and Implementation Research in Health: Translating Science to Practice. New York: Oxford University Press; 2012. ISBN13: 9780199751877, ISBN10: 0199751870 (an update will be published in 2017)

Departmental/Research Working Papers

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Journal Letters

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Journal Papers - Academic Journals

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 - 3) Richter C, Braunstein B, Winnard A, Nasser M, Weber T. Human Biomechanical and Cardiopulmonary Responses to Partial Gravity - A Systematic Review. Front Physiol. 2017 Aug 15;8:583. doi: 10.3389/fphys.2017.00583. eCollection 2017. Review. PubMed PMID: 28860998; PubMed Central PMCID: PMC5559498.
 - 4) Garner P, Hopewell S, Chandler J, MacLehose H, Schünemann HJ, Akl EA, Beyene J, Chang S, Churchill R, Dearness K, Guyatt G, Lefebvre C, Liles B, Marshall R, Martínez García L, Mavergames C, **Nasser M**, Qaseem A, Sampson M, Soares-Weiser K, Takwoingi Y, Thabane L, Trivella M, Tugwell P, Welsh E, Wilson EC; Panel for updating guidance for systematic reviews (PUGs). When and how to update systematic reviews: consensus and checklist. BMJ. 2016 Jul 20;354:i3507.
 - 5) de Silva AM, Hegde S, Akudo Nwagbara B, Calache H, Gussy MG, **Nasser M**, Morrice HR, Riggs E, Leong PM, Meyenn LK, Yousefi-Nooraie R. Community-based population-level interventions for promoting child oral health. Cochrane Database Syst Rev. 2016 Sep 15;9:CD009837.
 - 6) Moher D, Glasziou P, Chalmers I, **Nasser M**, Bossuyt PM, Korevaar DA, Graham ID, Ravaud P, Boutron I. Increasing value and reducing waste in biomedical research: who's listening? Lancet. 2016 Apr 9;387(10027):1573-86.
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 - 11) Ahangari Z, **Nasser M**, Mahdian M, Fedorowicz Z, Marchesan MA. Interventions for the management of external root resorption. Cochrane Database Syst Rev. 2015 Nov 24;11:CD008003. doi: 10.1002/14651858.CD008003.pub3. Review. PubMed PMID:26599212.
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 - 17) Shamliyan T, Ansari MT, Raman G, Berkman N, Grant M, Janes G, Maglione M, Moher D, **Nasser M**, Robinson K, Segal J & Tsouros S. Development and Implementation of the Standards for Evaluating and Reporting Epidemiologic Studies on Chronic Disease Incidence or Prevalence. *American Journal of Public Health Research*, 2013; 1 (7):183-190. DOI: 10.12691/ajphr-1-7-7 <http://pubs.sciepub.com/ajphr/1/7/7/> - This is a peer reviewed publication of part of an AHRQ report which also is peer reviewed and has a range of consultation that I was involved <http://www.ncbi.nlm.nih.gov/books/NBK53272/>.
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 - 19) **Nasser M**, Pandis N, Fleming PS, Fedorowicz Z, Ellis E, Ali K. Interventions for the management of mandibular fractures. *Cochrane Database Syst Rev*. 2013 Jul 8;7:CD006087.
 - 20) (T) Andrews JC, Schünemann HJ, Oxman AD, Pottie K, Meerpohl JJ, Coello PA, Rind D, Montori VM, Brito JP, Norris S, Elbarbary M, Post P, **Nasser M**, Shukla V, Jaeschke R, Brozek J, Djulbegovic B, Guyatt G. GRADE guidelines: 15. Going from evidence to recommendation-determinants of a recommendation's direction and strength. *J Clin Epidemiol*. 2013 Jul;66(7):726-35. doi: 10.1016/j.jclinepi.2013.02.003. Epub 2013 Apr 6. PubMed PMID: 2357074
 - 21) **Nasser M**, Ueffing E, Welch V, Tugwell P. An equity lens can ensure an equity-oriented approach to agenda setting and priority setting of Cochrane Reviews. *J Clin Epidemiol*. 2013 May;66(5):511-21.
 - 22) (T) Andrews J, Guyatt G, Oxman AD, Alderson P, Dahm P, Falck-Ytter Y, **Nasser M**, Meerpohl J, Post PN, Kunz R, Brozek J, Vist G, Rind D, Akl EA, Schünemann HJ. GRADE guidelines: 14. Going from evidence to recommendations: the significance and presentation of recommendations. *J Clin Epidemiol*. 2013 Jul;66(7):719-25.
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- 27) **Nasser M**, van Weel C, van Binsbergen JJ, van de Laar FA. Generalizability of systematic reviews of the effectiveness of health care interventions to primary health care: concepts, methods and future research. *Fam Pract.* 2012 Apr;29 Suppl 1:i94-i103.
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- 29) **Nasser M**. Evidence summary: can plastics used in dentistry act as an environmental pollutant? Can we avoid the use of plastics in dental practice? *Br Dent J.* 2012 Jan 27;212(2):89-91. doi: 10.1038/sj.bdj.2012.72. PubMed PMID: 22281636.
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- 39) de Souza RF, Chaves Cde A, **Nasser M**, Fedorowicz Z. A quantitative and qualitative evaluation of reports of clinical trials published in six Brazilian dental journals indexed in the Scientific Electronic Library Online (SciELO). *J Appl Oral Sci.* 2010 Apr;18(2):104-9.
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- 41) Chalkidou K, Tunis S, Lopert R, Rochaix L, Sawicki PT, **Nasser M**, Xerri B. Comparative effectiveness research and evidence-based health policy: experience from four countries. *Milbank Q.* 2009 Jun;87(2):339-67.
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 - 52) **Nasser M**, Fedorowicz Z, Newton JT, Nouri M. Interventions for the management of submucous cleft palate. *Cochrane Database of Systematic Reviews* 2008, Issue 1.
 - 53) Fedorowicz Z, Waters E, Tugwell P, **Nasser M**. Health research priority setting in developing countries of the Eastern Mediterranean region: partnering with the Cochrane Collaboration. *Eastern Mediterranean Health Journal.* 2007; 13 (3); 727-730.
 - 54) **Nasser M**, Al Hajeri A. A comparison of handsearching versus embase searching of the archives of Iranian medicine to identify reports of randomized controlled trials. *Arch Iran Med.* 2006 Jul; 9(3):192-5.
 - 55) Ahangari Z, Ashraf H, Oskooi M, Soltani Sh, **Nasser M**. Antibacterial activity of three endodontic sealers with various bases. *Beheshti Univ Dent J* 2005; 22(Special issue):1-6.

Official Reports: Whole Report

- 1) Shamliyan TA, Kane RL, Ansari MT, Raman G, Berkman ND, Grant M, Janes G, Maglione M, Moher D, **Nasser M**, Robinson KA, Segal JB, Tsouros S. Development of Quality Criteria To Evaluate Nontherapeutic Studies of Incidence, Prevalence, or Risk Factors of Chronic Diseases: Pilot Study of New Checklists [Internet]. Rockville (MD): Agency for Healthcare Research and Quality (US); 2011 Jan. Available from <http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=methresdisease>
 - 2) **Nasser M**, Sawicki P. Institute for Quality and Efficiency in Health Care: Germany. Issue Brief (Commonw Fund). 2009 Jul;57:1-12. The full report was published on the Commonwealth fund website on 28 July 2009
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<http://www.commonwealthfund.org/Content/Publications/Other/2009/Comparative-Effectiveness-Across-Countries.aspx>

Other Publications – Research

- 1) Karimkhani C, Boyers LN, **Nasser M**, Dellavalle R. Mapping research prioritisation by The Cochrane Collaboration to Global Burden of Disease 2010 data. Cochrane Methods. Issue September 2014.
<http://www.thecochranelibrary.com/SpringboardWebApp/userfiles/ccoch/file/Files/CochMethods2014.pdf>
- 2) **Nasser M**, Crowe S, Welch V, Ueffing E. Proposed Agenda setting and priority setting methods group. Cochrane Methods. Cochrane DB Syst Rev 2011 Suppl 1: 37-38.
http://www.cochrane.org/sites/default/files/newsletters/coch_meth_2011.zip
- 3) **Nasser M**. Priority setting in the Cochrane Collaboration. Cochrane Methods. Cochrane DB Syst Rev 2010 Suppl 1: 6.
<http://www.cochrane.org/sites/default/files/uploads/Newsletters/Cochrane%20Methods%202010.pdf>
- 4) Fox DM, **Nasser M**. Informing the politics of prioritizing (and funding) systematic reviews: another potential step for the Agenda and Priority Setting Methods Group. Cochrane Methods Supplement 2013. ISSN: 2044-4702.
<http://www.thecochranelibrary.com/SpringboardWebApp/userfiles/ccoch/file/Files/Cochrane%20Methods%202013.pdf>
- 5) Pooler J, **Nasser M**. Challenges in conducting priority setting exercises for Cochrane entities. Cochrane Methods Supplement 2013. ISSN: 2044-4702.
<http://www.thecochranelibrary.com/SpringboardWebApp/userfiles/ccoch/file/Files/Cochrane%20Methods%202013.pdf>
- 6) **Nasser M**, Tibi A, Savage-Smith E. Ibn Sina’s Canon of Medicine: 11th century rules for assessing the effects of drugs. The James Lind Library. (www.jameslindlibrary.org). Accessed Sunday 6 July 2008.
- 7) **Nasser M**, Tibi A (2006). Ibn Hindu and the science of medicine. The James Lind Library (www.jameslindlibrary.org).

Other Publications - Research Equivalent

I wrote blog post for the following websites

- 1) Cochrane Blog - What is a good topic for a Cochrane Review? What is a “real uncertainty”?
<http://www.cochrane.org/news/blog/what-good-topic-cochrane-review-what-%E2%80%9Creal-uncertainty%E2%80%9D>
- 2) British Medical Journal (BMJ) blogs - How can research publication be improved?
<http://blogs.bmj.com/bmj/2015/09/30/mona-nasser-how-can-research-publication-be-improved/>
- 3) ISSR blog (currently ISSR is called Earth Sustainability Institute) - Uncertainties, knowledge gaps and research priorities. Uncertainties, knowledge gaps and research priorities
<http://issrplymuni.blogspot.co.uk/2013/08/june-2013-uncertainties-knowledge-gaps.html>

Other Media - Research

There is a short interview with me in the Anniversary video of Cochrane talking about the Priority Setting Methods Group <http://www.youtube.com/watch?v=iaAmnAXOSwA#t=102> at time 1:40. I have also been asked by the Pan American Health Organisation (PAHO), which serves as the regional office for World Health Organisation (WHO) in the Americas, to host and run four webinars on my work on research priority setting. I ran the webinars but did not edit or prepare the videos.

- 1) Session one – Meet the Methods Group: An introduction to the Cochrane Priority Setting

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- Methods Group - <http://www.youtube.com/watch?v=Y1bCO3wNZOY>
- 2) Session two – An Equity Lens for Priority-Setting Approaches in Systematic Reviews
<http://www.youtube.com/watch?v=0OT2C0bMO5Y>
- 3) Priority Setting for Cochrane Review Groups: Tips, Tricks, and Case Studies
<http://www.youtube.com/watch?v=WIPOV96uubl>

Public Appearances (research-related only)
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- **Interviews** - I have been interviewed about my work with Cochrane by state TV in Bosnia (I was keynote speaker at the first Cochrane symposium in Bosnia). In 2007, I was interviewed for my work to get patient and consumers involved in systematic reviews in Iran (Cochrane Consumer Network <https://youtu.be/HvXNN8gUexl>). I have also been interviewed as part of a series for videos to celebrate the 20th Anniversary of Cochrane. It celebrates the work of researchers like me who designed and implemented projects that contributed to the goal of the Collaboration (www.cochrane.org), the leading evidence based health organisations in the world. I have been interviewed in three videos:
 - Cochrane Authors <https://youtu.be/fAmepEVL4cs>
 - Working together in the Collaboration <https://youtu.be/IJInSOZG6vQ>
 - Happy Anniversary Cochrane Collaboration IV <https://youtu.be/iaAmnAXOSwA>
 - **Social Media** - I run a personal blog <http://monanasser.wordpress.com> and a twitter account @monalisa1n. I talk about my research along with my personal interests in aviation. This makes the public more engaged. With others, I also run research focus twitter accounts @capsmg (priority setting) @ebrnetwork (evidence based research network) and sometimes curate twitter chats on issues faced by Cochrane authors (#cochraneauthor). As part of this project, I curated other research-focused twitter accounts. These are the reports:
 - Introduction - Smiling wide and flying high – Mona Nasser joins Real Scientists
<http://realscientists.wordpress.com/2014/07/13/smiling-wide-and-flying-high-mona-nasser-joins-real-scientists/>
 - Final report - Crowdsourcing the best in science: thanks and farewell to Mona Nasser
<http://realscientists.wordpress.com/2014/07/20/crowdsourcing-the-best-in-science-thanks-and-farewell-to-mona-nasser/>
 - Curating @wepublichealth 22-28 Sep 2014
<http://blogs.crikey.com.au/croakey/wepublichealth-an-experiment-in-citizen-journalism-meets-public-health/>
 - Curating @wethehumanities 12-19 Jan 2015
<https://wethehumanities.wordpress.com/2015/01/10/12th-19th-january-mona-nasser/>
 - **Press Releases**- There were a few press releases based on my research:
 - [International lecture links 10th-century medical philosophy to computer simulation in medical research](#): This was picked up by a few other websites for example: [Medical Express](#), [Science newswire](#). It was even translated and reported in an [Iranian journal](#).
 - [Review addresses value and waste in biomedical research](#): This was picked up by other news sources like [Science Daily](#)
 - [Plymouth academic to support Bosnian-Herzegovinian scientists on setting priorities for medical research](#). The event was also reported in an editorial “Mahmic-Kaknjo M, Novo A, Krleza-Jeric K. *FIRST BH COCHRANE SYMPOSIUM HELD. Mater Sociomed. 2016 Feb;28(1):74-6.*”
 - International role for dental school academic: This was picked up by other news sources like dentistry.co.uk
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c) Conferences

Major conferences attended over the last three years (including current year) plus any significant participation in previous years. – *I marked the one that I was invited speaker in blue*

Dates	Title	Nature of involvement
30 November - 1 December 2017	Funding bodies and late modern science, Utrecht University, Cultural History Research Group and Descartes Centre,	Oral presenter Nasser M, Reijmerink W. How research funders respond to the call for reducing research waste and ensuring responsible research conduct
5 Oct 2017	Health and Care Research Wales conference 2017, Cardiff. 5 Oct 2017	Invited Speaker Nasser M. How research funders respond to the call for reducing research waste and ensuring responsible research conduct. Health and Care Research Wales conference 2017, Cardiff. 5 Oct 2017
25-29 Sep 2017	68 th International Astronautical Congress, Adelaide, Australia	Contributor to an oral presentation that was accepted Velho R, Winnard A, Nasser M, Gradwell D, Winnard A, Boudreau E Introducing an aerospace medicine systematic review group.
13-16 Sep 2017	Global Evidence Summit, Cape Town, South Africa	Contributor to a poster presentation - Nasser M, Winnard A, Velho R, Welch V. Introducing an aerospace medicine systematic review group.
16-18 august 2017	Off the lip, Plymouth, UK	Oral presentation- Nasser M. The concept of creativity and innovation in setting priorities for research
28-31 May 2017	Work Research integrity conference, Amsterdam, Netherlands	Invited speaker - How can research funders add value to research as part of a special session on responsible research conduct for funding agencies
29 April – 4 May 2017	ASMA - 88th Annual Scientific Meeting of the Aerospace Medical Association, Denver USA,	Contributor to an oral presentation that was presented Winnard A, Nasser M, Gradwell D, Winnard A, Velho R, Boudreau E Introducing an aerospace medicine systematic review group.
7-9 Dec 2016	International Evidence-Based Health Care Society Congress,	Keynote speaker – “Our roles and responsibilities in reducing research waste.” I also helped in the negotiation between Cochrane and the Ministry of Health in Iran to establish

	Kish, Iran	Cochrane Iran
23 -27 Oct 2016	Cochrane Colloquium in Seoul, South Korea.	<p>I organised and presented in a special session focusing on reducing research waste. I gave a talk on how funders can contribute to reducing research waste. As part of the preparation of the special session, I worked with Sylvia De Haan to organise a survey to inform the session.</p> <p>Nasser M, Wood J, De Haan S, Glasziou P – Special Session: Cochrane and REWARD –Is there more we can do to address the problem. Cochrane Colloquium 23-27 Oct 2016, Seoul, South Korea</p> <p>A blog post was written by Sylvia De Haan following session http://community.cochrane.org/news/reducing-research-waste-%E2%80%93-messages-cochrane-community</p> <p>In another session I gave a long oral presentation on how funders currently contribute to reducing research waste (Nasser M, Clarke M, Chalmers I, Bruberg KG, Nukvist H, Lund H, Glasziou P. What funders do to minimize waste in research. Cochrane Colloquium 23-27 Oct 2016, Seoul, South Korea).</p> <p>I organised two workshops, one focusing on reporting guidelines for priority setting and the other one on using systematic reviews to inform future research. I also organised and chaired the meetings for the Cochrane Priority Setting Methods Group and Evidence-Based Research Network. As I am a member of the Governing Board and a Trustee of Cochrane, I also attended a 3-day board meeting during the Colloquium in Seoul.</p>
18 May 2016	NIHR 10 th year anniversary	Invited speaker - I gave a talk on role of funders in reducing research waste in a special meeting during the conference celebrating 10 years of NIHR.
12 th Oct 2015	<p>“Prospect of Evidence- Based Medicine and Cochrane in Bosnia and Herzegovina”, Sarajevo, Bosnia and Herzegovina</p> <p>http://mf.unsa.ba/podaci/kongresi_seminari_skupovi/Cochrane_program.pdf</p>	Invited speaker – title of talk – “Setting priorities in Clinical Research”. We issued a press release associated with it. https://www.plymouth.ac.uk/news/plymouth-academic-to-support-bosnian-herzegovinian-scientists-on-setting-priorities-for-medical-research
2 Oct 2015	2015 Annual Cochrane Methods Symposium, Vienna,	Invited speaker – “Towards an evidence informed approach to set priorities for topics of systematic reviews.”

	Austria	
3-7 Oct 2015	Cochrane Colloquium in Vienna, Austria	<p>I had two oral presentations:</p> <p>Nasser M et al. “EBRNetwork – a call to action for more (efficient) systematic reviews”, 3-7th Oct 2015, Cochrane Colloquium, Vienna, Austria.</p> <p>Nasser M, Glasziou P, Chalmers I, Clarke M. “Do international funders use systematic reviews to inform future funding decisions?” Special Session: “Systematic reviews guiding future research: opportunities and challenges”. 3-7th Oct 2015, Cochrane Colloquium, Vienna, Austria.</p> <p>I organised a special session on using systematic reviews to inform future research involving different stakeholders, including funders, journal editors, etc. I presented the funder project again as part of the special session. I also organised and chaired the Priority Setting Methods Group meeting and Evidence-Based Research Network meeting and organised the following workshops:</p> <p>Akl E, Brunnhuber K, Lund H, Mbuagbaw L, Nasser M, Robinson K, Schuenneman H. Using Cochrane reviews to inform future research (workshop), 3-7th Oct 2015, Cochrane Colloquium, Vienna, Austria.</p> <p>Bhaumik S, Crowe S, Morley R, Nasser M, Pardo J, Synnot A, Tong A, Welsh E. Practical approaches to conducting an evidence-informed research priority-setting exercise (workshop).</p> <p>Bhaumik S, Dellavalle, Karimkhani, Nasser M. Using Global Burden of Disease database to inform priority setting (workshop), 3-7th Oct 2015, Cochrane Colloquium, Vienna, Austria.</p> <p>As I am a member of the Governing Board and a Trustee of Cochrane, I also attended a 3-day board meeting during the Colloquium in Vienna</p>
28-30 Sep 2015	The inaugural EQUATOR/REWARD Conference, Edinburgh, Scotland.	<p>I gave an oral presentation during this conference</p> <p>Nasser M, Glasziou P, Chalmers I. Do international funders use systematic reviews to inform future funding decisions, 28-30 Sep 2015 the inaugural EQUATOR/REWARD conference, Edinburgh, Scotland. I also helped in advocating the use of social media to encourage reduced research waste, and by giving interviews and organising discussions.</p>
14-16 Sep 2015	British Social of Orofacial and Dental Research conference	<p>I gave an oral presentation . Nasser M, Karimkhani C, Dellavalle R. Global burden of oral and oropharyngeal diseases in 2010 as reflected in Cochrane Database of Systematic Reviews (16.09.2015), 14-16 Sep BSODR 2015, Cardiff, UK.</p> <p>My PhD student also gave an oral presentation. Allen Z, Nasser M, Stenhouse E, Richardson J, Moles, DR. Referral pathways from general dental services to other primary dental care services in the UK: A systematic review and critical interpretive synthesis (15.09.2015), 14-16 Sep BSODR 2015,</p>

		Cardiff, UK.
4 June 2015	Fifth and final event of Avicenna: a strategy for in silico clinical trials, Barcelona, Spain http://avicenna-isct.org/events/event-5/ http://avicenna-isct.org/wp-content/uploads/2015/02/Avicenna-Event-5-Agenda.pdf	Invited speaker – “Avicenna’s Canon of Medicine: rules for assessing the effectiveness of drugs”
3 Dec 2014	1 st Evidence Based Research Network Symposium http://ebrnetwork.org/wp-content/uploads/2015/02/Mona-Nasser.pptx	Invited speaker – Survey of funders
16 June 2014	The Campbell Colloquium, Belfast, Northern Ireland	Invited speaker to give the opening plenary on research priority setting. The talk is available on youtube https://www.youtube.com/watch?v=YaB074Rgg7w
2 May 2014	The Third Annual ISSR Sustainability Research Event 2014. Challenge Accepted! Creating Solutions for Horizon 2020 http://www1.plymouth.ac.uk/research/issr/Pages/The-Third-Annual-ISSR-Sustainability-Research-Event-2014.aspx	Invited speaker – “Using Research Priority Setting Methods to identify uncertainties on sustainability issues: an example from the dental school” The Presentation is available on youtube https://www.youtube.com/watch?v=5b3_qGu2URY
19-23 Sep 2013	21th Cochrane Colloquium in Quebec City, Canada. 19-23	Workshop - Nasser M , Crowe S, Welch V, Ueffing E, Li T. Priority Setting Exercise for a Cochrane entity. 21th Cochrane Colloquium in Quebec City, Canada. 19-23 Sep 2013.

	Sep 2013.	<p>I also organised and presented in a special session on Developing evidence in a responsive approach. I gave a talk on Prioritisation of topics in Cochrane at the micro, meso and macro level and chaired the discussion</p> <p>I organised and chaired the Priority Setting Methods Group meeting</p> <p>There are blog posts available on those sessions</p> <p>http://methods.cochrane.org/prioritysetting/blog/special-session-developing-evidence-responsive-approach</p> <p>http://methods.cochrane.org/prioritysetting/blog/special-session-developing-evidence-responsive-approach</p> <p>As I am a member of the Governing Board and a Trustee of Cochrane, I also attended a 3-day board meeting during the Colloquium in Quebec.</p>
9-11 Sep 2013	BSODR Annual Meeting – Bath, UK 9-11 Sep 2013	Poster - Nasser M , Javaheri H. Oral Health Research Priority setting: systematic review with interpretive analysis (Poster) BSODR Annual Meeting – Bath, UK 9-11 Sep 2013
28 - 31 August 2013	ADEE, 28 - 31 August 2013, Birmingham, UK.	<p>Two posters:</p> <p>Nasser M, Moles DR. An evidence-informed approach to developing a postgraduate dental education module (Poster). 39th ADEE ANNUAL MEETING, Electronic Learning @ADEE, 28 - 31 August 2013, Birmingham, UK.</p> <p>Nasser M, Moles DR. An evidence-informed approach to developing a mentorship programme for dental academic trainees (Poster). 39th ADEE ANNUAL MEETING, Electronic Learning @ADEE, 28 - 31 August 2013, Birmingham, UK.</p>
30 Sep – 3 Oct 2012	Cochrane Colloquium 30 Sep – 3 Oct 2012, Auckland, New Zealand	<p>Oral presentation - Nasser M, Carlo R, Crowe S, Welch V. Challenges in conducting priority-setting exercises for Cochrane entities (oral) Cochrane Colloquium 30 Sep -3 Oct 2012, Auckland, New Zealand.</p> <p>Workshop - Nasser M, Crowe S, Li Tianjing. Personalising research priority-setting exercises: developing a research priority-setting exercise to achieve the objectives of a Cochrane entity (workshop) Cochrane Colloquium 30 Sep – 3 Oct 2012, Auckland, New Zealand</p> <p>I organised and chaired the Cochrane priority setting methods group meeting</p> <p>As I am a member of the Governing Board and a Trustee of Cochrane, I also attended a 3-day board meeting during the Colloquium in Auckland</p>

12-15 Sep 2012	IADR/PER, 12-15 Sep 2012, Helsinki, Finland.	Oral presentation - Nasser M , Fedorowicz Z, Sequeira-Byron P, Freitas de Souza R, Carter B, Heft M. Endodontic Irrigants in Root Canal Treatment: a Comparative Effectiveness Review. IADR/PER, 12-15 Sep 2012, Helsinki, Finland.
19-22 October 2011	Cochrane Colloquium 2011, Madrid, Spain.	<p>Nasser M, Ueffing E, Tugwell P, Welch V, Chalkidou K, Sawicki P, Crowe S. Evaluating research priority setting approaches: tools for a Cochrane methodology review. (oral) Cochrane Colloquium 2011, Madrid, Spain.</p> <p>Nasser M, Welch V, Crowe S, Oliver S, Liberati A. Cochrane agenda setting and priority setting methods group: establishing a research methods program (oral) Cochrane Colloquium 2011, Madrid, Spain.</p> <p>Nasser M, van Weel C, van Binsebergen JJ, van de Laar F, Buechter R. External validity of systematic reviews in primary care: adapting the methodology to conduct reviews (poster) Cochrane Colloquium 2011, Madrid, Spain.</p> <p>I also chaired and organised the Cochrane priority setting methods group meeting.</p> <p>As I am a member of the Governing Board and a Trustee of Cochrane, I also attended a 3-day board meeting during the Colloquium in Madrid.</p>
12-15 Sep 2011	BSODR/IADR, 12-15 Sep 2011, Sheffield, UK.	Poster - Nasser M , Fedorowicz Z. External validity of trials on smoking cessation in Dental Practice. BSODR/IADR, 12-15 Sep 2011, Sheffield, UK.
Dec 2010	"Practice-based Evidence for Weight Management: Alliance between Primary Care and Public Health" sixth Heelsum workshop, Heelsum Collaboration, Heelsum, Netherlands	Invited speaker - External validity and generalizability of systematic reviews in primary health care: adapting the methodology to conduct the review
18 - 22 October 2010	Cochrane Colloquium 2010, Keystone, Co, USA	<ol style="list-style-type: none"> 1) Nasser M, Tugwell P, Welch V, Ueffing E, Oliver S, Crowe S, Buckley B, Rader T, Lydiatt A. Agenda setting: Evidence & Equity. (workshop) Cochrane Colloquium 2010, Keystone, Co, USA. 2) Rader T, Lyddiatt A, Cattivera C, Gunderson J, Idzerda L, Nasser M, Maxwell L, Tanjong-Ghogomu E. International Panel for Consumers in Arthritis Research: an initiative of the Cochrane Musculoskeletal Group. (Oral) Cochrane Colloquium 2010, Keystone, Co, USA. 3) Nasser M, van Binsbergen JJ, van de Laar F, van Weel C, Fedorowicz Z, Newton TJ. Evaluating

		<p>external validity, applicability and transferability of evidence to primary care setting. (Poster) Cochrane Colloquium 2010, Keystone, US.</p> <p>4) Nasser M, Fedorowicz Z, de-Souza RF, Owise-Sharif M, Hu N, Sequeira P, Pedrazzi V. Evaluating three informal capacity building networks for systematic reviews. (Poster) Cochrane Colloquium 2010, Keystone, US.</p> <p>5) Nasser M, Fedorowicz Z, Sequeira P. Ideal conditions or usual practice? The position of trials from two Cochrane reviews within the pragmatic - explanatory continuum. (Poster) Cochrane Colloquium 2010, Keystone, US.</p>
Oct 2009	<p>Prioritising Cochrane review topics to reduce the know-do gap in low and middle income countries (Special session) XVII Cochrane Colloquium 11-14 October 2009, Singapore.</p>	<p>1) Krleza-Jeric K, Djulbegovic B, Nasser M, Reveiz L, Huic M, Lemmens T, Sim I, Armstrong W, Metz C, Elemam K, Wager E. International standards for Public Reporting of Clinical Trial Outcomes and Results (PROCTOR): a proposal to increase the quality of evidence produced by systematic reviews. XVII Cochrane Colloquium 11-14 October 2009, Singapore.</p> <p>2) Nasser M, Welch V, Tugwell P, Waters L, Doyle J, Ueffing E. Priority setting for The Cochrane Collaboration: methods, challenges and opportunities (workshop) XVII Cochrane Colloquium 11-14 October 2009, Singapore.</p> <p>3) De Souza R, Sequeira P, Nasser M, Fedorowicz Z, Shahiri M. Is Google Translate useful for the selection of studies to be included in Cochrane reviews. (poster) XVII Cochrane Colloquium 11-14 October 2009, Singapore.</p> <p>4) Bastian H, Waltering A, Nasser M. Thumps up, thumps down: An analysis of online user ratings of summaries of systematic reviews (poster) XVII Cochrane Colloquium 11-14 October 2009, Singapore.</p> <p>5) Nasser M, Welch V, Tugwell P, Ueffing E, Bastian H. An Equity Lens for identifying priority topics for Cochrane reviews (Oral) XVII Cochrane Colloquium 11-14 October 2009, Singapore</p> <p>6) Nasser M, Bastian H, Knelagen M, Waltering A. Does the message still reflect the evidence? (Poster) XVII Cochrane Colloquium 11-14 October 2009, Singapore.</p> <p>7) Nasser M, Fedorowicz Z, Sequeira P, Newton T, Souza RD, Javaheri H. Evaluating the impact of the ViTaMIN (Virtual Training and Mentoring International Network) project (Poster) XVII Cochrane Colloquium 11-14 October 2009, Singapore.</p>
5-7 March 2009	<p>10 Jahrestagung des Deutschen Netzwerks Evidenzbasierte Medizin,</p>	<p>Nasser M, Fedorowicz Z, Gruen R, Tavender E, Mayhew A. Komplexität bei der Durchführung systematischer Übersichten zur Versorgung im Gesundheitssystem. (poster) Evidenz und Entscheidung: system unter Druck. 10 Jahrestagung des Deutschen Netzwerks Evidenzbasierte</p>

	Berlin	<p>Medizin. Berlin. 5-7 March 2009.</p> <p>Nasser M, Türp JC, Antes G, Motschall E. Systematische Übersichten in der Zahnmedizin: Eine Landkarte der zahnmedizinischen Evidenz. (poster) Evidenz und Entscheidung: system unter Druck. 10 Jahrestagung des Deutschen Netzwerks Evidenzbasierte Medizin. Berlin. 5-7 March 2009.</p>
3-7 October 2008	XVI Cochrane Colloquium 3-7 October 2008, Freiburg, Germany	<p>Piennar E, Cahill K, Kjeldstrom M, Nasser M. RevMan 5 for Cochrane Intervention review authors – learn to use all the features hands – on. (workshop) XVI Cochrane Colloquium 3-7 October 2008, Freiburg, Germany.</p> <p>Mahdian M, Nasser M. Assessment of the methodological quality of reporting of randomized trials in Iranian dental journals (poster) XVI Cochrane Colloquium 3-7 October 2008, Freiburg, Germany.</p> <p>Shahiri M, Nasser M, Javaheri H. Developing a sensitive search strategy in Farsi for retrieving reports of randomized trials in Iranmedex (poster) XVI Cochrane Colloquium 3-7 October 2008, Freiburg, Germany.</p> <p>Nasser M, Türp JC, Antes G, Motschall E. Panoramic overview of systematic reviews in Oral Health. (poster) XVI Cochrane Colloquium 3-7 October 2008, Freiburg, Germany.</p> <p>Bastian H, Knelangen M, Lange S, Nasser M. Cochrane versus non-Cochrane reviews: An exploration of discordance, comparative quality and relevance for patient information. XVI Cochrane Colloquium 3-7 October 2008, Freiburg, Germany.</p> <p>Mahdian M, Nasser M, Fedorowicz Z. How do clinicians decide treatment when there is no evidence? (poster). XVI Cochrane Colloquium 3-7 October 2008, Freiburg, Germany.</p> <p>Nasser M, Khoshnevisan M, Ahangari Z, Houshmand B, Nouri M, Shakhssalim N, Hajebrahimi S, Javaheri H, Yassiny K. Evidence production and dissemination in Iran: the Iranian Cochrane Informal Network. (poster). XVI Cochrane Colloquium 3-7 October 2008, Freiburg, Germany.</p> <p>de Souza RF, Chaves CAL, Nasser M, Fedorowicz Z. Brazilian Oral Health Journals in Scielo: an open access tropical treasure? (poster). XVI Cochrane Colloquium 3-7 October 2008, Freiburg, Germany.</p> <p>Nasser M, Fedorowicz Z, Bastian H. Comparing the priorities in oral health with the existing evidence in the Cochrane Library (poster). XVI Cochrane Colloquium 3-7 October 2008, Freiburg, Germany.</p> <p>Nasser M, Tugwell P, Welch V, Morris E, Waters E, Doyle J. Ensuring relevance and building enthusiasm for Cochrane reviews: determining appropriate methods for identifying priority topics for future Cochrane reviews (workshop). XVI Cochrane Colloquium 3-7 October 2008, Freiburg, Germany. http://www.equity.cochrane.org/Files/Priority_Setting_Minutes_2008.pdf</p>

25-26 Dec 2008	Iranian Section of International Association of Dental Research Congress, Tehran, Iran.	Nasser M , Fedorowicz Z, Khoshnevisan MH. A Cochrane Collaboration workshop. Iranian Section of International Association of Dental Research Congress. 25-26 Dec 2008, Tehran, Iran
Sep 2008	WONCA Europe, Istanbul, Turkey	Invited plenary speaker - Cochrane Primary Health Care Field: Introduction to systematic reviews and the Cochrane Primary Health Care Field, WONCA Europe, Istanbul, Turkey
June 2008	Iberoamerican Cochrane Network conference, Costa Rica, June 2008	Invited speaker - the Cochrane Developing Countries Network
Dec 2007	“Creating supportive Environments for Nutrition Guidance: towards a Synergy between Primary Care, and Public Health.” Fifth Heelsum workshop, Heelsum Collaboration, Heelsum, Netherlands	Invited speaker - Diet and nutrition advice from The Cochrane Library: is it useful for the consumers and family physicians?
23-27 October 2007	XV Cochrane Colloquium, Sao Paulo, Brazil.	Poster - Nasser M , Ortiz Z, Berenstein G, Garcia Dieguez M, Angel Exposito J, Pardo J. Guidelines for preparing Cochrane Reviews relevant to Developing Countries. XV Cochrane Colloquium 23-27 October 2007, Sao Paulo, Brazil. Oral presentation - Nasser M , van Binsbergen JJ, Javaheri H, Yassiny K. Nutritional Guidance for Cochrane Reviews: A Consumer Approach. XV Cochrane Colloquium 23-27 October 2007, Sao Paulo, Brazil. Oral presentation Nasser M , Lodge M, Fedorowicz Z. The relevance of Cochrane Reviews to the Cancer Priorities in Iran. XV Cochrane Colloquium 23-27 October 2007, Sao Paulo, Brazil.
23-26 Oct 2006	Cochrane Colloquium, Dublin, Ireland	Poster - Nasser M , Al-Hajeri A, Eisinga A, Fedorowicz Z. Developing a sensitive search strategy for retrieving reports of randomized trials in Iranmedex. 138. 23-26 Oct 2006 Cochrane Colloquium, Dublin. Poster - Nasser M , Al-Hajeri A, Eisinga A, Fedorowicz Z. Assessment of the methodological quality of reporting of randomized trials in Iranian healthcare journals. 120. 23-26 Oct 2006 Cochrane

		Colloquium, Dublin.
June 28 - July 1, 2006	84th General Session & Exhibition of the IADR 1st Meeting of the Pan-Asian-Pacific Federation (Australian/New Zealand, Chinese, Korean, Japanese, and Southeast Asian Divisions of the IADR), Brisbane, Australia..	Nasser M , Oskoui M, Ahangari Z. Antimicrobial Activity of MTA, Portland cement and Calcium Hydroxide. 2153. 3.84th General Session & Exhibition of the IADR 1st Meeting of the Pan-Asian-Pacific Federation (Australian/New Zealand, Chinese, Korean, Japanese, and Southeast Asian Divisions of the IADR), Brisbane, Australia..
Jan 2006	Shiraz University of Medical Sciences on the third Regional Conference on Medical Journals in the Eastern Mediterranean Region WHO/EMAME, Shiraz, Iran	Workshop on Evidence-Based Medicine

Appendix 2 –An overview of reviews on priority setting strategies

Citation	Description	Summary of the results
Noorani 2007 (42)	A systematic review of methods for priority setting for the assessment of new or diffused health technologies	(a) Twelve priority setting systems from 11 health technology assessment (HTA) agencies. (b) Most processes used a panel or committee to advise the agencies regarding priorities and mostly involved health care system funders, health professionals, and researchers. (c) Consumers were involved only in some of these processes. (d) Each agency used 3-10 criteria for the prioritisation process. (e) Most of the agencies used criteria that addressed clinical impact, economic impact and budget impact.
Oxman 2006(99)	A review of priority setting strategies to inform future policies in the World Health Organisation (WHO)	They recommended that the WHO should consider the following criteria for prioritisation (1) "Problems associated with a high burden of illness in low and middle-income countries, or new and emerging diseases. (2) No existing guidelines or recommendations of good quality. (3) The feasibility of developing recommendations that will improve health outcomes, reduce inequities or reduce unnecessary costs if they are implemented. (4) Implementation is feasible, will not exhaustively use available resources, and barriers to change are not likely to be so high that they cannot be overcome. (5) Additional priorities for WHO include interventions that will likely require system changes and interventions where there might be a conflict in choices between individual and societal perspectives" Considering the process, they recommended that a prioritisation process should be part of a routine budgeting process and should consider the following issues: "1. Criteria for establishing priorities should be applied using a systematic and transparent process. 2. Because data to inform judgments are often lacking, unmeasured factors should also be considered explicitly and transparently. 3. The process should include consultation with potential end users and other stakeholders, including the public, using well-constructed questions, and possibly using Delphi-like procedures. 4. Groups that include stakeholders and people with relevant types of expertise should make decisions. Group processes should ensure full participation by all members of the group. The process used to select topics should be documented and open to inspection."

IOM 2008(35)	An overview comparing the methods of identifying topics in different national and international organisations.	The new IOM report recommends five guiding principles to be considered in future priority setting projects: consistency, efficiency, objectivity, responsiveness, and transparency. They recommend that the priority setting process should be open, transparent, efficient, and timely and should consider the impact of evidence-based medicine on improving health outcomes across life spans, reducing the burden of disease and health inequities, and reducing undesirable practice variations. The economic burden of the disease and the intervention should be considered. The priority setting advisory committee needs to include individuals with different expertise and interests and strategies need to be placed to minimize conflict of interest
Stewart 2008 (43)	The James Lind Alliance aimed to develop a systematic map of studies focusing on patients' and clinicians' research priorities.	<ul style="list-style-type: none"> • 258 relevant studies. • In the identified studies, the role of the clinicians and patients in setting the research agenda varied from a more passive consultative role to a more active and collaborative approach. • In most of the studies, the clinicians were more involved than the patients and they were usually working separately rather than collaboratively.
Montorzi 2009 (34)	An overview of the methods for priority setting of research.	Divides methods to priority setting in two sections: methods to identify priority topics and methods to rank the priority topics. Methods to identify priority topics were further categorized into: (a) methods that focus on using existing data like burden of disease or cost effectiveness and resources (compound approaches); and (b) methods that consider future health research priorities (foresighting approaches) such as horizon scanning which is used explore novel and unexpected issues along with persistent problems and trends in health care.
Viergever 2010 (41)	The World Health Organisation aimed to develop an overview of the methods for research priority setting exercises in their departments and also quantifies the volume of research priority setting work done in certain health areas.	<ul style="list-style-type: none"> • Most of the work was done in infectious disease and communicable diseases. • They found a wide variety of methodological approaches but were not able recommend certain strategies over others. • There was an expressed need for further methodological guidance and coordination in this field.

Swingler 2005 (100)	Evaluating national child health research priorities in sub-Saharan Africa.	<ul style="list-style-type: none"> • Four studies had children as a separate group but addressed specific areas of child health like school health or perinatal care. • Four studies looked at research priorities for both children and adults but had included specific categories of child health. • The research of the priority setting strategies did not distinguish children from adults. • The authors concluded that there are few national research priority exercises for child health done and those with combined groups may not adequately cover children's interest.
Rylance 2010 (101)	Reviewing priority setting strategies on tuberculosis.	<ul style="list-style-type: none"> • 33 research agendas for tuberculosis published between 1998 and 2010. • Two clear research priorities: development and testing of both new drugs and treatment regimens, and new diagnostic tests for tuberculosis. • The other priority areas were epidemiology, health services research, basic research, and vaccine development and use. • The methods to reach these priorities vary.
Myers 2011 (102)	Pubmed search 1990-2010 for studies on research prioritisation and value of information analysis along with searching US based funding organisations	<p>Outside of the UK NICE/HTA program, systematic reviews were rarely cited as important sources for identifying evidence gaps for research prioritisation. Cost-effectiveness and VOI analyses were the most commonly used modelling-based methods, but, outside of the UK, it is unclear to what degree the priorities identified by these methods were translated into actual research funding. Stakeholders in our two case studies found modelling and VOI to be potentially useful tools, but there are a variety of methodological and operational issues that need to be considered and resolved if these methods are to be used to assist with prioritizing research gaps identified through systematic reviews. These include identifying ways to compare the impact of different prioritisation methods on the likelihood that priority questions will be answered through research, identifying the appropriate resources (including technical expertise) to conduct the analyses, defining the appropriate timing of the modelling and analyses, and identifying the appropriate level of modelling complexity.</p>

Tomlinson 2011 (103)	A review of selected research priority setting processes at national level for low and middle income countries. Data were gathered from presentations at a meeting held at the World Health Organisation (WHO) in 2008 and a web-based search. Based on this literature review a number of criteria were developed to evaluate the priority setting processes.	<p>Methods used by the countries in their priority setting processes ranged from ones developed by the countries themselves to the use of existing methodologies. These included the Combined Matrix Approach (CAM) ; the Council on Health Research and Development (COHRED) ; and the Child Health and Nutrition Research Initiative (CHNRI). Countries have used a variety of approaches to include different stakeholders.</p> <p>Intentionally include only individuals with diverse and relevant experiences and view- points as opposed to including representatives from a variety of societies and associations.</p> <p>A small Executive Committee that guides the process and decision making; while a larger decision making group (comprised of stakeholders) would then be charged with implementing the chosen methodology and to make decisions. An Advisory Council comprising a much larger number of stakeholders (possibly separated into smaller groups) might also be created in order to advise, deliberate, provide viewpoints, and to provide support to the smaller decision making groups.</p> <p>Establishment of a communication channel with neighboring countries about the priority setting process. This serves as a gesture of goodwill, but may also aid the priority setting process.</p>
Bitter 2011 (104)	The focus of the review of reviewing the multi-stakeholder involvement in research priority setting. Searching of databases was conducted along with cross referencing. They used two conceptual frameworks to evaluate the outcomes	<p>Eight different stakeholder involvement approaches:</p> <ol style="list-style-type: none"> 1. Delphi technique, 2. nominal group approach, 3. Dialogue model, 4. listening model, 5. James Lind Alliance Partnerships, 6. the approach of the Scandinavian Rheumatism Associations, 7. focus groups, and 8. the Primary Health Care Research Evaluation and Development Strategy <p>4 approaches were executed on the level of partnerships: 1 on the level of placation, 3 on the level of consultation</p> <p>Diversity not only in the methods but also implementation and execution; affected by objective and vision of the stakeholder involvement.</p>

Appendix 3 - An introduction to Research Priority Setting (RPS) for research groups in Cochrane

Guidance sheet -1 - What is research priority setting and what you need to do before starting? (105)

Written by: Mona Nasser & Sally Crowe

What is research priority setting?

A collective activity for deciding which uncertainties are most worth trying to resolve through research; uncertainties considered may be problems to be understood or solutions to be developed or tested; across broad or narrow areas (Sandy Oliver).

Figure 4 is providing the steps that a RPS exercise might include. All RPS exercises that we have identified up to now have included all or some of these steps in their approach (however, they do not necessarily report all steps in one report).

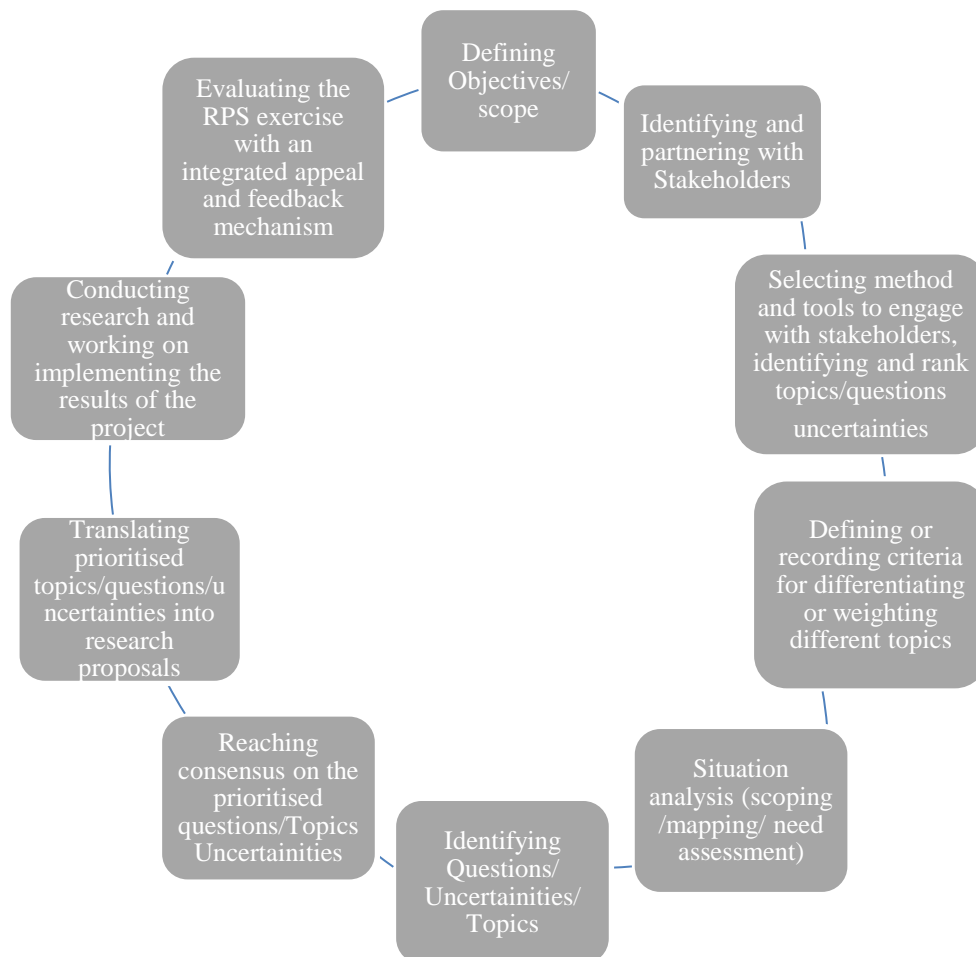


Figure 4 - Wheel of Research Priority Setting exercises (1, 2)

A RPS exercise is initiated, designed and implemented in a specific context, setting and population with specific principles, values and preferences. A research group selects different methods to fulfil each of the steps of a RPS exercises as outlined in Figure 4. It is important that methods are selected that have a reasonable chance to help the group in achieving their objectives. If the

objective of a RPS exercise is to engage with stakeholders from disadvantaged groups in a developing country, an online Delphi consensus approach has a limited chance to reach them. Ideally selection of the methods needs to be done based on the most recent empirical evidence (see our commentary in Journal of clinical epidemiology that gives some indication of recent empirical research (5)).

Similar to any project, the research team needs the required skills to effectively conduct certain methods, and also effectively manage the project. It is common that research teams not consider adequately the role of a chair or facilitator for the stakeholder engagement step, so that diverse groups of stakeholders can be effectively engaged and involved in the priority setting process. Research teams and associated stakeholders are people with a certain social and cultural background and bring their own views, values and preferences in their group. The social dynamics and power relation between these individuals affect the conduct and results of a RPS exercise, Figure 5

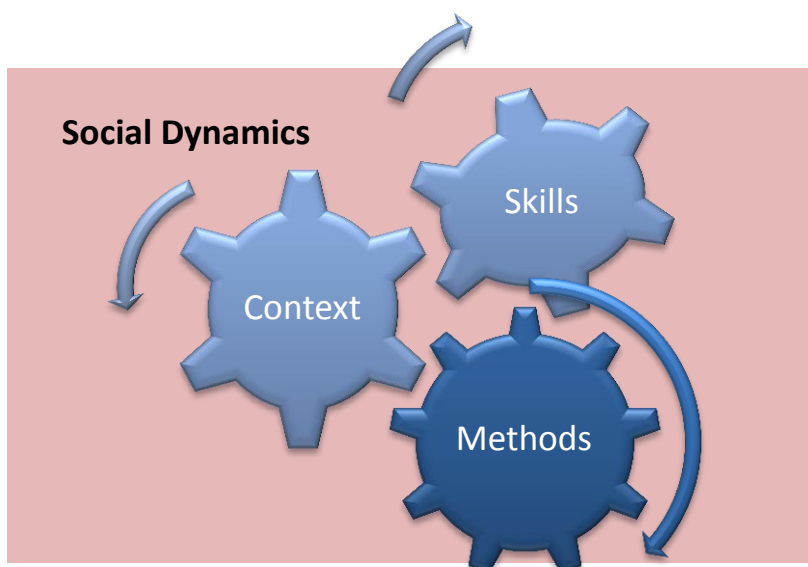


Figure 5- Wheel of RPS exercises (2) ¹⁰

RPS exercises could be as a decision making tool to improve the management of an organisation and support better decision making. However, they are also a research tool aiming to minimize bias in the research agenda in a certain health care field.

RPS exercises could help in identifying overall gaps in the research agenda (imbalance in the number of high quality research projects conducted in drug related topics versus behavioural

¹⁰ from Nasser M, Cochrane Agenda and Priority Setting Methods Group. International workshop on Research Priority Setting Methods, June 2012, Plymouth. UK. Available at: <http://capsmg.cochrane.org/sites/capsmg.cochrane.org/files/uploads/Plymouth%20workshop%20%28Mona%20Nasser%29%5B1%5D.pdf>

intervention topics) or the construct of a research question (imbalance in the number of high quality research focusing on biomedical outcomes versus patient relevant outcomes).

Before starting a RPS exercise:

Step –1 -Defining the level of RPS

Macro-level: identifying and prioritising broad topic areas for the group to define the general direction of the group in a specific field

Meso-level: identifying and prioritising research questions for the group. The questions might be broad and narrow depending on the data (qualitative or quantitative) derived from the exercise

Micro-level: identifying and prioritising focused clinical questions for systematic reviews. The questions are constructed to be addressed either by a Cochrane Systematic Review or Cochrane Overviews of Review. However, this is the most difficult one as there are still a lot of open methodological questions how we best can translate uncertainties of our stakeholders into focused questions for systematic reviews.

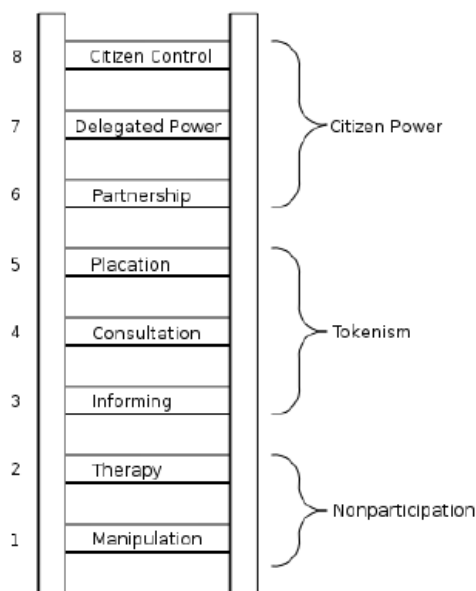
Step 2 – Setting up systems to collect the required data to inform the RPS exercise

The quality of your research priority setting exercise partially depends on the quality and availability of the necessary data to inform your decisions. Examples of data that are collected: Cochrane groups usually have registries of clinical trials and defining areas in which we have a large amount of clinical trials; Cochrane Fields tag Cochrane groups based on topic areas e.g. Child health and provide a map on potential gaps in the current reviews; Wiley (the publisher of the Cochrane Library) collects data on the use of Cochrane reviews. There are other types of data that review groups can collect to inform their work: (a) collecting data on research priorities identified by research priority setting exercises outside the collaboration (b) burden of disease data in their own clinical area (c) regular survey engaging with the stakeholders of Cochrane groups.

Step 3 – Building the group to establish partnerships with stakeholders

Research priority setting is a collective social activity. The research group needs to define who needs to be part of this collective activity and to whom is the RPS exercise accountable. Engaging with stakeholders usually requires building longer term relations between different stakeholders groups, understanding the best approaches to communicate and engage with them, sharing respective views and understanding about research and sustaining communication and updates during the process to maintain momentum and interest. This might require some capacity building or discussion workshops to ensure that different stakeholders have the same understanding on the definition and structure of the related research projects. Some groups might find a mapping exercise whereby drawing a diagram of actual and potential stakeholders and drawing lines representing the relationships (strong, weak, influential, etc) as a useful first step to identify the

stakeholders that they work with. It is also important to reflect the cultural, ethnical and organisational differences in the stakeholders that might affect the process of reaching a consensus in research priority setting. Moreover, the group requires having a clear idea of the level of engagement that the group is planning to have with those groups. The ladder of citizen participation can be a good guide on reflecting on the mechanism of engaging with stakeholders.



Depending on the complexity of the topic, you might require several informal meetings and discussions with stakeholders groups so that concerns can be elicited, and their complexity revealed and understanding the areas that might be more controversial than others(106). It is important that you are clear with your stakeholders that you are focusing on concerns and uncertainties that they have around health care rather than their opinion about research. The discussion should aim to identify the most pressing uncertainties/problems that stakeholders face and the areas of practice or policy that shapes (or could shape) those pressing problems.

Figure 6 - a ladder of citizen participation (Arnstein 1969) (107)

The nature of the prior engagement with stakeholders might differ depending on the topic itself and controversies around it along with the social and political context in which the discussions are conducted. Sometimes, there is a need for processes of negotiation preceding the prioritisation to prepare the grounds to ensure a constructive discussion in a research priority setting exercise.

Step 4 – Clarity and transparency on the objectives of the exercise

The objectives of the exercise define should the methods and approaches that are used to construct the research priority setting exercises. As RPS exercises sit in the overall pathway of constructing, conducting and implementing research, therefore, the sole aim of a RPS exercises is not limited to developing a list of research questions. They provide additional value for example changing the power relations, or how the allocation of resources in research are decided (either financial resources or human resources), provide opportunities for mutual learning between stakeholders, facilitate establishing partnerships and make the group more accountable and transparent towards their stakeholders and users of systematic reviews. The success of a RPS exercise depends on the ability of the team in developing clear objectives and having a coherent plan in selecting methods and process have the highest chance in achieving these objectives.

What are you looking for in a RPS exercise?

As explained beforehand, you need to have clarity about the objectives of your research priority setting project and how you conceptualize the engagement of different stakeholders. This also extends to what is the question/topic that you are looking for in in priority setting process, is it a broad area or a specific question? If you ask a group of people, what do you think should be research priorities; they might associate research with some fancy, futuristic (maybe even sci-fi like in TV/movies). I once asked a dentist what he thinks should be our research priorities and he gave me an example of something that he had tried on a monkey and was wondering whether we could do the same research on humans. In reality, dentistry is an area where there is huge amount of uncertainty around the effectiveness of conventional dental interventions. However, the misconception of the dentist (whom I approached) that research is focused on something new and innovative that nobody has tried, rather than looking back on our uncertainties was interesting. I had a similar situation when asking a member of the public about dental research and she asked me why isn't there more research on a vaccine for dental caries. If you ask the same people, what are your uncertainties and questions around the dental care that you practice or received. They come up with a lot of critical questions on their uncertainties. Both approaches can be potentially valid depending what you are hoping to achieve from a research priority setting exercise.

In Cochrane, we usually conceptualize questions in the form of PICO (or variations of it with other questions). Some Cochrane groups use a more a more detailed approaches to conceptualize and construct questions using the GRADE working group methodology (108). Some research priority setting initiatives like James Lind Alliance and PenCLAHRC tried to use the PICO structure to collect questions from stakeholders with different level of success (PenCLAHRC attempted to enhance the engagement of stakeholders by accompanying the PICO with a plain language summary description of the questions)¹¹. The James Lind Alliance initiative conceptualizes the topics that they gather in a priority setting exercise as uncertainties about the effects of treatments and give some generic examples to help people (although people do not necessarily always adhere to it)¹². Previous experience by James Lind Alliance has shown that complex surveys using PICO or incorporating lots of demographic info increases the attrition rate and yield with much less useful information. Many of the research priority setting exercises do not report that they have attempted to conceptualize the question/topic beforehand and leave it to stakeholder to decide. This can be a potential source of problems especially in a diverse group of stakeholders. People's interpretation of the concept "research questions" might vary (this could be people who are sharing their views or people who are analysing data to derive with new questions) and makes it more complicated to find consensus.

¹¹ <http://clahrc-peninsula.nihr.ac.uk/submit-question.php>
<http://www.library.nhs.uk/duets/>

This lack of clarity and discordance can potentially adversely affect the research priority setting exercises and results in questions that are difficult to interpret, aggregate, prioritise and more critically be used by researchers. The finalised list of questions might end up being uninformative for researchers and research organisations.

The research priority setting group needs to also decide how much contextualised information (and the nature of the information) they want collect along with the questions. This information can be valuable to understand why the question is important, why it needs to be prioritised. It can also help future researchers (if the question is prioritised) to understand how to refine, construct and design the research questions. In the question/topic identification step, this information can be used in two ways (a) translating the topic/question into a more coherent structure: in some priority setting exercises, the group translate the topic/question into a more coherent and harmonized structure and this requires some understanding on the context to ensure that the question doesn't get 'lost in translation'. This applies both to a situation in which the question is derived from engaging with stakeholders and from the data analysis (b) ranking the topic/questions, the information can be used to inform a consensus group to rank the topic or used in analysing the data to rank them. This collaboration (and discussion) around the contextual information around the question also provides a wider "mutual learning" opportunity between the researchers and stakeholders (information derived from the data).

Some groups might prefer to develop a strict structure how they collect questions to prioritise but others might prefer to engage with stakeholders first (as part of your preparation step) and discuss how they mutually conceptualize research questions and what they are intending to get from your exercises. This can be helpful in establishing a shared understanding on this topic between stakeholders and has the additional benefit that the group would have an opportunity to capture some of the complexity that might come up in some questions that might be lost if you restrict people to a clear structure. Obviously, this approach can only be useful if you have a smaller number of stakeholders that you engage with in person and wouldn't work as part of a big online survey.

Research questions can be derived from stakeholders (e.g. the six "Ps" of patient, practitioner, public, policy maker, private sector, and press) (109) but they can also be derived from other data sources. Most Cochrane reviewers are familiar with the 'implications for research' part of a review that can be constructed in a structure form and can be used in a research priority setting exercises as a source of questions for primary research. For systematic reviews, you might have structured or unstructured recommendations for future systematic reviews from overview of reviews or clinical guidelines. Other data-driven sources of research questions are burden of disease, research

use/health information use data (in the case of the collaboration, library use data). Most of the ways to conceptualize questions that are suggested here focus on the concept of finding gaps on what we know, and filling them as a priority. Another way to conceptualize is to identify ideas that could be important in the future but are not necessarily big now (“foresighting” approach). This can be of relevance to the collaboration in prioritising methodological innovation or even in the field of review groups around prospective meta-analysis.

The conceptualization of research questions/topics as part of the prioritisation also guides and defines the methods to translate the topics into a focused research questions for a Cochrane Review. There is a remarkable amount of work done on the issue around “outcome selection” inside and outside the collaboration as part of this translation (or refinement of the topic) outside a prioritisation process. However, the possibilities to use them as part of constructing research questions are not adequately explored. The James Lind Alliance Eczema partnership (which was triggered by lack of evidence in a Cochrane Review and used to guide future primary research) also provided some steps in engaging through a workshop(110). Other organisations used also intensive approaches to refine and translate questions e.g. AHRQ (111).

Step 5 – Available Resources and Timeline

Research priorities change over time. Therefore, it is critical that they are regularly conducted, or preferably there is a continuous plan to conduct a RPS exercises in specific time points. The group needs a clear idea on the available resources, as these are limiting factor in defining the methods and processes that can be used to conduct a RPS exercise. A resource intensive RPS exercises that takes a few years to be conducted might end up with out of date priorities.

Appendix 4 – Equity guide for developing a priority setting strategy for Cochrane Review Groups

Authors: Mona Nasser, Erin Ueffing

Introduction

As described in the prioritisation and Cochrane Review Groups draft (that was submitted for the mid-year Steering group meeting in Split, Croatia), prioritisation for the Cochrane Review Groups (CRGs) can broadly occur at three levels:

- Selecting the titles that a CRG would consider essential to their portfolio, so that they can be actively commissioned
- Selecting from titles that have been submitted
- Deciding which reviews are most important to update

The implementation of prioritisation can occur in two stages in defining an overall research agenda for the work of the CRG as part of a strategic planning or more specifically a prioritisation strategy in identifying topics/titles for Cochrane Reviews (both conducting new ones and updating ones).

The draft for the steering group also highlights the importance of incorporating the views of a broad and inclusive network of stakeholders including end users and funders in the work of the CRG and incorporating the concept of health equity in the work of the CRG. Moreover, it recognizes that the views of certain stakeholders are, in practice, under-valued in the work of the CRG if no active attempts are made to gather these viewpoints.

The current draft intends to highlight strategies and approaches that CRG could use to ensure that priorities of diverse group of stakeholders including disadvantaged group are considered in the development of prioritisation strategies. Moreover, it intends to guide CRGs to incorporate the concept of equity in their prioritisation strategy.

Equity Lens:

The proposed priority setting and agenda setting methods group along with the Campbell-Cochrane Equity Methods Group has developed an equity lens to guide future prioritisation and agenda setting strategies that could guide CRGs in developing a prioritisation strategy. CRGs could also contact the members of the proposed methods group for further guidance (1). Depending on the clinical context, one or more of the questions might not be completely applicable for the prioritisation strategy. The equity lens is supposed to act as a guide to help CRGs to identify important topics and is not needed that all questions are fulfilled.

1. Are different stakeholders who might be affected by the choice of research (review) topics involved in the prioritisation process (different age, sex, sexual orientation, disability, ethnicity, and religion, place of residence, occupation, education, socioeconomic status, and social capital groups)? In which steps are they involved?
2. Does the prioritisation project consider reducing inequity as part of its objectives?
3. Are the selected methods and tools to identify, prioritize, implement, disseminate, and communicate research topics understandable, transparent and relevant for different stakeholders (different age, sex, sexual orientation, disability, ethnicity, religion, place of residence, occupation, education, socioeconomic status, and social capital groups)?
4. Are specific strategies considered to minimize the barriers to reach disadvantaged or less accessible populations?
5. In the stage of situation analysis (evaluating the current health research coverage, identifying gaps, evaluating healthcare needs, etc.), does the analysis consider the differences in the prevalence, severity and urgency of health problems along with potential differences in the impact or value of the health care interventions assessed across different subgroups (age, sex, sexual orientation, disability, ethnicity, religion, place of residence, occupation, education, socioeconomic status,
6. Do the criteria for prioritisation consider the potential differences in the severity and urgency of health problems in disadvantaged populations or less accessible groups as opposed to the health problems in privileged populations?
7. Do the criteria for prioritisation consider the potential differences in the impact of a health care intervention in disadvantaged populations as opposed to the health problems in privileged populations?
8. Do the criteria for prioritisation consider that different population groups might have different values and preferences?
9. Are different stakeholder groups (representing age, sex, sexual orientation, disability, ethnicity, and religion, place of residence, occupation, education, socioeconomic status, and social capital groups) provided with an opportunity to provide feedback and appeal the process and results of the prioritisation process?
10. Did the prioritisation result in more research topics (in this case Cochrane Reviews) that are relevant to disadvantaged groups?
11. Did the dissemination and implementation strategy increase the likelihood that funders and research institutes become aware of the prioritised research topics and consider them as part of their research agenda or strategic planning?

12. Did the dissemination and implementation strategy increase the likelihood that the prioritised research topics that are relevant to disadvantaged groups get funded and conducted?
13. Did the dissemination and implementation strategy increase the likelihood that researchers who work with disadvantaged groups conduct or get involved in the prioritised research projects (in this case the research project is a Cochrane systematic review review)?
14. Did the dissemination and implementation strategy increase the likelihood that disadvantaged groups or decision makers or practitioners who work with disadvantaged groups get involved in the prioritised research topics?
15. Does the dissemination and implementation strategy increase the likelihood that policy makers and decisions makers who work with disadvantaged groups use the result of the prioritised research topics?
16. Did the results of the prioritised research topics changed policies, legislation or clinical practice in favour of disadvantaged groups?
17. Did the appeal and enforcement strategy increase the likelihood that disadvantaged groups or decision makers, researchers and practitioners who work with disadvantaged group had provided feedback and comments on the prioritisation process or results? (Nasser 2011)

How can equity be considered as part of the recommendation made by the Editorial unit

<i>Recommendation from the editorial unit</i>	<i>Suggestion on incorporating an equity-oriented approach</i>
Evaluating the extent coverage of key question areas in their discipline	<p>1) Selecting the dimensions of the PROGRESS PLUS mnemonic that is relevant to the discipline in which the prioritisation is done</p> <p>2) Identifying the major relevant clinical problems/issues related to the selected dimensions of PROGRESS PLUS mnemonic in step 1. Potential sources to acquire this information is:</p> <ul style="list-style-type: none"> a. Priorities in the clinical field: Conducting a systematic review of current prioritisation strategies in the specific discipline and exploring whether the priorities of those dimensions that were selected in step had been considered example Rylance J, Pai M, Lienhardt C, Garner P. Priorities for tuberculosis research: a systematic review. Lancet Infect Dis. 2010 Dec;10(12):886-92 (101). b. Collecting information on the burden of disease, urgency of the health problem or potential differences in the impact or value of the health care interventions for different stakeholders considering the dimensions identified in step 1. c. Consulting a group of stakeholders which can represent the priorities of disadvantage individuals considering the dimensions identified in step 1 <p>3) Mapping the topics of the Cochrane Reviews against the clinical problems/issues identified in step 1 and demonstrates potential gaps.</p> <p>4) Developing plans on how to address this gap.</p>
How the group aims to identify unaddressed and important questions	<p>1) Revising the research agenda and strategic planning of the CRG based on the evaluation of extend coverage of key questions in the area of their discipline.</p> <p>2) Identifying stakeholders who can represent the views that are currently under-valued in the work of the CRG and involving them</p> <p>3) Developing and conducting a priority setting strategy using the equity lens for priority setting and agenda setting.</p>
How the group seeks to identify review teams to address identified review questions	<p>1. Allocation centralized resources e.g. staff that focus on supporting review teams which work on prioritised topics (One of the CRGs had developed a research funding proposal that included conducting a prioritisation strategy and funding a centralized research team that would support volunteer authors working on these reviews.</p> <p>2. Building collaboration and networks with research institutes and individual researchers who focus on research project that were identified as research priorities in the previous steps or institutes and practitioners who have experience working with the identified target disadvantaged groups as identified in the previous steps. This can be in a form of an informal collaboration, advisory group or establishing a satellite. This can facilitate recruiting authors, peer reviewers and editors who can help in ensuring the relevant of the Cochrane Reviews. Recruiting researchers and practitioners who have experience working with specific disadvantaged groups as authors, peer reviewers or editors. Transparent process in</p>

	selecting, prioritisation or rejecting titles increases the accountability of the topic selection process in Cochrane and probably increases the interest of the stakeholders in the work of it.
How submitted titles are prioritised	<ol style="list-style-type: none"> 1. If the research agenda and priorities of the CRG is transparently provided for the authors. The authors could provide description how their topics relate to the research agenda. The infectious diseases group for example provides an opportunity for the authors to explain how their titles can help in achieving the Millennium development goals (MDGs). 2. The CRG could provide the editorial team with specific criteria to guide them in prioritising the submitted titles. This could include criteria that incorporate the aspect of health equity for example a possible criteria could be “would you say that the underprivileged would be the most likely to benefit from the results of the proposed review after its implementation” (112). One possibility is that the CRG do not respond immediately to a title request and do it in certain time periods e.g. 6 months and prioritise the titles that they receive in this timeframe. As many author teams are volunteers, flexibility in the process is crucial to ensure continuity and sustainability.

Prioritising Clinical Content:

In this draft, we used the different dimensions of the PROGRESS-PLUS acronym which is an extension of Evans and Browns framework PROGRESS to highlight the diversity of the stakeholders. This includes PROGRESS: Place of residence; Race/ethnicity; Occupation; Gender; Religion; Education; Socioeconomic status; and Social capital, with “PLUS” representing additional dimensions such as age, sexual orientation, and disability (113, 114). However, some of these dimensions might be more relevant in certain clinical fields compared to the others. Each CRGs would need to make a decision which of these dimensions are more relevant to their clinical field and what is the best approach to incorporate these dimensions in the work of the CRG. For example, there is much more research done on sexual differences in the field of cardiovascular research compared to restorative dental research and based on the current evidence base the former one seems be much more crucial than the latter one.

Process and politics:

We mentioned in previous sections the importance of stakeholder involvement. However, involvement of stakeholders covers a broader aspect and could include a passive involvement that assumes the stakeholders lacks sufficient knowledge or capacity to get involved in the process to an active model in which the stakeholder is directly involved in the process (115). This is especially

important in the involvement of patients in the process. The James Lind alliance has extensive experience in involving patients in the prioritisation process.

The Prioritisation cycle:

Prioritisation strategies do not end with selecting the prioritisation topics. Prioritisation is a cycle that starts in selecting priority topics, implementing, disseminating, evaluating and afterwards updating the prioritisations. Stakeholders who were involved in the prioritisation strategy could be further involved in the work of the CRG as peer reviewers to ensure that their views are also considered in conducting the Cochrane Reviews.

Updating and upgrading Cochrane Reviews:

The Cochrane editorial unit provides a framework for updating Cochrane Reviews. Some additional issues that might be considered are the priorities of disadvantage groups and how much they are addressed in the current reviews. The equity checklist developed by the Campbell-Cochrane equity methods group could help authors in identifying the gaps in their finished Cochrane Reviews that they might want to consider in updating their reviews.

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