

**“PRIORITY SETTING: A METHOD THAT INCORPORATES A HEALTH EQUITY LENS AND THE  
SOCIAL DETERMINANTS OF HEALTH”**

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## ABSTRACT

**Research Question:** This research adapted, tested, and evaluated a methodology to set priorities for systematic reviews topics within the Cochrane Collaboration that is sustainable and incorporates the social determinants of health and health equity into the analysis.

**Background:** In 2008 a study was conducted to review, evaluate and compare the methods for prioritization used across the Cochrane Collaboration. Two key findings from that study were: 1) the methods were not sustainable and 2) health equity represented a gap in the process. To address these key findings, the objective of this research was to produce and test a method that is sustainable and incorporates the social determinants of health and health equity into the decision making process. As part of this research, the methods were evaluated to determine the level of success.

**Methodology:** With assistance from experts in the field, a comparative analysis of existing priority setting methods was conducted. The Global Evidence Mapping (GEM) method was selected to be adapted to meet our research objectives. The adapted method was tested with assistance of the Cochrane Musculoskeletal Group in identifying priorities for Osteoarthritis. The results of the process and the outcomes were evaluated by applying the “Framework for Successful Priority Setting”.

**Results:** This research found that the priority setting method developed is sustainable. Also, the methods succeeded in incorporating the social determinants of health and health equity into the analysis. A key strength of the study was the ability to incorporate the patients’ perspective in setting priorities for review topics. The lack of involvement of disadvantaged groups of the population was identified as a key limitation. Recommendations were put forward to incorporate the strengths of the study into future priority setting exercises within Cochrane and to address the limitations.

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## Table of Contents

Chapter 1: INTRODUCTION .....	1
1.1 Contributions .....	2
1.2 Chapter Outline.....	4
Chapter 2: SITUATIONAL ANALYSIS .....	6
2.1 Key terms and concepts.....	6
What is priority setting? .....	6
What is the Cochrane Collaboration?.....	6
What is a Collaborative Review Group (CRG)? .....	7
What is a systematic review? .....	7
What are the social determinants of health?.....	7
What is health inequity?.....	8
2.2 Importance of Setting Priorities.....	8
Importance of Setting Priorities for Systematic Reviews .....	9
Presumed Consequences of the lack of priority setting methods .....	10
2.3 The evolution of priority setting within the Cochrane Collaboration.....	10
Cochrane Collaboration: Past Approaches to Selecting Topics for Systematic Reviews.....	10
Recent efforts by the Cochrane Collaboration to set priorities in a consistent manner .....	11
Current Status within Cochrane .....	12
2.4 Conclusions Drawn from the Literature Review .....	13
2.5 What will this thesis do to help address the outstanding issues?.....	14
Chapter 3: METHODS.....	15
3.1 Selecting an existing method and modifying it to meet research objectives.....	15
3.1.1 Comparing existing priority setting methods .....	15
3.1.2 Selecting the Most Appropriate Method for this research .....	18
3.1.2.1 Comparative Analysis of the Methods .....	19
3.1.3 Modifying the GEM methods to meet our research goals .....	21
3.1.3.1 Summary of Changes.....	21
3.1.3.2 Comparing the Process Step by Step .....	23
3.1.3.3 Comparing databases included in the Literature Search .....	25
3.1.3.4 Comparing Study Types included in the Literature Search .....	26
3.2 Selecting a Cochrane Entity and a Medical Condition to Test the Methods .....	28
3.2.1 Selecting a Cochrane Entity to Test the Methods .....	28
3.2.2. Selecting a Medical Condition to Test the Methods .....	29
3.3 Evaluating the Priority Setting Exercise .....	29

3.3.1 Applying the Framework for Successful Priority Setting .....	30
3.3.2 Additional criteria utilized to evaluate the methods.....	31
Chapter 4: RESULTS.....	33
4.1 Adapted GEM Methods .....	33
4.1.1 Identification and Recruitment of Research Participants .....	33
4.1.2 Inclusion and Exclusion Criteria in Selecting Participants .....	34
4.1.3 Sample Size Calculation .....	35
4.1.3.1 Breakdown of sample by stakeholder group .....	36
4.1.4 Data Management Practices .....	36
4.1.5 Addressing Privacy Concerns.....	37
4.1.6 Addressing the possibility of coercion, duress or undue incentive.....	37
4.1.7 Describing the 5 steps of the Adapted GEM Methods.....	38
4.1.7.1 Identifying Existing Evidence.....	39
4.1.7.2 Identifying Priorities.....	45
4.1.7.3 Converting topics into research questions.....	51
4.1.7.4 Prioritizing the top ten research questions.....	60
4.1.7.5 From Knowledge to Action.....	64
4.2 The top priority research questions for osteoarthritis .....	66
4.3 Assessing the methods and the research objectives .....	67
4.3.1 Application of the Framework for Successful Priority Setting to evaluate the results .....	67
4.3.2 Evaluating Sustainability and the Ability to Effectively Incorporate the Social Determinants of Health and Health Equity in the Process .....	71
Chapter 5: DISCUSSION.....	73
5.1 Overview of Results and Main Conclusions Reached .....	73
5.2 Top 3 Methodological Strengths.....	74
5.2.1 Top Strength 1: Using the map of evidence to inform the process .....	74
5.2.1.1 A holistic approach that better meets the needs of patients.....	74
5.2.1.2 Focus on the needs of those that require the information regardless of how Cochrane operates .....	75
5.2.1.3 A tool to help contextualize the information for those that are outside of the Cochrane Collaboration.....	75
5.2.2 Top Strength 2: Patients as champions of the process .....	76
5.2.3 Top Strength 3: Patient/Clinician Overlap Analysis.....	76
5.3 Methodological limitations and Recommendations for future applications of the methods.....	77
5.3.1 Lack of involvement of disadvantaged groups of the population .....	77
5.3.2 Lack of validation of data captured under the equity dimension.....	78

5.3.3 Lack of understanding of the blanks in the Map of Evidence for Osteoarthritis .....	79
5.3.4 Lack of validation of research questions derived from broad research topics .....	79
5.3.5 Lack of clarity of ownership of priority topics .....	80
5.4 Thesis Contributions.....	80
5.4.1 Applying the methods outside of Cochrane and the healthcare system .....	82
Chapter 6: EQUITY AND THE SOCIAL DETERMINANTS OF HEALTH (SDH) .....	83
6.1 Why develop a priority setting methodology for the Cochrane Collaboration that incorporates the Social Determinants of Health? .....	83
6.2 How were the social determinants of health and health equity incorporated into the methods? .....	84
6.2.1 Identifying Existing Evidence .....	85
6.2.2 Identifying Priorities .....	86
6.2.2.1 Incorporating the SDH into the Consultations with Experts .....	86
6.2.2.2 Incorporating the SDH into the Workshops .....	87
6.2.3 Converting Topics into Research Questions .....	88
6.2.4 Prioritizing the Top 10 Research Questions .....	91
6.2.5 From Knowledge to Action .....	93
6.2.5.1 Identifying research questions that fall under the social determinants of health .....	93
6.2.5.2 Suggesting Next Steps for Future Systematic Reviews .....	98
6.2.5.3 List of Questions that Relate to SDH and Proposed Course of Action for Future Systematic Reviews .....	100
6.3 Conclusions reached from incorporating Health Equity and Social Determinants of Health into the prioritization exercise .....	105
6.3.1 Forging ahead with SDH .....	107
6.3.1.1 Beyond Healthcare Interventions .....	107
6.3.1.2 Beyond Randomized Controlled Trials (RCTs).....	107
Chapter 7: CONCLUSIONS .....	109

## Annexes

Annex 1. 1 Comparison of Priority-Setting Approaches .....	111
Annex 4. 1 Invitation Letter to Participate in the Research Project .....	122
Annex 4. 2 Participant Information Sheet and Consent Form.....	123
Annex 4. 3 Invitation email for consultations with experts.....	127
Annex 4. 4 Prioritization Survey.....	128
Annex 4. 5 Map of Evidence for Osteoarthritis .....	132

## Tables

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Table 3. 1 Applying the four criteria against the methods .....	19
Table 3. 2 Summary of Changes Made to the GEM Methods.....	22
Table 3. 3 Comparing the Process.....	24
Table 3. 4 Comparing Databases.....	25
Table 3. 5 Comparing Study Types.....	26
Table 4. 1 Adapted GEM Methods: Sample size and number of participants by activity .....	35
Table 4. 2 Original GEM Methods: Number of participants by activity.....	35
Table 4. 3 Results of Literature Search Broken Down by Source.....	44
Table 4. 4 Priority research topics drawn from the mapping workshops.....	49
Table 4. 5 Priority research topics identified by clinical experts .....	50
Table 4. 6 Listing of 43 Research Questions .....	52
Table 4. 7 Identifying the top 10 research questions .....	62
Table 4. 8 Ranking of top 10 research questions from top priority to lowest priority .....	64
Table 4. 9 Top Research Questions for Osteoarthritis.....	67
Table 4. 10 Evaluating the Process .....	68
Table 4. 11 Evaluating the Outcomes .....	70
Table 6. 1 Listing of 43 Research Questions .....	88
Table 6. 2 Questions asked in on-line patient questionnaire .....	91
Table 6. 3 Top 10 Research Questions.....	92
Table 6. 4 List of Priority Topics that relate to the Social Determinants of Health .....	94
Table 6. 5 Recommended Level of Analysis to address Health Equity in Future Systematic Reviews .....	100

## Chapter 1: INTRODUCTION

The Cochrane Collaboration, established in 1993, is an international network dedicated to assisting healthcare providers, policy makers, patients, and their advocates and carers make informed decisions about health care. The Cochrane Collaboration helps these groups make informed decisions by conducting systematic literature reviews in order to synthesize relevant information and make the results available to them. Health care providers, for example, could access Cochrane to obtain a summary of the most up to date information available on a particular topic in order to determine the best treatment for a patient. To date, the Cochrane Collaboration has prepared over 4,000 systematic reviews, which are published online in The Cochrane Library.<sup>1</sup> Alongside other health organizations around the world,<sup>2</sup> Cochrane faces a scarcity of financial resources and qualified staff. These shortages are forcing Cochrane to take a closer look at the way resources are allocated and consumed. Historically, the selection of systematic review topics was established primarily on the personal values of the professionals conducting the reviews, or, alternatively, on the interests of those providing the funds. More recently, efforts have been made to adopt structured approaches to allocate resources based on the needs of those that require the information being produced by Cochrane. One such structured approach is priority setting. Priority setting, also known as rationing or resource allocation, is a method used to distribute resources (e.g. money, time, beds, drugs) among competing interests (e.g. institutions, programs, people/patients, services, diseases).<sup>3</sup> When developing a priority setting method, it is important to conceptualize it as an iterative process not a one-time event.<sup>4</sup> This allows the process to be influenced by the results and the thinking of the previous step. Within Cochrane however, the methods are neither iterative nor sustainable: only 13 out of 66 entities that form the Cochrane Collaboration have a structured method of setting priorities and were designed as one-time methods.<sup>5</sup>

In addition to sustainability, with the recent publication of the report from the Commission on Social Determinants of Health (CSDH) that summarized the need to address health inequity in the

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<sup>1</sup> Cochrane Collaboration Website: [www.cochrane.org](http://www.cochrane.org)

<sup>2</sup> *10/90 report on health research 2000* [2nd annual report]. Geneva: Global Forum for Health Research; 2000.

<sup>3</sup> M. F. McKneally, B. M. Dickens, E. M. Meslin, and P. A. Singer **Bioethics for clinicians: 13. Resource allocation**, *Can. Med. Assoc. J.*, Jul 1997; 157: 163 - 167.

<sup>4</sup> COHRED (Council on Health Research for Development) 2000. *A Manual for Research Priority Setting Using the ENHR Strategy*. Geneva: Council on Health Research for Development, COHRED Document No. 2000.3, Pages: 47.

<sup>5</sup> Nasser, M, Welch V, Tugwell P, Ueffing E, Doyle J, Waters E. Ensuring relevance for Cochrane reviews: evaluating the current processes and methods for prioritization and developing an equitable framework for prioritizing systematic reviews. (In the process of being submitted for publication).

world,<sup>6</sup> it became evident that aiming to attain health equity in our study was also an important element to consider. The CSDH defines health inequity as a moral position: “Where systematic differences in health are judged to be avoidable by reasonable action they are, quite simply, unfair.” It is this avoidable unfairness that the CSDH labels as *health inequity*. The report from the CSDH encouraged organizations to address health inequity through action on the social determinants of health. The social determinants of health refer to the conditions of daily life (circumstances in which people grow, live, work, and age) that impact the health of populations.<sup>7</sup> The current priority setting practices within Cochrane neither incorporate the social determinants of health nor consider health equity in a consistent way: only 1 out of the 66 entities of the Cochrane Collaboration have considered health equity in their priority setting practices.<sup>8</sup>

The current research study will take into account both health equity and the social determinants of health in the creation of a sustainable priority setting method for the Cochrane Collaboration. The method will be tested in the field by partnering with the Cochrane Musculoskeletal Group in setting priorities for Osteoarthritis.<sup>9</sup> The outcomes and the process will be evaluated in a systematic manner by applying Sibbald’s 2009 framework for successful priority-setting.<sup>10</sup> Several recommendations will be made to further streamline the priority setting process and to increase efficiency in reducing health inequity in the population.

## 1.1 Contributions

The outcome of this research has both theoretical and practical importance.

From a theoretical perspective, it was important to include the social determinants of health and health equity into a priority setting process specifically designed for systematic review topics. This research work is different from previous priority setting exercises within Cochrane in that it explicitly attempts to contribute to reducing health inequity.

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<sup>6</sup> *Closing the gap in a generation: health equity through action on the social determinants of health*. Commission on Social Determinants of Health Final Report. Geneva, World Health Organization, 2008

<sup>7</sup> *Closing the gap in a generation: health equity through action on the social determinants of health*. Commission on Social Determinants of Health Final Report. Geneva, World Health Organization, 2008

<sup>8</sup> Nasser, M, Welch V, Tugwell P, Ueffing E, Doyle J, Waters E. Ensuring relevance for Cochrane reviews: evaluating the current processes and methods for prioritisation and developing an equitable framework for prioritising systematic reviews. (In the process of being submitted for publication).

<sup>9</sup> Details on the process followed to select the Cochrane Review Group and the Condition to pilot the methods are provided in Chapter 3.

<sup>10</sup> Sibbald SL, Singer PA, Upshur R, Martin DK. Priority setting: what constitutes success? A conceptual framework for successful priority setting. *BMC Health Serv Res* 2009; 9:43.

Another theoretical contribution is the “Map of evidence for Osteoarthritis”, which was developed to inform the process by capturing existing evidence that related to both, the treatment of the condition and the social determinants of health that impact the condition. This map captured all existing systematic reviews and identified the gaps in evidence. The analysis was conducted independently from the way in which Cochrane entities are organized in order to focus on the needs of those suffering of the condition and avoid introducing bias by trying to identify topics based on Cochrane’s organizational structure. This approach is different from past work, which limited priority setting exercises to topics that would be of interest to one particular Cochrane Review Group. The map of evidence allows for a holistic view of the condition and the needs of decision-makers independently from the way in which the Cochrane Collaboration entities are organized.

We also incorporated health equity into the prioritization criteria which allowed us to test the feasibility of its usage by patients that were asked to rank the top 10 research questions. Several recommendations as to how the ranking process can be improved are included in this study. Finally, in terms of theoretical importance, the empirical validation of the following three conceptual frameworks contributed to the development of the underlying conceptual theories:

1. The Social Determinants of Health conceptual framework developed by the CSDH was used to systematically classify priority review topics that relate to social determinants of health. Using the framework we concluded that from 43 priority topics identified through this priority setting exercise, 25 could be classified under the social determinants of health. This allowed us to verify the methods had been successful in incorporating the social determinants of health into the decision-making process.
2. The five-level framework developed by the Priority Public Health Conditions Knowledge Network was used to suggest a level of health equity analysis for future systematic reviews. This framework provided a practical way of continuing to move the health equity agenda forward. By applying the framework we concluded all systematic review topics conducted by the Cochrane Collaboration could incorporate a level of analysis on health equity and social determinants of health. Thus, we recommend this to be incorporated as best practices in the Cochrane manual.
3. The “Framework for Successful Priority Setting”,<sup>11</sup> was used to evaluate the process and the outcomes of our priority setting exercise. This framework provided a high-level analysis of the process but lacked input as to ways of dealing with what the evaluation framework identified as an

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<sup>11</sup> Sibbald SL, Singer PA, Upshur R, Martin DK. Priority setting: what constitutes success? A conceptual framework for successful priority setting. BMC Health Serv Res 2009; 9:43.

issue. The evaluation process would be of more value if it offered suggestions to address the issues identified.

From a practical standpoint, we propose a sustainable priority setting method that can be utilized by all Cochrane Review groups to set priorities for systematic reviews on a continuous basis. Specific recommendations to streamline the priority setting method, such as converting broad research topics at the mapping workshops and not afterwards, are included in this study in order to increase the likelihood of its usage amongst all Cochrane entities.

## 1.2 Chapter Outline

Chapter two provides the rationale for this thesis and is broken down into three sections. The first section describes key terms used throughout this chapter and contextualizes concepts that could be applied outside of the health care system. The main objective of this first section is to provide a common foundation of knowledge. The second section establishes the importance of setting priorities and discusses past and current practices within the Cochrane Collaboration. Finally, the third section describes the problematic situation and identifies key issues that will be addressed by this thesis

Chapter 3 provides an overview of the methodology used in this study and is subdivided into three sections. The first section describes the methods applied to select an existing priority setting methodology and to modify it in order to meet the specific objectives of this research. The second section focuses on the steps followed to select a review group within Cochrane and a condition to test the new methods developed. The last section of this chapter describes the actions taken to evaluate the process and the outcomes of the priority setting exercise.

Chapter 4 provides the results of this research project and is organized in three sections. The first section describes the method that was adapted to set priorities within Cochrane. The top priority topics that were identified in the pilot exercise are summarized and analyzed in the second section. Finally, the results of the assessment of the process and outcomes are presented in the last section.

Chapter 5 begins with an overview of the results and main conclusions reached. Following this overview, the top three strengths of the methodology are presented along with a short discussion on how to further strengthen these activities. The limitations of the study and potential risks associated to the implementation of these methods are discussed in the third section. Finally, what this thesis added to the state of knowledge and research is presented in the fourth and final section.

Chapter 6 focuses on the social determinants of health. First a rationale for incorporating the social determinants of health in the process is provided. Subsequently, the resulting priority topics identified in the process that relate to social determinants of health are presented. Finally, conclusions are drawn and recommendations provided to improve future priority setting exercises in this area.

Chapter 7 summarizes the conclusions that were reached by this research project along with the 10 recommendations that were put forward to continue to improve the methods.

## Chapter 2: SITUATIONAL ANALYSIS

This chapter provides the rationale for this thesis and is broken down into three sections: (1) a description of key terms used throughout this thesis and a contextualization of concepts that could be applied outside the health care system; (2) a discussion of the importance of setting priorities, as well as a description of past and current practices within the Cochrane Collaboration; and (3) an outline of the problematic situation, which involves Cochrane lacking a priority setting method that is sustainable and that addresses health equity, and identification of key issues that will be addressed by this thesis.

### 2.1 Key terms and concepts

#### What is priority setting?

Since a standard definition of priority setting is not available, organizations use different definitions depending on their priority setting goals and practices. However, in 1997, the Council on Health Research for Development (COHRED) reviewed priority setting processes worldwide and identified key commonalities and differences among the processes used by organizations worldwide to set research priorities.<sup>12</sup> COHRED concluded that the frameworks, perspectives, and actual practices of priority setting differ among research groups, although the ultimate impact is common to all groups. According to COHRED, priority setting processes are used to guide stakeholders in three tasks: (1) planning health research programs, (2) mobilizing and allocating research resources, and (3) strengthening research capacity.

#### What is the Cochrane Collaboration?

The Cochrane Collaboration is a global network of individuals interested in summarizing healthcare research, and includes researchers, clinicians, and patients, who aim to improve evidence-based decision-making. This is done by conducting systematic reviews of the literature, synthesizing the information and making the results of the reviews available to those that need health information to make decisions. Decision-makers that benefit from the information produced by Cochrane include policy-makers, health administrators, clinicians, and general consumers of health services. Reviews are prepared by volunteer authors who are part of a Collaborative Review Group (CRG). Such systematic

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<sup>12</sup> COHRED. 1997. *Essential National Health Research and Priority Setting: Lessons Learned*. Geneva: Council on Health Research for Development, COHRED Document No. 97.3, Pages: 66.

reviews of the literature bring together multiple countries worldwide that work to increase the body of knowledge in a variety of domains in order to assist decision-makers globally.<sup>13</sup>

### **What is a Collaborative Review Group (CRG)?**

CRGs are comprised of individuals with common interests in a particular healthcare problem. The main purpose of a CRG is to prepare and maintain systematic reviews of the effects of healthcare interventions within the scope (i.e. health care area) of the group's focus (e.g. Acute Respiratory Infectious Group). Members participate in CRGs by drafting research questions, searching for relevant literature and preparing reports to summarize this information. For example, a recent report produced by the Hepato-Biliary Group, summarized the findings on the effectiveness of antioxidant supplements for the prevention of mortality in healthy participants and patients with various diseases. After searching all the relevant literature, the authors concluded "no evidence exists that supports antioxidant supplements prevent mortality in healthy people or patients with various diseases". Each CRG is coordinated by an editorial team, responsible for regularly updating and submitting an edited module of systematic reviews and information about the CRG, for publication in The Cochrane Library.

### **What is a systematic review?**

A systematic review is a clearly formulated question that allows for systematic and explicit methods to identify, select, and critically appraise relevant research and information, and to collect and analyse data from the studies included in the review. Statistical methods may be used to analyse and summarise the results of the included studies.<sup>14</sup>

### **What are the social determinants of health?**

Historically, systematic reviews developed by Collaborative Review Groups focused mainly on addressing clinical questions (e.g. does drug A work better than drug B for patients under the age of five?). However, in recent years it has become evident that there are factors that impact the health of populations that originate outside of the health care system. Such factors refer to the circumstances in which people grow, live, work, and age – these are known as social determinants of health.<sup>15</sup> To ensure

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<sup>13</sup> (Cochrane Collaboration s.d.)

<sup>14</sup> Green S, Systematic Reviews and Meta Analysis, *Singapore Med J* 2005 Vol 46(6):270-274

<sup>15</sup> The term 'social determinants of health' identifies these external factors and was first introduced by the World Health Organization (WHO) Commission on Social Determinants of Health in 2008. CSDH (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health*. Geneva, World Health Organization.

a comprehensive approach in setting priorities for Cochrane, we will develop a priority setting method that incorporates these underlying factors.<sup>16</sup>

### What is health inequity?

In 2008 the Commission on Social Determinants of Health (CSDH) published a report that summarized the importance that the social determinants of health play in addressing health inequity in the world.<sup>17</sup> The CSDH defined health inequity as a moral position: “Where systematic differences in health are judged to be avoidable by reasonable action they are, quite simply, unfair.”<sup>18</sup> It is this avoidable unfairness that the CSDH labels as *health inequity*. Three measures are commonly used to describe inequities: (1) health disadvantages due to differences between segments of populations or between societies; (2) health gaps, arising from differences between disadvantaged and privileged individuals; and (3) health gradients, relating to differences across the entire spectrum of the population.<sup>19</sup> The report from the CSDH encouraged organizations to address health inequity through action on the social determinants of health. The current priority setting practices within Cochrane neither incorporate the social determinants of health nor consider health equity in a consistent way.<sup>20</sup> The current research study will take into account both health equity and the social determinants of health in the creation of the priority setting method.

## 2.2 Importance of Setting Priorities

It is important to set priorities for two reasons: financial and human resources available to healthcare systems are limited<sup>21</sup> and those existing resources are being unequally distributed, which, in turn, increases health inequity. The current shortage of resources is forcing stakeholders and decision-makers to take a closer look at the way the resources are allocated and consumed at both global and national levels. Problems arise when individuals in power, normally decision-makers, tend to selectively

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<sup>16</sup> *Closing the gap in a generation: health equity through action on the social determinants of health*. Commission on Social Determinants of Health Final Report. Geneva, World Health Organization, 2008

<sup>17</sup> *Closing the gap in a generation: health equity through action on the social determinants of health*. Commission on Social Determinants of Health Final Report. Geneva, World Health Organization, 2008

<sup>18</sup> *Closing the gap in a generation: health equity through action on the social determinants of health*. Commission on Social Determinants of Health Final Report. Geneva, World Health Organization, 2008.

<sup>19</sup> Kelly PM et al. *The social determinants of health: developing an evidence base for political action*. Final Report of the Measurement and Evidence Knowledge Network to the Commission on Social Determinants of Health. Geneva, World Health Organization, 2007.

<sup>20</sup> Nasser, M, Welch V, Tugwell P, Ueffing E, Doyle J, Waters E. Ensuring relevance for Cochrane reviews: evaluating the current processes and methods for prioritisation and developing an equitable framework for prioritising systematic reviews. (In the process of being submitted for publication).

<sup>21</sup> *10/90 report on health research 2000* [2nd annual report]. Geneva: Global Forum for Health Research; 2000.

allocate resources to resolve their problems and meet their needs. The Global Forum for Health Research has highlighted a major global imbalance between the magnitude of health problems in low- and middle-income countries and the resources devoted to addressing them.

In 1990 COHRED estimated that only approximately 5% of the world's resources for health research were being applied to health problems of low and middle income countries (LMICs), where 93% of the world's preventable deaths occurred.<sup>22</sup> This is known as the "10/90 gap," that is, only 10% of global spending on health research is directed towards the problems that affect the 90% of the world's population.<sup>23</sup> Recent improvements have been made, especially in the increase in number of actors engaged in funding or conducting health research relevant to the needs of LMICs. Nevertheless, recent studies continue to demonstrate that the 10/90 measure might no longer be current, health research in this area remains substantially under-resourced and the gap persists.<sup>24 25 26</sup>

### Importance of Setting Priorities for Systematic Reviews

While priority setting in health research has continued to accumulate over the last two decades at a global level,<sup>27</sup> there has been a lack of sustainable methodologies to set priorities within Cochrane. From its inception in 1993, the Cochrane Collaboration has produced over 4000 systematic reviews. However, Cochrane's administration estimates that at least 10,000 systematic reviews are needed to summarize the information produced by new healthcare interventions and that these reviews will need to be updated at the rate of 5000 per year.<sup>28</sup> Evidently, existing resources are not sufficient to keep up with the the needs of all Cochrane stakeholders, such as clinicians, researchers, patients and policy-makers. This means that resources need to be allocated to the address the most urgent needs first. In order to do so, it is important to determine what those urgent needs are. This thesis proposes that developing priority setting methodologies is a key step in determining which research topics should be tackled first. At minimum, the process should consider the needs of all stakeholder groups and set priorities in an objective, unbiased way.

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<sup>22</sup> Commission on Health Research for Development (1990): Health Research, Essential Link to Equity in Development.

<sup>23</sup> Saxena S, Paraje G, Sharan P, Karam G, Sadana R. The 10/90 divide in mental health research: trends over a 10-year period. *Br J Psychiatry* 2006; 188: 81-2 doi: [10.1192/bjp.bp.105.011221](https://doi.org/10.1192/bjp.bp.105.011221) pmid: [16388075](https://pubmed.ncbi.nlm.nih.gov/16388075/).

<sup>24</sup> Global Forum for Health Research (2004). The 10/90 Report on Health Research 2003-2004. <http://www.globalforumhealth.org/> Website accessed: July 20, 2009.

<sup>25</sup> World Bank's 1993 World Development Report, *Investing in Health*

<sup>26</sup> Priority-Setting Workshop, Cochrane Colloquium, Freiburg, Germany. October 4, 2008.

<sup>27</sup> (Council on Health Research for Development (COHRED) 2006)

<sup>28</sup> Clarke, M. Systematic reviews and the Cochrane Collaboration. Available at: [www.cochrane.org/docs/whycc.htm](http://www.cochrane.org/docs/whycc.htm)

## **Presumed Consequences of the lack of priority setting methods**

In practice the lack of priority setting methodologies translates into selecting systematic review topics based on the personal interests of a select group of individuals. However, the needs and interests of the broader population and relevant stakeholder groups are not considered, creating an impact on both, decision-makers and researchers. Allowing a dominant group to choose the topics of systematic reviews increases the risk of biasing the research process. As a result public health policy, medical practice, public health campaigns, medical research, etc., which are all developed based on information produced by systematic reviews, will likely meet the needs and interests only of a select group. This ultimately promotes health inequality given that only the health needs of a few individuals are being taken into consideration. Furthermore, under these circumstances, the needs of underprivileged groups of the population are more likely to be ignored given that they tend to lack the knowledge and the skills required to lobby for their own interests and needs.

While biasing the research process, the lack of priority setting methodologies can also limit certain areas of knowledge. Because systematic reviews are normally the starting point of a formal research process, if they are not produced in certain areas, then it is less likely that research will continue to progress in that area. Systematic reviews should be produced in all areas that are considered important by the majority of stakeholders, not only those funding the research or in an influential position. Furthermore, ignoring priority setting methodologies can also result in a waste of resources. This occurs if systematic reviews are being produced based on personal interests but not on needs assessments. Given the already existing scarcity of resources, it is of vital importance to verify that a systematic review is in fact needed. When the values and interests of a select group are considered, researchers risk losing perspective on the needs of the general population and can ultimately produce systematic reviews that will not be used in the long run by health care providers, policy-makers, and other decision-makers.

## **2.3 The evolution of priority setting within the Cochrane Collaboration**

### **Cochrane Collaboration: Past Approaches to Selecting Topics for Systematic Reviews**

Historically, Cochrane established health research priorities mainly on the personal values of health professionals conducting the systematic reviews, or on the interests of those providing the funds. This situation was compounded by the fact that systematic reviews are normally conducted by volunteers, who select topics to work on based on their personal interest. Volunteers are, in fact,

encouraged to select a title in an area of high interest to them, given that they are expected to keep the review up-to-date according to Cochrane policy. This policy indicates that systematic reviews should be updated every two years. Given the long-term commitment that volunteers are required to assume, this policy perpetuated the issue of selecting topics based on personal interest and not on the needs of the general population or decision-makers.

## **Recent efforts by the Cochrane Collaboration to set priorities in a consistent manner**

In the last twenty years, the Cochrane Collaboration has led two main efforts in order to promote more structured approaches to setting priorities. First, in the early 1990s,, the Cochrane administrators encouraged Cochrane Review Groups to take on various strategies to set priorities. Examples of these early efforts to incorporate a structured topic selection process are those conducted by the Breast Cancer CRG, the Consumers and Communications CRG, and the Musculoskeletal CRG who involved consumers in setting priorities within each one of their groups<sup>29 30 31 32</sup>. Later, in 2005, the Cochrane Collaboration called for proposals to continue the development of priority setting methodologies.<sup>33</sup> In response to this call for proposals, the following five projects were funded by the Cochrane Collaboration to continue to develop priority setting methodologies within Cochrane:

- 1) Delivering on priorities: developing and implementing effective collaboration between a Cochrane Review Group and a Cochrane Field, led by Rajan Madhok of the Cochrane Bone, Joint and Muscle Trauma Group.
- 2) Using practice guidelines to determine review priorities: a pilot project, led by Kay Dickersin of the United States Cochrane Center.
- 3) Prioritization of Cochrane reviews for consumers and the public in low and high-income countries as a way of promoting evidence-based health care, led by Janet Wale of the Cochrane Consumer Network.

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<sup>29</sup> Ebrahim S, Moore T. Priority setting for review topics in the Cochrane Review Groups. 7th Cochrane Colloquium, 5-9 October 1999, Rome, Italy <http://www.cochrane.org/colloquia/abstracts/rome/romeO58.htm>

<sup>30</sup> Ghersi D, Kennedy G, Rio P, Shea B. Consumer Setting Priorities for Cochrane Review Groups. 7th Cochrane Colloquium 5-9 October 1998, Rome, Italy <http://www2.cochrane.org/colloquia/abstracts/rome/romeO59.htm>

<sup>31</sup> Vet HCW, Korese MEAL, Scholten RJPM. The efficacy Of treatments for chronic benign pain disorders: setting research priorities by literature searches With minimal reading. 8th Cochrane Colloquium 25-29 October 2000, Cape town, South Africa.

<sup>32</sup> Walker J, Judd M, Qualman A, Santesso N, Tugwell P. Consumer priority survey: bridging the gap between producers and users of systematic reviews. 12 th Cochrane Colloquium 2004, Ottawa, Canada. <http://www.cochrane.org/colloquia/abstracts/ottawa/O-033.htm>

<sup>33</sup> (Cochrane Collaboration 2007)

- 4) Prioritizing Cochrane review topics to reduce the gap between what is known and what is actually done in low and middle income countries, led by Peter Tugwell of the Cochrane Health Equity Field.
- 5) Piloting and evaluation of a patient-professional partnership approach to prioritizing Cochrane reviews and other research, led by Adrian Grant of the Cochrane Incontinence Group.

These five projects have been almost completed and are now in the process of reporting their results. But even before all the results are reported, it is clear that the 2005 initiative raised awareness about the need for more inclusive and objective methods to set priorities across Cochrane entities.<sup>34 35</sup> As the awareness increased, other national and international initiatives began funding projects to develop methodologies to set priorities for systematic reviews. For example, the NHS Cochrane Collaboration Programme Grant Scheme funded a number of Cochrane reviews for the UK based Cochrane review groups, which included a prioritization process to determine the review titles that a CRG would work on. The Cochrane Gynaecological Cancer Review Group was funded by this UK initiative<sup>36</sup>.

### Current Status within Cochrane

In 2008, Cochrane continued to investigate priority setting methods with a study that evaluated and compared the current methods and processes for prioritization used across the Cochrane Collaboration.<sup>37</sup> Peter Tugwell, one of the supervisors of this thesis, was the principal investigator on the grant for this comprehensive study. The work conducted by Peter Tugwell and his research group is the most current and complete evaluation of the prioritization processes used by the Cochrane Collaboration.<sup>38</sup> This study involved a survey of Cochrane review groups (CRGs), fields, and networks to determine:

- 1) Whether they had established any systematic prioritization processes for selecting titles of Cochrane reviews

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<sup>34</sup> (Bellorini et Dorée 2006) *Jenny Bellorini, Carolyn Dorée; A method for prioritising review topics: map of distribution of randomized controlled trials (RCTs) in the Cochrane Review Group Trials Register*. 14<sup>th</sup> Cochrane Colloquium 23-26 October 2006, Dublin, Ireland.

<sup>35</sup> Nasser M, Lodge M, Fedorowicz Z. The relevance of Cochrane Reviews to the Cancer Priorities in Iran. 15<sup>th</sup> Cochrane Colloquium 23-27 October 2007, Sao Paulo, Brazil. <http://www.imbi.uni-freiburg.de/OJS/cca/index.php/cca/article/view/5059>

<sup>36</sup> Williams C, Jess C, Quinn G, Oestmann A, Dickinson HO, Bryant A. Gynaecological Cancer Group - NHS Cochrane Collaboration Programme Grant Scheme. 16<sup>th</sup> Cochrane Colloquium 3-7 October 2008, Freiburg, Germany. <http://www.imbi.uni-freiburg.de/OJS/cca/index.php/cca/article/viewArticle/6735>

<sup>37</sup> Nasser, M, Welch V, Tugwell P, Ueffing E, Doyle J, Waters E. Ensuring relevance for Cochrane reviews: evaluating the current processes and methods for prioritisation and developing an equitable framework for prioritising systematic reviews. (In the process of being submitted for publication).

<sup>38</sup> Ibid

- 2) Whether they had undertaken projects on prioritizing titles as a one time event or if they had been planned it as an iterative process
- 3) Whether they had considered health equity in the priority setting process or not.

The results of the survey were summarized and discussed at workshops during two Cochrane Symposiums: at the 16<sup>th</sup> Cochrane Colloquium in Freiburg, Germany (October 2008)<sup>39</sup> and at the 17<sup>th</sup> Cochrane Colloquium in Singapore (October 2009).<sup>40 41</sup> In these workshops, Tugwell's research group presented the results of the surveys, as well as several case studies on priority setting projects within Cochrane. Workshop participants included members of the Collaboration and external stakeholders such as the World Health Organization. The main findings from the survey and the workshops were the following: only 13/66 entities had a structured method to setting priorities, none of the methods were sustainable (except one), and none considered health equity (except one).<sup>42 43</sup>

## 2.4 Conclusions Drawn from the Literature Review

Five important themes emerge from the current literature review:

- 1) Field members, reviewers, editors, consumer representatives and subject matter experts recognize health equity as a gap in the priority setting process and identify the need to assist Cochrane review groups in addressing health equity issues.<sup>44 45</sup>
- 2) There are no sustainable processes to identify priority topics within Cochrane. Most priority setting exercises are one-time pilots that are not repeated.
- 3) Further research is needed to improve the methodology on priority setting. Studies that compare and evaluate existing methods are recommended.

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<sup>39</sup> 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](http://www.equity.cochrane.org/Files/Priority_Setting_Minutes_2008.pdf)

<sup>40</sup> 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.

<sup>41</sup> Nasser M. 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.

<sup>42</sup> Nasser, M, Welch V, Tugwell P, Ueffing E, Doyle J, Waters E. Ensuring relevance for Cochrane reviews: evaluating the current processes and methods for prioritisation and developing an equitable framework for prioritising systematic reviews. (In the process of being submitted for publication).

<sup>43</sup> Sutton AJ, Donegan S, Takwoingi Y, Garn (Council on Health Research for Development (COHRED) 2006)er P, Gamble C, Donald A. An encouraging assessment of methods to inform priorities for updating systematic reviews. *J Clin Epidemiol.* 2009 Mar;62(3):241-51.

<sup>44</sup> Priority-Setting Workshop Minutes: [http://www.equity.cochrane.org/Files/Priority\\_Setting\\_Minutes\\_2008.pdf](http://www.equity.cochrane.org/Files/Priority_Setting_Minutes_2008.pdf)

<sup>45</sup> Holm S: Goodby to the simple solutions: the second phase of priority setting in health care. *British Medical Journal* 1998, 317:1000-1002.

- 4) New techniques are required to help put priority topics into context both during and following the prioritization process.
- 5) A strategic plan is required to increase the number of priority topics that are undertaken and increase the impact of the reviews on patient care.

## **2.5 What will this thesis do to help address the outstanding issues?**

The thesis will develop, test, and evaluate a priority setting method that is feasible and sustainable for Cochrane entities and that incorporates health equity considerations and the social determinants of health. More specifically, this thesis will contribute to new knowledge in the following areas:

- Improving the sustainability of a priority setting method tailored for use by CRGs
- Addressing health equity issues while setting priorities
- Evaluating priority setting methodologies

The results and recommendations of this thesis can be used by the Cochrane Collaboration in general and also by each individual CRG to further develop methods that are feasible within their group.

## Chapter 3: METHODS

This chapter provides an overview of the methodology used in this. The first section describes the methods applied to select an existing priority setting methodology and how it was modified in order to meet the specific objectives of this research. The second section focuses on selecting a review group within Cochrane and a medical condition to test the methods. The last section of this chapter describes the evaluation of the priority setting exercise. This includes a description of the Framework for Successful Priority Setting,<sup>46</sup> which was developed by an independent group of researchers and also, applying evaluation criteria we developed to assess whether our research objectives were met. These criteria include sustainability and the ability to effectively incorporate health equity and the social determinants of health into the priority setting process.

### 3.1 Selecting an existing method and modifying it to meet research objectives

Given Cochrane's shortage of resources, my thesis supervisors and I agreed to build on existing knowledge in order to avoid duplication of efforts. Therefore, instead of developing an entirely new method, we will review existing methods and select one for modification in order to meet our research objectives. This selection and modification was done with approval of the original authors of the priority setting methods. It was expected that such modifications would continue to improve the methods, thus benefiting the original authors as well. In selecting an existing method we first conducted a literature review to identify the most relevant priority setting methods for our research. The criteria applied to determine whether a method was relevant or not was established by the research group and are explained in detail later on in this chapter. The results of the literature review were reviewed with Cochrane members that had previously conducted work on priority setting so that based on their practical previous experience on implementing priority setting methods within Cochrane, they could help select the ones that were the most promising for the work we were doing. Six methods were selected to conduct a comparative analysis of approaches.

#### 3.1.1 Comparing existing priority setting methods

After consultation with Cochrane members experienced in priority setting processes, the following six methods were selected to conduct the comparative analysis:

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<sup>46</sup> Sibbald SL, Singer PA, Upshur R, Martin DK. Priority setting: what constitutes success? A conceptual framework for successful priority setting. *BMC Health Serv Res* 2009; 9:43.

- 1) Accountability for Reasonableness<sup>47 48 49 50</sup>
- 2) The James Lind Alliance Methodology<sup>51 52</sup>
- 3) Health Sector Wide Disease Based Model<sup>53</sup>
- 4) The Global Evidence Mapping<sup>54</sup>
- 5) The Combined Approach Matrix<sup>55</sup>
- 6) Evidence Based Public Health Policy and Practice<sup>56</sup>

The criteria used to select the six methods were as follows:

- 1) Applicability: Is the method appropriate for defining research priorities within the context of systematic reviews?
- 2) Proven results: Have the methods have been tested before and were they deemed successful?
- 3) Flexibility: Can the modifications can be easily adapted (i.e., Can we incorporate health equity into the decision-making process)?
- 4) Agreement: Do the original authors agree that we can build on their methods and make the modifications that are necessary to meet our research goals.

As part of our discussion with these experts, it was agreed the following information would be collected for each one of the methods, and that the following factors would be the basis for comparing the methods:

- 1) What is the objective of priority-setting?
- 2) Is the focus global, national, or both?

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<sup>47</sup> Martin KD, Giacomini M, Singer PA (2001). Fairness, accountability for reasonableness, and the views of priority setting decision-makers. *Health Policy* 61; 279-290.

<sup>48</sup> Daniels Norman and Sabin James (1998). The Ethics of Accountability in Managed Care Reform. *Health Affairs*, Vol.17 Number 5

<sup>49</sup> Mshana Simon et. al. (2007). What do District Health Planners in Tanzania think about improving priority setting using 'Accountability for Reasonableness? *BioMedCentral Health Services Research* 7:180

<sup>50</sup> Martin Doug and Singer Peter (2003). A Strategy to Improve Priority Setting in Health Care Institutions. *Health Care Analysis*, Vol. 11, No. 1.

<sup>51</sup> Oliver S, Gray J (2006). A bibliography of research reports about patients', clinicians' and researchers' priorities for new research. London: James Lind Alliance.

<sup>52</sup> Crowe S, (2006). Priority Setting Approaches for James Lind Alliance (JLA) Working Partnerships.

<sup>53</sup> Monash University, Centre for Health Economics (2006). Priority Setting in Osteoarthritis. Research Paper.

<sup>54</sup> The Global Evidence Mapping Initiative (2008). Preliminary Evidence Mapping Report: Rehabilitation, subacute & Long-term care of patients with traumatic brain injury or spinal cord injury.

<sup>55</sup> Global Forum for Health Research (2004). The Combined Approach Matrix, a priority-setting tool for health research.

<sup>56</sup> Doyle J et. al (2005). Global priority setting for Cochrane systematic reviews of health promotion and public health research. *J. Epidemiol Community Health*; 59:193-197.

- 3) What are the strategies or principles applied? (a belief that is accepted as a reason for acting in a particular way)
- 4) What are the criteria for priority setting?
- 5) What is the burden of disease?
- 6) How are the determinants of disease burden analyzed?
- 7) Are the interventions cost-effective?
- 8) Is equity considered in the burden of the disease, the analysis of determinants of disease burden, and in the cost-effectiveness of interventions?
- 9) Which institutions participate in the process?
- 10) Who makes the decisions?
- 11) What factors do decision-makers consider?
- 12) What are the reasons for the decisions?
- 13) What is the process of decision-making?
- 14) Are decisions and their rationale publicly accessible? (publicity condition)
- 15) Are the rationales based in evidence, reasons, and principles that all fair-minded parties agree are relevant? (relevance condition)
- 16) Is there an appeal mechanism for challenging decisions? (appeal condition)
- 17) Are there voluntary or regulatory enforcement channels in order to ensure that the publicity condition, relevance condition and appeals condition are met?
- 18) What are the techniques for deciding what topics are considered a priority?
- 19) What a priori assumptions are made?
- 20) To what degree can the priority setting method be adapted to Cochrane and Campbell review groups?
- 21) In which countries has the process been conducted?
- 22) What are the key references?

Annex 1 summarizes the data collected for each of the six selected methods. The table in Annex 1 contains the data elements described above for each one of the six methods, along with references to main research papers describing empirical validations of each method.

The top findings from the comparative analysis of approaches are:

- 1) Only one of the six approaches was developed specifically to set priorities within the context of systematic reviews.

- 2) Only two out of the six approaches considers an economic dimension in analysing and determining research priorities.
- 3) Five out of six approaches are flexible in the criteria they use for selecting priorities.
- 4) Only the Accountability for Reasonableness Framework (AFR) considers some dimension of equity in the process, mainly in ensuring the participants are selected fairly. However, it does not incorporate equity into the outcome of the priority setting exercise. The needs of disadvantaged groups of the population are also not expressly considered.
- 5) All 6 processes can potentially be applied at both a national and global level.
- 6) One of the 6 processes did not include patient participation—only academics, researchers and policy-makers participated in the process. The remaining five processes incorporated some form of patient input.
- 7) All six processes vary in their reasons and methods for selecting and setting priorities.
- 8) The conditions of publicity, relevance, enforcement, and appeal mechanisms were considered only under the Accountability for Reasonableness approach.

### **3.1.2 Selecting the Most Appropriate Method for this research**

After compiling the results of our comparison between the six selected methods, a meeting of experts took place to review the table and the findings in order to select one of the six methods. This meeting included some of the original authors of the priority setting methods being compared. After discussion of pros and cons of each approach as well as considering feasibility within Cochrane, the experts concluded the Global Evidence Mapping (GEM) method<sup>57</sup> was the most appropriate foundational method for modification. This method was developed by a network of people and organizations interested in producing evidence maps, which identify, evaluate, and summarize research evidence pertaining to clinical questions about medical conditions. The objective of the GEM method is to identify the strengths and weaknesses of evidence in certain health areas. For example, spinal cord injury (SCI) is a medical condition and a related clinical question is: “What are effective interventions for managing pain in SCI patients?”<sup>58 59</sup> In producing a map to answer this question, the first step is to search for all relevant literature. Next, relevant data from the literature is extracted, reviewed, and

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<sup>57</sup> The Global Evidence Mapping Initiative (2009): Description & Development of Methods and Future Directions.

<sup>58</sup> The Global Evidence Mapping Initiative (2008): Preliminary Evidence Mapping Report. Rehabilitation, Subacute & Long term care of patients with Traumatic Brain Injury or Spinal Cord Injury.

<sup>59</sup> Katz DL, Williams AL, Girard C, Goodman J et. al. The evidence base for complementary and alternative medicine: methods of Evidence Mapping with application to CAM. *Alternatives Therapies in Health and Medicine* 2003;9(4):22-30.

evaluated. After the evidence is evaluated, the findings are summarized, indicating gaps in the existing evidence. As a final step, the map is published and disseminated to those interested in the clinical question.

The GEM methods were selected for five reasons: (1) Different types of research, including systematic reviews, can be contained in an evidence map as long as it addresses the clinical question. Since the Cochrane Collaboration produces systematic reviews, experts felt the GEM methods could be easily adapted for their purposes; (2) Input is gathered from a variety of stakeholder groups, such as administrators, decision-makers, clinicians, researchers, and patients, which increases the level of transparency and inclusiveness. This is important given that in order to address health equity issues with our methods we need to be able incorporate input from several stakeholder groups; (3) The methods identify and prioritize clinical questions. The prioritization criteria are flexible, which offers the possibility of including health equity in the criteria; (4) The methods have already been applied to set research priorities in other areas, such as Spinal Cord Injury and Traumatic Brain Injury. The process followed in both cases has been documented following academic standards, which enabled us to build on existing knowledge; and (5) The original authors of the GEM methods agreed to work with our group to make the modifications required to meet our objectives.

### 3.1.2.1 Comparative Analysis of the Methods

The criteria that were applied to compare the methods were four:

- The first criteria was “applicability”, which referred to the suitability of the method within the context of Cochrane
- The second criteria was called “proven results”- this assessment was based on the number and quality of published articles in peer-reviewed journals related to the method
- The third criteria was “flexibility” – for this we conducted a quick assessment to determine whether the methods could be adapted and how easy it would be to make the adaptations
- The fourth and final criteria was “agreement”, which referred to the willingness of the creators of the methods to work with us to adapt them to meet our research objectives

Table 3.1 summarizes the analysis that we conducted.

**Table 3. 1 Applying the four criteria against the methods**

Method	Applicability	Proven Results	Flexibility	Agreement	Selected
AFR	No	Yes	Yes	No	No
JLA	Partially	Yes	No	No	No

HsW – DBM	No	Yes	No	No	No
<b>GEM</b>	<b>Yes</b>	<b>Yes</b>	<b>Yes</b>	<b>Yes</b>	<b>Yes</b>
CAM	No	Yes	N/A	N/A	No
Global Priority Setting	No	Yes	No	No	No

The methods are listed in the first column. The second, third, fourth, and fifth columns refer to the criteria that was applied against each method. The last column on the right indicates whether the method was selected or not. The method that was selected is highlighted in blue and is the GEM method; the rest were excluded based on the results presented on this table. We will go through each one of the methods that were excluded first and then summarize the reasons for selecting the GEM method.

- First, the Accountability for Reasonableness method (AFR), which we concluded did not meet the applicability criteria as it offers guiding principles to implement a fair priority setting process but is not a method in itself.
- Second, The James Lind Alliance (JLA) addresses uncertainties about the effects of treatments but does not allow room for social determinants of health; also, the stakeholder groups that participate in the process are clinicians and patients but it does not incorporate the perspective of policy-makers or researchers. Therefore we concluded it was not applicable.
- Third, the Health Sector Wide Disease Based Model (HsW – DBM) focuses on reallocating resources based on identifying highly cost- effective interventions. Given that we did not have cost information going into this process we concluded the method was not applicable.
- Next, the Combined Approach Matrix (CAM) assists with priority setting but it is not a priority-setting process in itself; it only helps classify the information. Therefore, we concluded it was not applicable.
- Finally, the global Priority Setting Method for Cochrane Systematic Reviews, although it was developed to set priorities within Cochrane; it is focused on setting priorities with organizations that can fund systematic reviews and that can benefit from them, therefore we concluded, again, this method was not applicable.

When we applied the four criteria to the Global Evidence Mapping (GEM) method, we concluded it was suitable to set priorities within Cochrane; it offered the flexibility we need to extend the scope of the research topics to the social determinants of health and to extend the prioritisation criteria to

include health equity. Also, the methods had already been applied to set research priorities in Spinal Cord Injury and Traumatic Brain Injury and their process was documented following academic standards, which enabled us to build on existing knowledge. Finally, in terms of agreement the authors of the methods were very supportive of our project and were willing to work closely with us to ensure the project was completed successfully.

### **3.1.3 Modifying the GEM methods to meet our research goals**

After the foundational method was selected, we identified and made modifications to the methods in order to meet our research objectives of sustainability and health equity. We developed our method using an iterative approach, with regular meetings of the Ottawa team and the GEM team, which led to the modifications described in Section 3.1.3.1 below. The main reason for the modifications was the consideration of social determinants of health in the process and outcomes, and the decision to provide/create the map of available systematic reviews before the prioritization process rather than after the prioritization process (as is done in GEM). The adapted GEM methods are described in detail in Chapter 4, Section 4.1. In summary, the methods developed include the following high-level steps to prioritize research topics:

- 1) Populating a map of evidence with existing systematic reviews to inform the process.
- 2) Conducting mapping workshops with patients, clinicians, researchers, and experts to identify topics of interest and priorities from their perspective.
- 3) Conducting formal consultations with clinical experts to identify topics of interest and priorities from their perspective.
- 4) Producing an initial list of priority topics which specify the population, intervention, comparison, and outcomes of interest.
- 5) Prioritizing the top ten priority topics through an on-line survey completed by patients

#### **3.1.3.1 Summary of Changes**

Table 3.2 below lists the main modifications made to the GEM methods and provides a brief rationale for each one. Column A describes change that was made and Column B describes the objective to be accomplished with the change. In total, nine major modifications were made. Our key objective was to produce an evidence map first in order to inform the process. This was the most substantial modification since the evidence map is normally produced at the end. This evidence map was also different in that it did not answer one particular clinical question but included all systematic reviews

related to the medical condition, which were organized and classified using the National Service Improvement Framework.<sup>60</sup>

Before selecting an appropriate framework we selected the Cochrane Review Group and the condition that to pilot the adapted GEM methods. We agreed the method would be tested in the field by partnering with the Cochrane Musculoskeletal Group in setting priorities for Osteoarthritis.<sup>61</sup> With the condition in mind, we chose this framework because it encompassed all treatment stages and interventions for osteoarthritis and allowed us to incorporate the social determinants of health. Another important factor was that one of the authors of the framework, Peter Brooks, had worked with Peter Tugwell, who supervises this thesis. The relationship between Peter Brooks and Peter Tugwell facilitated us getting in touch with the authors of the framework and obtaining approval to use it and modify it for our purposes. This framework was produced by a group of experts on osteoarthritis, which included patients, clinicians, researchers, policy-makers, and administrators. As a result, the framework offers a holistic view of osteoarthritis across its different stages and from the perspective of the patient, the healthy community, and the population at risk of developing the condition. The map of evidence is described in detail in Chapter 4, Section 4.1.3.

**Table 3. 2 Summary of Changes Made to the GEM Methods**

#	Change Made Column A	Objective (s) Column B
1	Added an evidence map for the condition	<ul style="list-style-type: none"> <li>– To provide a framework to categorize and analyze the data</li> <li>– To incorporate the social determinants of health into the analysis</li> <li>– To inform the overall priority setting process</li> </ul>
2	Added a patient-only workshop	<ul style="list-style-type: none"> <li>– To increase the patients’ level of participation in the process</li> </ul>
3	Added formal interviews with experts after the workshops	<ul style="list-style-type: none"> <li>– To collect input from a clinician perspective</li> <li>– To incorporate priorities from clinicians into the analysis</li> </ul>

<sup>60</sup> National Health Priority Action Council (NHPAC) (2006) National Service Improvement Framework for Osteoarthritis, Rheumatoid Arthritis, and Osteoporosis, Australian Government Department of Health and Ageing, Canberra.

<sup>61</sup> Details on the process followed to select the Cochrane Review Group and the Condition to pilot the methods are provided in Chapter 3.

4	Provided experts with a copy of the evidence map before conducting the interviews	– To inform experts on existing evidence in the form of systematic reviews
5	Eliminated the on-line survey to collect additional priority topics	– To eliminate steps that did not prove to add value in previous pilots
6	Added an on-line survey for patients to prioritise the top priority topics	– To increase the patients’ level of participation in the process
7	Added health equity into the prioritization criteria	– To incorporate health equity into the ranking of topics
8	Analyzed data based on the Social Determinants of Health conceptual framework developed by the Commission on Social Determinants of Health (CSDH)	– To analyze the topics produced from the perspective of the social determinants of health. – To verify that the topics identified as related to social determinants of health in fact are related.
9	Suggested a specific level of health equity analysis for all priority topics identified through this exercise.	– To put forward recommendations in terms of incorporating health equity when choosing priority topics for systematic reviews?

In order to provide a clear picture of changes made, three tables are included below with more details. Table 2 identifies steps that were added or deleted from the process. Table 3 compares the databases used to conduct the literature search. Finally, Table 4 compares the type of studies that were included to populate the maps of evidence.

### 3.3.1.2 Comparing the Process Step by Step

Table 3.3 below provides a detailed comparison of the modification process. Column A identifies the steps contained in the original methods. Column B identifies the steps carried out in this study. An “X” under Column A or Column B indicates steps carried out. An “N/A” indicates the activity was not conducted. The main modification made was the incorporation of a map of evidence at the beginning of the exercise to inform and guide the process. This map of evidence provided a holistic view of evidence relevant to the medical condition. The main objective of this modification was to incorporate the social determinants of health into the process and to classify existing, available systematic reviews using a disease-specific framework. We also decided that in order to inform the process it would be more useful

to have the map of evidence developed before prioritizing topics, whereas the original GEM methods developed the map after prioritizing topics. More details on how the map of evidence was developed are provided in *Chapter 4, Section 4.1.3*. Details regarding the benefits obtained by incorporating the social determinants of health into the priority setting process are provided in *Chapter 6*.

**Table 3.3 Comparing the Process**

Steps in the process	Original GEM	Modified GEM
	Column A	Column B
Build Map of Evidence and populate with existing systematic reviews	N/A	X
Search and selection of studies	N/A	X
Develop of search strategy	N/A	X
Develop inclusion criteria	N/A	X
Conduct literature search	N/A	X
Select studies	N/A	X
Produce evidence overview	N/A	X
Identify evidence gaps	N/A	X
<b>Develop and Prioritise Questions</b>	<b>X</b>	<b>X</b>
Conduct expert consultations	X	X
Scoping search	X	N/A
Conduct mapping workshop	X	X
Conduct on-line survey	X	N/A
Develop questions	X	X
Prioritise questions	X	X
<b>Build Complete Evidence Maps</b>	<b>X</b>	<b>N/A</b>
Search and selection of studies	X	N/A
Develop of search strategy	X	N/A
Develop inclusion criteria	X	N/A
Conduct literature search	X	N/A
Select studies	X	N/A

Assign unique identifiers to studies	X	N/A
Export data	X	N/A
Extract data	X	N/A
Produce evidence overview	X	N/A
Identify evidence gaps	X	N/A

### 3.3.1.3 Comparing databases included in the Literature Search

Table 3.4 below contains two columns. Column A includes a listing of the databases that were included in the literature search in the original GEM methods to produce a map of evidence at the end of the process. Column B includes a listing of the databases that were included in the literature search to build the map of evidence at the beginning of the process as part of the adapted methods. From table 3, we can deduce that the adapted methods included only databases that contained systematic reviews, whereas the original GEM methods included databases on clinical trials and other types of information.

**Table 3. 4 Comparing Databases**

Original GEM Column A	Modified GEM Column B
Databases included in literature search to build COMPLETE evidence maps	Databases included in literature search to build the Map of Evidence
CINAHL (Cumulative Index to Nursing and Allied Health Literature) EMBASE Medline OTSeeker PEDro PsycINFO The Cochrane Library Web of Science	The Cochrane Library Database of Abstracts of Reviews of Effects AHRQ Systematic Reviews U.S. Preventive Services Task Force
<b>Auxiliary Databases</b>	
AMED (Allied and Complementary Medicine database)	

KoreaMed	
IndiaMed	
LILACS	
Panteleimon	
PubMed	
<b>Trials Registries</b>	
WHO – International Clinical Trials Registry Platform (ICTRP)	
Includes:	
• Australian Clinical Trials Registry	
• ClinicalTrials.gov (US trials)	
• ISRCTN (Current controlled trials)	
The UK National Research Register	

**3.3.1.4 Comparing Study Types included in the Literature Search**

Table 3.5 below contains two columns. Column A includes a listing of the type of studies that were included in the literature search to produce the map of evidence in the original GEM methods. Column B includes a listing of the electronic databases that were included in the literature search to build the map of evidence as part of the adapted methods. In Table 4 we can clearly see that the adapted methods included only systematic reviews, whereas the original GEM methods included primary studies such as randomized controlled trials (RCTs). Primary research (also called field research) involves the collection of data that does not already exist. While on the contrary, systematic reviews are considered secondary research because *all the* existing primary research on a topic is searched for and assessed to establish whether or not there is conclusive evidence to answer a particular research question. Since the Cochrane Collaboration produces only systematic reviews, we focused only on that type of study.

**Table 3. 5 Comparing Study Types**

Original GEM Column A	Modified GEM Column B
Study types included in literature search to build COMPLETE evidence map	Study types included in literature search to build PRELIMINARY evidence map

<p>Primary or ongoing studies (including theses) investigating therapy, diagnosis, prognosis or aetiology using the following study designs:</p> <ul style="list-style-type: none"> <li>-Randomised Controlled Trials (RCTs)</li> <li>-Cluster RCTs</li> <li>-Pseudo RCTs</li> <li>-Non randomised experimental trials</li> <li>-Crossover studies</li> <li>-Cohort studies (prospective and retrospective)</li> <li>-Historical control studies</li> <li>-Case-control studies</li> <li>-Cross-sectional studies</li> <li>-Case series</li> <li>-Case reports</li> <li>-Interrupted time series with control group</li> <li>-Interrupted time series without control group</li> <li>-Screening Intervention</li> </ul> <p>Systematic reviews of RCTs</p> <p>Systematic reviews of randomised and non randomised studies</p>	<p>Systematic reviews of RCTs</p> <p>Systematic reviews of randomised and non-randomised studies.</p>
<p>Exclude:</p>	<p>Exclude:</p>
<p>Studies of educational and other strategies aimed at prevention</p> <p>Animal studies</p> <p>Laboratory studies not involving clinical application</p> <p>Studies using simulated patients or simulated training programs</p> <p>Cadaver studies</p>	<p>Studies that are not systematic reviews</p>

## 3.2 Selecting a Cochrane Entity and a Medical Condition to Test the Methods

This second section describes how the Cochrane Review Group and a condition were selected to test the adapted methods.

### 3.2.1 Selecting a Cochrane Entity to Test the Methods

The Cochrane Collaboration has different types of Cochrane entities; this includes Review Groups (CRGs), Cochrane fields/networks, and Methods Groups. CRGs focus on a particular health programs and consider different health interventions in their reviews including treatment, prevention and rehabilitation. A Cochrane field focuses on another dimension of health care such as type of consumer e.g. Child Health Field or the setting of a case e.g. Primary care field.<sup>62</sup> In principle, the methods could have been piloted with any type of entity. However, after discussing the possibilities with the supervisors of this thesis and due to time limitations and resources we decided to choose a group that would be accessible and willing to participate in the study. Thus, it was agreed that we would pilot the methods with the Cochrane Musculoskeletal Group (CMSG). The CMSG is made up of health care professionals, researchers and consumer representatives that belong to the Cochrane Collaboration. The group is responsible for producing reliable, up-to-date reviews of interventions for the prevention, treatment or rehabilitation of musculoskeletal disorders in the form of systematic reviews.<sup>63</sup>

The key elements that played part in the selection of the CMSG were:

- 1) We had buy-in from a representative of the consumer group who has access to an extensive network of patients and was willing to assist us in trying to ensure a high-level of patient participation in the study.
- 2) Prof. Peter Tugwell, supervisor of this thesis, is a co- Chief Editor of the CMSG, which provided easy access to the editing group to discuss the study and obtain their buy-in.
- 3) Prof. Peter Tugwell, supervisor of this thesis, is a clinician with extensive experience in treating musculoskeletal conditions and sits on the Osteoarthritis Research Society International (OARSI) and on the Outcome Measures in Rheumatoid Arthritis Clinical Trials (OMERACT) board of directors, with access to clinical experts in this area.
- 4) The CMSG agreed to incorporate the results of the priority setting exercise into their process for selecting future topics for systematic reviews. Thus, providing us with the opportunity to apply the

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<sup>62</sup> The Cochrane Collaboration website: [www.cochrane.org](http://www.cochrane.org)

<sup>63</sup> CMSG website: [musculoskeletal.cochrane.org](http://musculoskeletal.cochrane.org)

results of the study in a practical way and to reassure participants that their contribution would actually have an impact.

- 5) The CMSG, wasn't new to priority setting. They had done work in the past that allowed them to develop knowledge in this area. For example, in 2004 the CMSG surveyed people with arthritis, about which topics of prevention, management and treatment most interested them, and for which musculoskeletal conditions they felt more research was needed. They collected data for five months, tabulated it, and presented the results at the 2004 Cochrane Symposium.<sup>64</sup>

### 3.2.2. Selecting a Medical Condition to Test the Methods

Osteoarthritis (OA) was chosen as a suitable case study for application and further refinement of the methods, primarily on the basis of the high level of burden of the disease. There are many kinds of arthritis but the most widespread kind is OA. It is an extremely common condition, affecting 3,000,000 (1 in 10) Canadians. OA affects men and women in equal numbers and most people develop osteoarthritis after the age of 45, but it can occur at any age. Regardless of the age in which it develops, OA is responsible for a substantial reduction in their quality of life.<sup>65</sup> In addition to the burden of the disease, we also took into consideration that consumers participating in CMSG activities suffer from OA. So, if we selected OA as the medical condition to test the methods, it was expected they would feel a high sense of ownership of the project and assist us in attaining the research goals.

### 3.3 Evaluating the Priority Setting Exercise

To evaluate the results of the priority setting exercise we applied two different techniques:

- 1) We first assessed the process and the outcomes of the process by applying the "Framework for Successful Priority Setting", which is described in section 3.3.1 below.
- 2) Subsequently, we evaluated the methods against criteria specifically developed for the purposes of this research. Sustainability and the ability to effectively include the social determinants of health and health equity in the decision making process were evaluated using this method. Details are provided in section 3.3.2 below.

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<sup>64</sup> Consumer priority survey: bridging the gap between producers and users of systematic reviews; Joelle Walker, Maria Judd, Ann Qualman, Nancy Santesso, Peter Tugwell. Presentation delivered at the 2004 Cochrane Symposium. <http://www2.cochrane.org/colloquia/abstracts/ottawa/O-033.htm>

<sup>65</sup> The Arthritis Society website: <http://www.arthritis.ca/types%20of%20arthritis/osteoarthritis/default.asp?s=1&province=on> Accessed on: 11/08/2010

### 3.3.1 Applying the Framework for Successful Priority Setting

This evaluation framework was chosen because of its high level of suitability and comprehensiveness. In addition, empirical validation of the methods had already taken place.

The factors that were considered for determining the level of suitability were as follows:

- 1) The evaluation framework was developed specifically for a health systems context
- 2) The evaluation framework was developed keeping in mind the needs of decision makers at all levels of all health systems, including macro (e.g. governments), meso (e.g. regional health authorities (RHAs), hospitals), and micro (e.g. clinical programs) levels.

The factors that were considered for determining the level of comprehensiveness were as follows:

- 1) The framework utilizes both, quantitative and qualitative methods to assess the results
- 2) The framework evaluates both, the process and the outcomes
- 3) Patients, researchers, clinicians and policy-makers were involved in its development
- 4) Scholars from developing countries provided input into the framework (i.e. Uganda)

In terms of previous empirical validations, although the results of such validations were not yet published, we were able to confirm the method had been successfully used by Nasser et. al in assessing the results of the 2009 comprehensive study on priority setting practices within the Cochrane Collaboration (personal communication, Mona Nasser 2010).

The elements contained in the Framework for Successful Priority Setting that were applied to evaluate the priority setting exercise can be broken down into two types: criteria to evaluate the process and criteria to evaluate the outcomes.

The 5 criteria applied to evaluate the process were:

- **Stakeholder Engagement:** assesses the ability to effectively identify and engage all relevant stakeholders in the process.
- **Explicit Process:** the process should be explained not only to those participating in the process but also to stakeholders not participating and verify the level of understanding of the process.
- **Information Management:** refers to identifying relevant information that was shared and information that was lacking. All relevant information should be tailored to specific audiences and disseminated through different communication tools.
- **Consideration of Context & Values:** Reasons for selecting priorities should be grounded in clear value choices, and those reasons and values should be made explicit.

- **Revision or Appeals Mechanism:** a process to review decisions and resolve disagreements should be in place and be made explicit to internal and external stakeholders.

The 5 criteria that were used to evaluate the outcomes were:

- **Improved stakeholder understanding:** assesses whether stakeholders have gained knowledge on the priority setting process itself and/or on the organization.
- **Shifted priorities/Reallocation of resources:** assesses whether the effort results in a clear action/change in the organization linked to the identified priorities.
- **Improved Decision Making Quality:** over a period of time, this element assesses whether greater consistency and quality in decision making has been obtained in the organization. The more the process is repeated, the more we can expect this outcome to be improved.
- **Stakeholder Acceptance & Satisfaction:** assesses whether stakeholders are willing to continue to participate in the process, thus, assuming that if they wish to continue, then they are pleased with the process.
- **Positive Externalities:** this element refers to external outcomes that could be interpreted as indicatives of success. For example: positive media coverage, peer-emulation or health sector recognition, changes in policies, and potentially changes to legislations or practice.

The results of this evaluation are described in detail in Chapter 4, Section 4.5 Application of the “Framework for Successful Priority Setting” to Evaluate the Priority Setting Exercise.

### 3.3.2 Additional criteria utilized to evaluate the methods

As mentioned in the introductory chapter, one of the research objectives of this thesis is to develop a feasible and sustainable priority setting method for the Cochrane Collaboration that incorporates the social determinants of health and health equity. In order to determine whether we met this research objective, three additional criteria were developed by the research group based on their initial expectations of the research study and were applied to evaluate the results. The three criteria are described below.

- 1) To assess the sustainability of the methods, we first developed a definition of sustainability for this context. A “sustainable process” was defined as a process that is repeatable, that takes into account the characteristics and mandate of the Cochrane Collaboration and that makes an efficient use of resources so that it can be executed on a regular basis. If the methodology meets these criteria, we will consider it to be sustainable.

- 2) In order to assess the ability to effectively include the social determinants of health (SDH) we reviewed the priority topics to identify those that can be classified under the SDH conceptual framework. If at least one topic fell within the SDH conceptual framework we considered the SDH were effectively incorporated into the priority setting process.
- 3) In order to assess the ability to effectively include health equity in the process we reviewed the priority topics to identify those that explicitly address health equity issues. If at least one topic explicitly addresses equity issues we determined health equity was effectively incorporated into the priority setting process.

The results of this complementary evaluation are described in detail in Chapter 4, Section 4.6 Evaluating Sustainability and the Ability to Effectively Incorporate the Social Determinants of Health and Health Equity in the Process.

## Chapter 4: RESULTS

Chapter 4 presents the results of this research project and is organized in three sections. The first section (4.1 Adapted Methods) describes the priority setting methodology that resulted from the adaptations made to the GEM methods, what we refer to as the “adapted GEM methods”. As discussed in Chapter 3, these modifications were made to meet the research objectives of sustainability and of including the social determinants of health and health equity in setting priorities. The priority topics resulting from this exercise are summarized and analyzed in the second section (4.2 Priority Research Questions). Finally, the results of the evaluation of the methods are presented in the third section (4.3 Evaluating the Methods).

### 4.1 Adapted GEM Methods

This section provides a description of the methods that were followed to set priorities. The description of the methods will start with the recruitment process, including the inclusion and exclusion criteria that were applied to select participants. Subsequently, the process to calculate the sample size will be presented along with a description of data management and privacy practices that were applied to protect the identify of patients. Finally, a detailed description of each one of the steps included in the methodology will be presented. The methodology incorporates the following five high level steps:

- 1) Identifying existing evidence
- 2) Identifying priorities
- 3) Converting topics into research questions
- 4) Prioritizing the top 10 research questions
- 5) From knowledge to action

These five steps are included in Figure 1: Visual Representation of the Priority Setting Methodology.

#### 4.1.1 Identification and Recruitment of Research Participants

The participating organization was the Cochrane Collaboration. The Cochrane Collaboration is a global network of dedicated volunteers assisting with the conduct of systematic reviews. Participation is voluntary and when registering as a Cochrane member, each participant decides whether their contact information is to be shared with others in the network. We recruited volunteers that habitually participate in activities organized by the Cochrane Musculoskeletal Group. Such volunteers included researchers, clinicians, health policy-makers and patients. This group of people periodically volunteer in

various capacities, including peer reviewing, promotion of Cochrane events, and dissemination of Cochrane research results to other research and patient groups. Initial contact was by an invitation letter. The text of the invitation letter is included in Appendix 4.1 Invitation Letter to participate in the Research Project.

#### **4.1.2 Inclusion and Exclusion Criteria in Selecting Participants**

Inclusion and exclusion criteria allow researchers to define the conditions that should be met by those participating in a particular research project. The criteria are aligned with research objectives and are defined upfront, before any potential participants are invited to participate. For the purposes of our research, we identified three conditions that needed to be met when selecting participants. First, we agreed we would collect input from four different stakeholder groups: researchers, clinicians, patients and policy-makers. This was decided following the original GEM methods, which proposed collecting input from researchers, clinicians, and patients. We added policy-makers to the stakeholder mix to allow taking into consideration the priorities of those developing policy for with Osteoarthritis. Second, we also wanted to ensure that we worked with people that felt ownership for the project either because of a personal interest in Osteoarthritis (e.g. Osteoarthritis patients) or because they were part of the Cochrane Review Group that would be ultimately be responsible for working on the priority topics identified as part of this exercise (e.g. editors of the Cochrane Musculoskeletal Group). The third and last criterion that was established had to do with resource and time limitations. In order to ensure we stayed within the budget and timelines for the project, we could only conduct the research in one language. Given that English is the most common language within the Cochrane Collaboration, we selected this language to test the methods and agreed we would only select participants that could read and write in English.

The resulting inclusion and exclusion criteria were the following:

Inclusion criteria:

- 1) who was one of the following: a researcher, a clinician, a health policy-maker or a patient
- 2) who was interested in defining health research priorities for Osteoarthritis
- 3) who was associated to the Cochrane Musculoskeletal Group
- 4) who could read and speak English

Exclusion Criteria:

- 1) who was not one of the following: a researcher, a clinician, a health policy-makers or a patient
- 2) who was not interested in defining health research priorities for Osteoarthritis
- 3) who was not associated to the Cochrane Musculoskeletal Group

- 4) who could not read or speak English

### 4.1.3 Sample Size Calculation

Sample size determination is the mathematical process of deciding, before a research project begins, how many subjects should be included in the project.<sup>66</sup> For the purposes of our study we estimated a sample size of eighty-five (85) participants. Table 1 “Adapted GEM Methods: Sample Size by Activity” provides a breakdown of the number of participants planned and the number of participants that actually participated in each activity.

The sample size of eighty five (85) participants was calculated based on data from the previous empirical validation of the GEM methods, which is contained in Table 2: Original GEM Methods: Number of Participants by activity. As shown in Table 2, the original GEM methods looked at three different phases of the condition: pre-hospital, acute care, and rehabilitation and repeated each activity for each phase. At the end priority topics were identified for each phase but a comprehensive list of priority topics for the condition was not generated. However, for our study we decided we would look at all phases at once. This was decided based on three factors. First, by not having to repeat each activity for each phase, we would be using resources more effectively. Second, by combining all phases into one priority setting exercise, at the end we would have an all-inclusive list of priority topics for OA. Finally, the third factor had to do with how the Cochrane Musculoskeletal Group (CMSG) operates. The CMSG does not consider the phase of the condition as a factor in deciding whether a systematic review should be conducted or not. The CMSG is interested in doing work based on a priority list generated by those making use of the information they produce, regardless of the stage of the condition to which the topic might be (or not) related to.

**Table 4. 1 Adapted GEM Methods: Sample size and number of participants by activity**

<b>Adapted GEM</b>	<b>No Workshops</b>	<b>Participants in workshop</b>	<b>Consultation with Experts</b>	<b>Prioritisation Survey</b>	<b>Totals</b>
Planned	2	15	10	60	<b>85</b>
Actuals	2	29 (8 and 21)	11	51/99	<b>91</b>
<b>Total</b>	<b>2</b>	<b>29</b>	<b>11</b>	<b>51/99</b>	

**Table 4. 2 Original GEM Methods: Number of participants by activity**

<b>Original GEM</b>					
<b>Phase of Medical Condition</b>	<b>No Workshops</b>	<b>Participants in workshop</b>	<b>Consultation with Experts</b>	<b>Prioritisation Survey</b>	<b>Totals</b>
Prehospital	1	14	2	11/20	<b>27</b>

<sup>66</sup> Last JM (Ed.). *A Dictionary of Epidemiology*. Oxford: Oxford University Press, 1995.

Acute Care	2	19 (8 and 11)	5	9/29	<b>33</b>
Rehabilitation	1	9	3	26/55	<b>38</b>
<b>Total</b>	<b>4</b>	<b>43</b>	<b>10</b>	<b>46/104</b>	<b>98</b>

As shown in Table 1, ultimately, we ended up recruiting ninety-one (91) participants for our study. We recruited more participants than what we had originally planned because as we conducted the study we noted more people were interested in participating. As long as those that were interested met the inclusion/exclusion criteria, we accepted them in the study. At the end of the exercise, we considered we were successful in both, our recruitment techniques and our sample calculations given that the actual number of participants surpassed the original estimates.

#### 4.1.3.1 Breakdown of sample by stakeholder group

An effort was made to engage all four types of stakeholder groups: patients, researchers, clinicians, and policy-makers. Despite this effort, policy-makers were not involved in the process. However, the lack of policy-maker involvement was not a major issue for this research project. The sample was not stratified to ensure representativeness among the four major groups. Rather, this was a purposive sample where we decided to give priority to patients. Giving priority to patients was a way to balance the level of influence between clinicians and patients. This was important as Cochrane traditionally had given priority to clinicians interests.

The population that participated in the research project was broken down as follows:

- Patients: 69.23%
- Researchers: 14.28%
- Clinicians: 16.48%
- Policy-makers/managers: 0%

These percentages were calculated based on the number of participants from each group that participated in the process from the total of 91.

#### 4.1.4 Data Management Practices

Data management practices refer to practices that will deal with how the data will be collected, stored, handled, and shared throughout the research project. The data was collected and stored in a database contained in a laptop assigned specifically for the purposes of this research. The laptop was password protected and encrypted. The research files and database were password protected as well.

The database itself was accessible only by two people participating in the research work: the principal investigator (Peter Tugwell) and the co-investigator (Alejandra Jaramillo). However, the Ottawa

Hospital Research Ethics Board, Ottawa Health Research Institute, and the University of Ottawa Ethics Board may request to audit study records. If the records have to be audited, access to the files will be granted to these three Research Ethics Boards.

The laptop itself was stored in an office located in a safe building within the school and in a cabinet that was locked. Care was taken to avoid collecting any identifying details of participants during the consultation process, the mapping-workshop, and the prioritization survey. Information about the individual's own condition was not collected. This was done to protect the identity of participants. Participants will not be identifiable in any publications or presentations resulting from this study. In order to be able to analyze data provided separately by each participant, participants were assigned a unique identifier. The master list linking the patient name and the unique patient identifier was maintained in a separate file in a secure laptop to which only the principal investigator and co-investigator had access. The file containing the master list was password protected.

As per current research regulations, the study records will be kept for 15 years after termination of the study. The study records will be destroyed once the 15 year record retention period has expired. Electronic files and paper files will be deleted at that time.

#### **4.1.5 Addressing Privacy Concerns**

Participants' privacy was protected by avoiding discussing the participation of individuals with others in the Cochrane musculoskeletal group. Personal identifiers were removed from any data shared with other investigators, and/or participants in the project. Results were presented in aggregate form only and participants were not quoted. Furthermore, personal identifiers were encrypted and removed from the database while the data was being captured in the database. All subsequent stages of the research process (including the analysis of the data) handled only de-identified data. Throughout the research project, data was stored within a secure database. Only people granted the proper permissions and with an assigned login id and password had access to that data.

#### **4.1.6 Addressing the possibility of coercion, duress or undue incentive**

No incentives were provided for participation in the project. The pool of participants from which we recruited included habitual volunteers of the Cochrane Musculoskeletal Group (CMSG). Participants were advised that their participation would affect neither their normal involvement in Cochrane Musculoskeletal activities nor the care they receive for their condition.

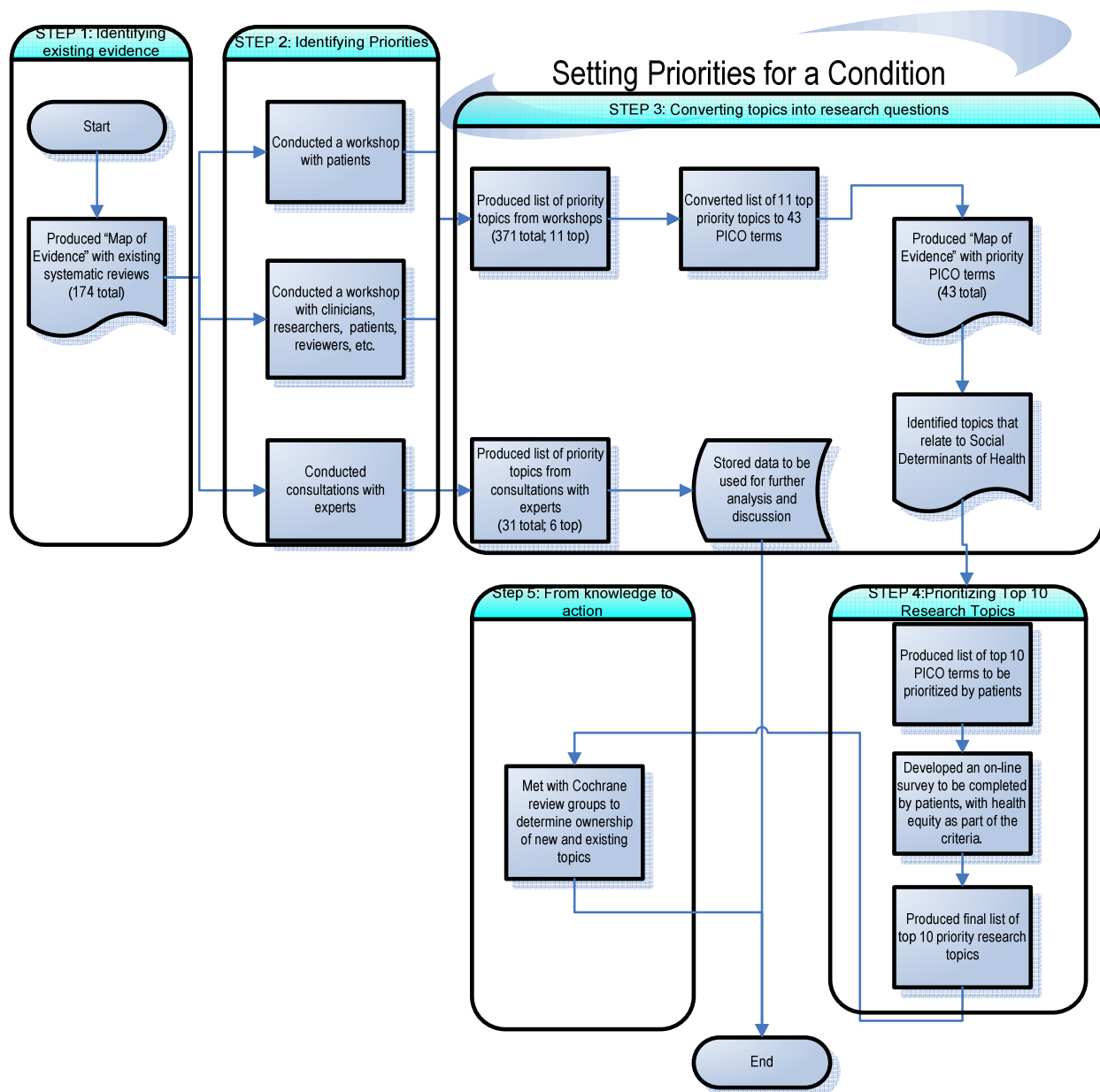
#### **4.1.7 Describing the 5 steps of the Adapted GEM Methods**

The goal of this section is to provide a detailed description of each one of the steps included in the methodology that was developed. The methodology incorporates the following five high level steps:

- 1) Identifying existing evidence
- 2) Identifying priorities
- 3) Converting topics into research questions
- 4) Prioritizing the top 10 research questions
- 5) From knowledge to action

These five steps are included in Figure 1: Visual Representation of the Priority Setting Methodology.

Figure 4.1 Work Flow – Priority Setting Methodology

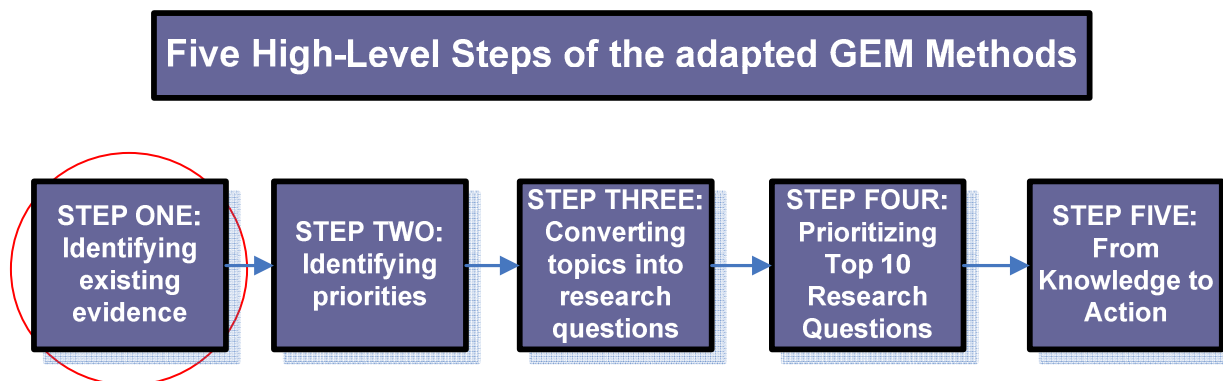


#### 4.1.7.1 Identifying Existing Evidence

As indicated in Figure 4.2, the first step in this process was to discover existing evidence. The main objective of this step was to inform the priority setting process by identifying all existing systematic reviews relevant to osteoarthritis and to present the information in such way that would be meaningful for individuals participating in the process. In order to accomplish this objective, we first searched the literature for existing frameworks that provided a blueprint to improve the quality of life of people living with osteoarthritis. We found only one framework that worked well for our purposes and modified it in order to incorporate the social determinants of health. We called this framework the

“Map of Evidence for Osteoarthritis”. Section 4.1.7.1.1 Building the Map of Evidence for Osteoarthritis describes how the map was built and provides a copy of the resulting map.

**Figure 4.2 Five High-Level Steps of the Adapted GEM Methods**



Subsequently, we searched four electronic databases for systematic reviews that were relevant to Osteoarthritis. A total of 174 systematic reviews were found. The abstract of each one of the systematic reviews was then reviewed to classify the research question in the “Map of Evidence for Osteoarthritis”. The resulting “Map of Evidence” contained 174 research questions, one for every systematic review. The information was organized by stage of the condition (e.g. early stages of OA, advanced stages of OA, etc.) and by key area of improvement (e.g. pharmacologic treatments, non-pharmacologic treatments, social determinants of health, etc.). Section 4.1.7.1.2 Populating the Map of Evidence for OA provides details on how the map was populated and provides a copy of the resulting “Map of Evidence of OA” with the 174 systematic reviews incorporated into it.

The goal of this step was achieved: we produced a Map of Evidence for OA containing all existing systematic reviews up to a given date. We used the map to identify existing evidence and to inform subsequent steps of the priority setting process.

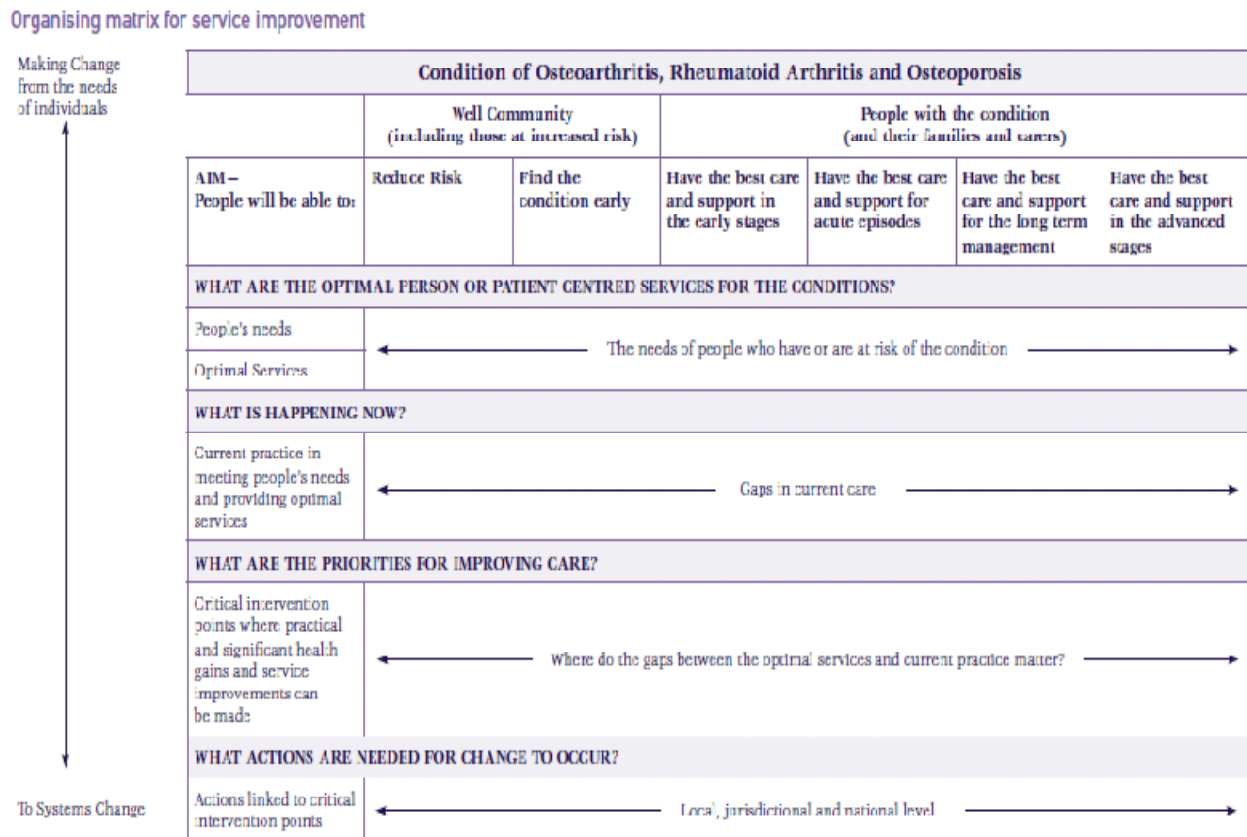
#### ***4.1.7.1.1 Building the Map of Evidence for Osteoarthritis***

In order to inform the priority setting process, the research team identified the need for a framework that would help organize existing systematic reviews in a clear and meaningful way for participants. After conducting a literature search, the National Service Improvement Framework was identified as the most suitable for organizing and classifying the information. This framework, was prepared by the Australian National Arthritis and Musculoskeletal Conditions Advisory Group and informed by advice from its working groups and stakeholders, including people with these conditions, and its goal was to provide a blueprint for national efforts to improve the health-related quality of life of

people living with osteoarthritis, rheumatoid arthritis and osteoporosis, reduce the cost and prevalence of those conditions, and reduce the impact on individuals, their carers and communities within Australia.<sup>67</sup> This framework was selected given that it was built considering the needs of the stakeholder groups that we were interested in incorporating: researchers, clinicians, patients and policy-makers. Also, the framework was flexible enough to allow us to incorporate the social determinants of health as a key area of improvement. Before making the changes, we consulted with one of the creators of the framework with whom we discussed our requirement. This creator agreed the framework worked well for our purposes and approved us using the framework as a foundation and to modify it to meet our research objective needs.

Figure 4.3 below provides a copy of a visual representation of the original framework (before modifications were made).

Figure 4.3 National Service Improvement Framework



<sup>67</sup> National Health Priority Action Council (NHPAC) 2006, National Service Improvement Framework for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis, Australian Government Department of Health and Ageing, Canberra.

The original framework already captured input from patients, clinicians, researchers and policy-makers. However, input from the perspective of a Cochrane Review Group (CRG) was missing. So, after agreeing on the suitability of the framework, the Cochrane Musculoskeletal Group was consulted to determine changes required to classify the information. Also, if the adapted GEM methods are to be sustainable, the Cochrane Review Group has to continue to update the Map of Evidence for OA with new systematic reviews developed. Therefore, it was essential to verify that the information contained in the Map of Evidence for OA was clear to them and that the framework provided a realistic and easy way of classifying the information.

When consulted, one of the main concerns of the CMSG was the need to balance the level of detail in classifying systematic reviews with the level of information consistently available. This was a concern given that not all systematic review topics incorporate the same level of detail when they are developed. For example, some systematic reviews address equity concerns when addressing a research question, while others do not. Thus, it was important to ensure the framework allowed the data to be consistently classified without having to request more information from the authors of the systematic reviews. Also, input from the CMSG was essential given that

The following changes were made to adjust it to the needs of the research projects:

- 1) In order to classify systematic reviews by pharmacologic and non-pharmacologic therapiesThe following key areas were added as rows down the first column of the table:
  - Pharmacologic therapies per stage of the condition
  - Pharmacologic therapies not specific to one stage of the condition
  - Non-pharmacologic therapies per stage of the condition
  - Non-pharmacologic therapies not specific to one stage of the condition
- 2) “Self-management” was incorporated into the non-pharmacologic therapies
- 3) The last row in the table (What actions are needed for change to occur?) was modified in order to allow room to capture the social determinants of health. The new row header reads as follows:  
Social determinants of health that impact the condition?

Figure 3 Map of Evidence for Osteoarthritis Template, is a copy of the Map of Evidence for OA, which was ultimately developed using an iterative approach, with regular meetings with the CMSG team.

Figure 4.4 Map of Evidence for Osteoarthritis Template

What is the Osteoarthritis Map of Evidence?							
This map outlines key areas where effort is required to improve the overall quality of life of people living with osteoarthritis. The intent is to use the map as a tool to assist in the identification of priority research topics on which to base upcoming systematic reviews							
		Well Community		People with osteoarthritis (and families and carers)			
		Reduce Risk	Find the Condition Early	Have the best care and support in the early stages	Have the best care and support for acute episodes	Have the best care and support for the long-term management	Have the best care and support in the advanced stages
1	The needs of people who have or are at risk of osteoarthritis What are the optimal person or patient-centred services?						
1.2	People's needs						
1.3	Optimal services						
2	What is happening now? Gaps in current care - Current practice in meeting peoples needs and providing optimal services						
2.1	Access to Care and Support						
2.2	Pharmacologic/Drug Therapies						
2.3	Non-pharmacologic/Drug therapies (including self management interventions)						
2.4	Lifestyle changes						
2.5	Support for high-quality services. Examples: information and communications technology, communication with patients, information and support for carers, decision support systems, etc.						
3	What are the priorities for improving care? Where do the gaps between current and optimal services matter?						
3.1	Critical intervention points where practical and significant health gains and service improvements can be made						
4	What actions across sectors are needed for change to occur? Social, educational, legal interventions required?						
4.1	Social determinants of health - applicable to a particular stage of the condition						

Once the skeleton of the Map of Evidence for OA was completed, we searched for relevant systematic reviews in six databases and populated the map with the titles of the systematic reviews that were found.

#### 4.1.7.1.2 Populating the Map of Evidence for OA

In order to populate the map we first needed to identify the systematic reviews that were relevant to OA. One of the key considerations was to ensure that the quality of the systematic reviews that were incorporated into the Map of Evidence met the minimum quality standards established by Cochrane. To accomplish this we met with the CMSG editor in chief whom identified four electronic databases that he considered met Cochrane's quality standards. The four databases that were searched were as follows:

- 1) Cochrane Library
- 2) Database of Abstracts of Reviews of Effects (DARE)
- 3) Agency for Health Care Research and Quality (AHRQ)
- 4) United States Preventive Services Task Force

The search for systematic reviews was done methodically, using relevant MeSH terms suggested by the CMSG members. The output of the search was a list of relevant OA systematic reviews generated to date. The results of the literature search are presented in Table 23: Results of Literature Search Broken Down by Source.

**Table 4. 3 Results of Literature Search Broken Down by Source**

Databases Used to Populate the Map of Evidence for OA	Number of OA Systematic Reviews Found
Cochrane Library + DARE	167
AHRQ	4
U.S. Preventive Services Task Force	3
Total OA Systematic Reviews identified	174

As indicated in Table 23, a total of 174 systematic reviews were found. The abstract of each one of the systematic reviews was then reviewed in order to classify the research question in the “Map of Evidence for Osteoarthritis”. The resulting “Map of Evidence” contained 174 research questions, one for every systematic review. The information was organized by stage of the condition (e.g. early stages of OA, advanced stages of OA, etc.) and by key area of improvement (e.g. pharmacologic treatments, non-pharmacologic treatments, social determinants of health, etc.). The resulting Map of Evidence contained a total of 16 pages. Figure 4 is a copy of page 1 of the map. This figure provides a sample of how the data was incorporated into the map. Each systematic review was numbered sequentially, in the order in which they were found, and referenced at the end of the map. A copy of the entire Map of Evidence is provided in Annex 4.5. Additional copies of the Map of Evidence can be provided upon request.

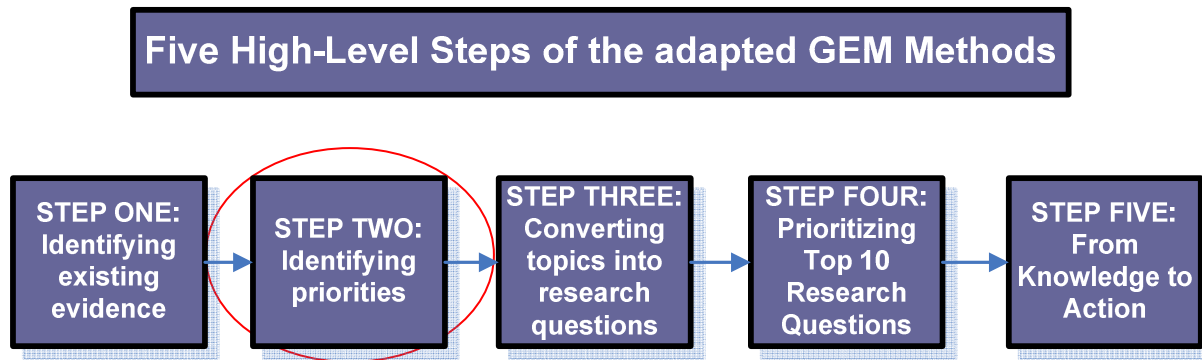
Figure 4. 5 Page 1 Map of Evidence for Osteoarthritis

What is the Osteoarthritis Map of Evidence?						
This map outlines key areas where effort is required to improve the overall quality of life of people living with osteoarthritis. In the map you will find a listing of relevant systematic reviews conducted in the field of Osteoarthritis - classified by stage of the condition and by key area. The map allows you to visually identify areas where gaps in evidence exist (i.e. areas where systematic reviews haven't been conducted). The intent is to use the map as a tool to assist in the identification of priority research topics on which to base upcoming reviews.						
	Well Community (some of whom are more at risk than others)			People with the condition (and families and carers)		
Stage of the Condition	Reduce the Risk	Find the condition early	Early Stages	Acute Episodes	Long-term Management	Advanced stages
What are the optimal person or patient-centred services for the conditions? The needs of people who have or are at risk of the condition.						
People's needs						
Optimal services						
What is happening now? Current practice in meeting peoples needs and providing optimal services						
Access to Care and Support						
Pharmacologic therapies per stage of the condition				(1) Evidence-based data on pain relief with antidepressants <sup>1</sup>	(2) Glucosamine long-term treatment and the progression of knee osteoarthritis: systematic review of randomized controlled trials <sup>2</sup> (3) Longterm efficacy of topical nonsteroidal antiinflammatory drugs in knee osteoarthritis: meta-analysis of randomized placebo controlled clinical trials <sup>3</sup>	
Therapies that could potentially apply to all stages of the condition: Early, Acute, Long-term, and Advanced stages of OA STUDY POPULATION NOT SUBDIVIDED						
Pharmacologic therapies not specific to one stage of the condition	N/A	N/A	(4) Acetaminophen for osteoarthritis <sup>4</sup> (5) Rofecoxib for osteoarthritis <sup>5</sup> (6) Tramadol for osteoarthritis <sup>6</sup> (7) Chondroitin for osteoarthritis <sup>7</sup> (8) Doxycycline for osteoarthritis of the knee or hip <sup>8</sup> (9) Oral or transdermal opioids for osteoarthritis of the knee or hip <sup>9</sup> (10) S-Adenosylmethionine for osteoarthritis of the knee or hip <sup>10</sup> (11) Efficacy of topical non-steroidal anti-inflammatory drugs in the treatment of osteoarthritis: meta-analysis of randomised controlled trials <sup>11</sup> (12) A meta-analysis of controlled clinical studies with diacerin in the treatment of osteoarthritis <sup>12</sup> (13) Structural and symptomatic efficacy of glucosamine and chondroitin in knee osteoarthritis: a comprehensive meta-analysis <sup>13</sup> (14) S-Adenosyl-L-Methionine (SAMe) for Depression, Osteoarthritis, and Liver Disease <sup>14</sup> (15) Intra-articular hyaluronic acid in treatment of knee osteoarthritis: a meta-analysis <sup>15</sup> (16) Glucosamine therapy for treating osteoarthritis <sup>16</sup> (17) Chloquinolones for the treatment of osteoarthritis <sup>17</sup> (18) Glucosamine and chondroitin for treatment of osteoarthritis: a systematic quality assessment and meta-analysis <sup>18</sup> (19) A comparison of the efficacy and safety nonsteroidal antiinflammatory agents acetaminophen in the treatment of osteoarthritis: a meta-analysis <sup>19</sup> (20) Cyclooxygenase-2 selective non-steroidal anti-inflammatory drugs (etodolac, mecloxam, celecoxib, rofecoxib, etoricoxib, valdecoxib and lumiracoxib) for osteoarthritis and rheumatoid arthritis: a systematic review and economic evaluation <sup>20</sup> (21) Devil's Claw (Harpagophytum prostratum) as a treatment for osteoarthritis: a review of efficacy and safety <sup>21</sup> (22) Does paracetamol (acetaminophen) reduce the pain of osteoarthritis: a meta-analysis of randomised controlled trials <sup>22</sup> (23) Dose-effect relationships of nonsteroidal anti-inflammatory drugs: a literature review <sup>23</sup>			

#### 4.1.7.2 Identifying Priorities

As indicated in figure 4.6, the second step in this process was to identify priority research topics. The main objective of this step was two-fold: 1) to brainstorm to identify topics of interest and 2) to identify the top priority research topics. In order to accomplish this we first conducted two "mapping workshops" and then consulted with several clinical experts.

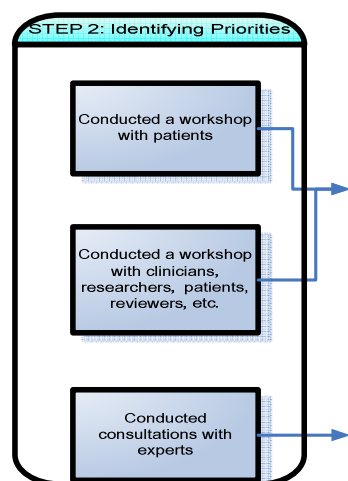
Figure 4. 6 Five High-Level Steps of the Adapted GEM Methods



The term “mapping workshops” was used to identify the workshops that were conducted as part of the original GEM methods. We used the same name for the adapted GEM methods. There were three main activities carried out during a mapping workshop. First, participants were asked to brainstorm and to identify as many research topics as they considered important based on their personal perspective. Topics were posted on the walls so that all participants could see what topics were being raised. Subsequently, each participant was asked to select the top 5 priority research topics. Finally, all research topics that were identified by participants as a priority were discussed in more detail to capture the context of the research issue in order to be able to convert it into a research question. A total of 371 research topics were raised by workshop participants, out of which eleven were identified as a priority. Section 4.1.7.2.1 Mapping Workshops describes the workshops in more detail.

Once the two workshops were completed, we met with 11 clinical experts to identify top research topics from a clinician perspective. Although we met individually with each clinician, the data was captured into one electronic database specifically developed for this purpose. The data was analyzed to identify the top research topics from a clinician expert perspective. Topics that were repeated at least once by experts were considered a priority. A total of 31 research topics were raised by clinical experts, out of which six were identified as a priority. Section 4.1.7.2.2 Consultations with experts describes the consultations in more detail. The aim of this step was achieved: we identified 11 priority research topics from the mapping workshops and 6 from the consultations with experts. Figure 4.7 shows a visual representation of the tasks included in Step 2 of the process.

**Figure 4.7 Step 2: Identifying Priorities**



#### **4.1.7.2.1 Mapping Workshops**

As indicated in figure 4.7, two mapping workshops were conducted. Only patients were invited to participate in the first workshop. In contrast, the second workshop included patients, researchers, and clinicians. The rationale for inviting only patients to the first workshop was to ensure that we were able to collect unbiased input from patients. This was recommended by an influential OA patient that regularly participates in CMSG activities. The argument was that patients tend to feel intimidated if researchers and clinicians are in the room. The recommendation was accepted and a patient-only was added to the process. After deciding how many workshops would be conducted and the type of stakeholder groups that would participate in the workshops, the next step was to select a venue and a date. An important consideration for the venue was that the group of volunteers working with the CMSG, from which we would recruit participants, was spread out across the world. So, in order to control costs we needed to pick a venue that would allow participation without having to incur in additional expenses. So, we decided we would hold both mapping workshops at the 17<sup>th</sup> annual Cochrane Colloquium held in Singapore in 2009, where volunteers normally tend to meet once a year. After the venue, time and date for each workshop was determined, an invitation letter was drafted, which was sent to all potential participants a month before the date. Participants confirmed their participation via email prior to the date.

At the workshop, participants were provided with a copy of the “Participant Information Sheet” and the “Consent Form”. These two forms were read and signed before the workshop was started. A copy of the text of the “Participant Information Sheet” and the “Consent Form” are attached in Annex 2.

After participants signed the required paperwork, the workshop was introduced by a workshop facilitator. The introduction included a brief description of the project and the project team, a description of what mapping workshops entailed, the aims of the mapping workshop and a definition of the different phases of OA and the key areas of improvement included in the map of evidence. After the introduction, the brainstorming session was initiated. During the brainstorming session workshop participants were asked to write on separate 'post-it' notes, research topics that they considered important. A suggested format of the notes, consistent with the PICO ('Problem', 'Intervention', 'Comparator', 'Outcome') approach, was outlined for participants, but fragments of ideas, single words, phrases were encouraged, and issues concerning to diagnostic tests, prognosis, interventions, social determinants of health and service delivery and organization were acceptable. This brainstorming was done without discussion. The 'post-it' notes were then placed by the participants on large sheets around the room.

A prioritization exercise followed the brainstorming session. Following a short break during which similar or identical notes were grouped on the sheets by the workshop organizers, participants were given five small red coloured sticky dots. The mapping workshop facilitator instructed participants to place their dots next to the post-it notes that they considered described the most important issues from their perspective. 'Most important' was defined for this purpose as the issue that was perceived by the participant to have the biggest impact on improving patient care. Out of 371 topics that were raised during the mapping workshops, 61 topics were identified as a priority given that at least one dot was placed on the topic. Out of the 61 topics, 11 had at least 4 dots. Table 4.4 lists the 11 priority research topics that were identified by mapping workshop participants. This table also indicates the number of red dots that were placed on each topic. The number of red dots ranged from 4 to 10 per topic.

After participants identified priority research topics, the workshop facilitator conducted an open discussion on the results of the prioritization to gain insight into their perspectives, as well as elaborating and developing consensus on the research topics. The facilitator also stimulated the discussion by asking participants to specify what contextual factors would influence the feasibility of obtaining health care services, the implementation of interventions, and the improvement health care outcomes. The discussion on contextual factors included the social determinants of health, such as socioeconomic status, culture, gender, income, and country of origin. This contextual information was collected and documented by organizers in separate notebooks; one for each workshop.

The open discussion was the last activity carried out in the workshop. At the end of the workshop participants were thanked for their involvement in the mapping workshop and were invited to remain involved in the project by reviewing the list of research questions that would be developed from the priority research topics, by participating in the prioritization survey and/or by reviewing the final research report.

**Table 4. 4 Priority research topics drawn from the mapping workshops**

<b>Generic Topic</b>	<b>Priority</b>
TOPIC 1: Self-management approaches in treating osteoarthritis	10 red dots
TOPIC 2: Interventions to reduce the risk of developing osteoarthritis in the well community	9 red dots
TOPIC 3: Increase the level and quality of communication	10 red dots
TOPIC 4: Prevent the progression of osteoarthritis in patients with early-stage osteoarthritis	4 red dots
TOPIC 5: Reduce inequities in waiting times for osteoarthritis surgery	9 red dots
TOPIC 6: Reduce decisional conflict about timing for joint replacement	9 red dots
TOPIC 7: Psychosocial impact of osteoarthritis in people living with the condition	8 red dots
TOPIC 8: Economic impact of osteoarthritis in people living with the condition	8 red dots
TOPIC 9: Weight management for people with osteoarthritis	7 red dots
TOPIC 10: Effectiveness of osteoarthritis interventions according to osteoarthritis patient preferences	5 red dots
TOPIC 11: Increase knowledge transfer to patients of treatment options available for treating osteoarthritis	5 red dots
TOPIC 11: Increase knowledge transfer (amongst health practitioners and to patients) of positive and negative side effects of drugs used to treat people with osteoarthritis	4 red dots

#### ***Section 4.1.7.2.2 Consultations with Experts***

After the mapping workshops were completed in Singapore, we flew to the city of Philadelphia in the United States where the American College of Rheumatology 2009 Annual Scientific Meeting was being held. Experts in Osteoarthritis participating in the ACR 2009 meeting were invited to take part in our study. An invitation email was sent to all potential participants before arriving in Philadelphia. A copy of the invitation email is included in Annex 3. Those that agreed to participate were provided with a copy of the “Map of Evidence for Osteoarthritis” and were asked to review it prior to the consultation. Consultations were conducted individually. At each consultation each participant was asked to use the map as a tool to note areas where gaps in evidence exist and to identify new priority research topics. Responses were documented by the researchers. Mimicking what was done during the mapping

workshops, after brainstorming, experts were asked to identify the top three research priorities. As in the mapping workshops, each research priority identified by an expert was given a red dot. A total of 31 research topics were raised by clinical experts, out of which 6 were considered as a priority by more than one clinician. A list of priority research topics from an expert clinician perspective is included in table 4.5.

In addition to asking clinical experts to identify priorities, during the consultations experts were also encouraged to provide information to put into context the research topics. This additional information was captured in table 4.5 below under column B.

**Table 4. 5 Priority research topics identified by clinical experts**

A Research Topic	B Research questions proposed by experts	C Priority
TOPIC 1: Exercise: Exercise as a preventive measure and as treatment	What dosage of exercise helps? Factors that predict the outcome of exercise. What type of exercise works (e.g. non-weight bearing equipment)?	4 red dots
TOPIC 2: Risk reduction among the well	Social economic factors impacting OA: what are the most significant ones? What are the main life style changes that need to be done to have an impact on prevention (e.g. weight loss, strengthening, exercise, etc.)? What factors predict the outcomes?	4 red dots
TOPIC 3: Disease modification	What disease modification drug therapies are available?	2 red dots
TOPIC 4: Weight loss	Prevention: weight loss as a risk reduction strategy Treatment: weight loss as part of a treatment plan for patients with OA	2 red dots
TOPIC 5: Multimodal treatments	Multimodal treatments compared to single interventions (e.g. packages of treatment versus single treatment options, combinations of pharmacological and non-pharmacological treatment versus single therapies, effective combinations of pharmacologic and complementary medicine therapies)	2 red dots
TOPIC 6: Cost & clinically effective interventions for the elder population	Clinically and cost effective interventions in the elderly Determine what is the most effective symptomatic treatment for OA in 'old' people; i.e. those with co-morbidities such as hypertension or Raynaud's	2 red dots

The following statistics were drawn from the consultations with clinical experts:

- Twelve experts in osteoarthritis were consulted.
- This group provided a total of thirty-one priority topics.

- From the thirty-one priority topics, six were identified as top priority topics as at least two experts considered the topic to be a priority.
- From the top six research topics, the following two topics were identified as top priority given that four clinical experts identified them as a priority:
  - 1) Exercise: as a preventive measure and as a formal treatment plan for people with OA (including dosage, types, etc.)
  - 2) Risk reduction among the well: Social economic factors impacting OA; what are the most significant ones? What are the main lifestyle changes that need to be done to have an impact on prevention?
- From the top six research topics, the following four topics were identified as a priority by at least two clinical experts:
  - 1) Disease modification therapies for OA
  - 2) Weight loss as a preventive measure and as a formal treatment plan
  - 3) Multimodal treatments for OA
  - 4) Cost and clinically effective interventions for the elder population

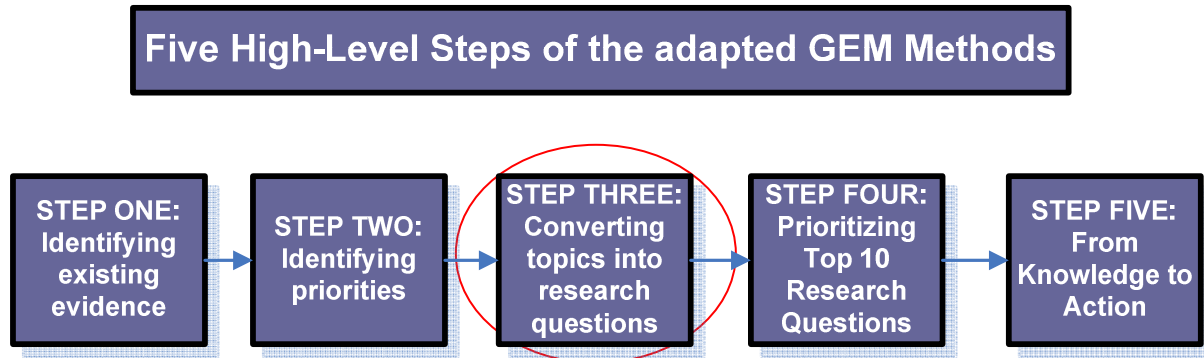
#### 4.1.7.3 Converting topics into research questions

As identified in figure 4.8, the third step of the process was to convert the 11 top research topics, identified through the mapping workshops, into research questions. The main objective of this conversion was to take the contextual information that was provided by participants during the discussion part of the workshops and to use that information to convert the topics into specific research questions. The format that was used for the research questions is referred to as PICO format. PICO stands for Population, Intervention, Comparison, and Outcome Measured. The contextual information was used to fill in the gaps for any information that was missing in order to convert the question into PICO format. For example, topic #3 was initially captured as *“Increase the level and quality of communication”*. After the contextual information was incorporated, the research question read as follows: *“Communication interventions to increase the level and quality of communication of inter-professional teams involved in treating osteoarthritis patients.”* Breaking down the research question into the PICO components, this is what we find:

- The population is *inter-professional teams treating osteoarthritis patients*,
- The type of intervention is *communication*,
- A comparison is not being applied in this case.

- The desired outcome measured is an increase in the level and quality of communication. This was important given that before the CMSG can work on a systematic review, a clear research question has to be identified.

**Figure 4. 8 Five High-Level Steps of the Adapted GEM Methods**



From the 11 broad priority research topics that were identified, a total of 43 clinical questions were developed and refined with assistance of the CMSG. An iterative process was used to convert the topics into research questions. In person meeting were conducted along with written communication, reviews and feedback conducted over email. This process was followed until the CMSG team agreed the topics were developed to its full extent. The list of 43 research questions drawn from the 11 top research topics is included in the table 4.4 below. In the table it is noticeable that in most cases, more than one question was drawn from each topic. This happened when the contextual information provided by workshop participants, covered more than one population or more than one intervention or more than one measurable outcome. Thus, we needed to divide the topic into as many questions as necessary in order to cover the full scope of the contextual information provided by participants during the workshops.

**Table 4. 6 Listing of 43 Research Questions**

Research Topic	Research Questions
TOPIC 1: Self-management approaches in treating osteoarthritis	1. Communication interventions directed to patients to increase awareness of long-term self-management approaches in treating osteoarthritis. 2. Educational interventions to change the behaviour in patients to increase the level of understanding of long-term self-management approaches in treating osteoarthritis. 3. Educational interventions to change the behaviour in patients to increase the uptake of self-management approaches in treating osteoarthritis. 4. Educational interventions to change the behaviour in patients to increase adherence to long-term self-management approaches in treating

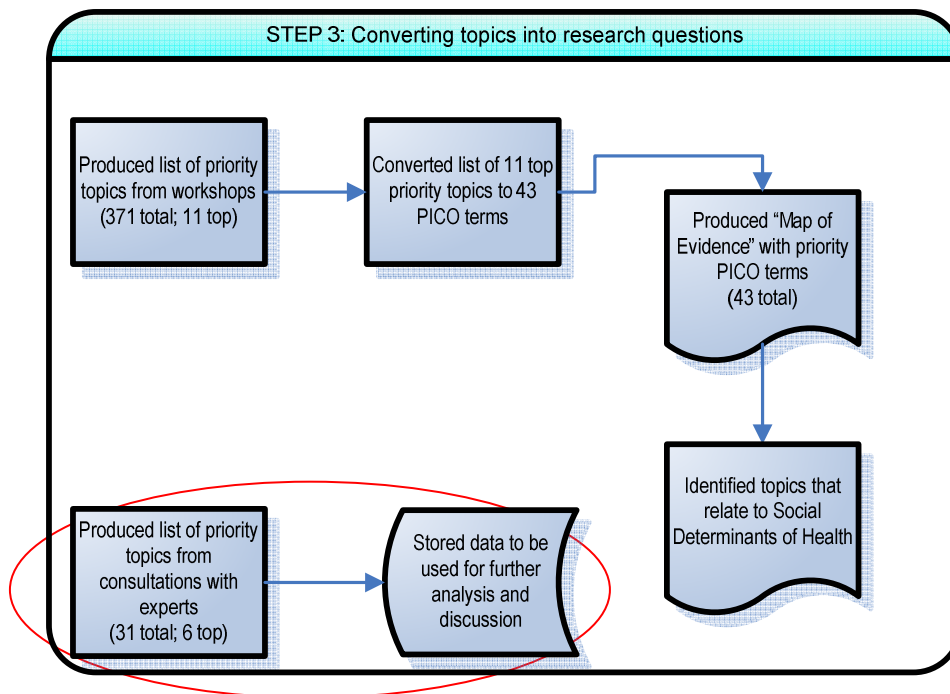
	<p>osteoarthritis.</p> <p>5. Educational interventions directed to osteoarthritis patients to increase the level of understanding of the need for continual &amp; on-going treatment.</p>
<p>TOPIC 2: Interventions to reduce the risk of developing osteoarthritis in the well community</p>	<p>6. Lifestyle-related interventions aimed at people who have not been diagnosed with the condition to reduce the risk of developing osteoarthritis.</p> <p>7. Health promotion interventions aimed at people who have not been diagnosed with the condition to increase the adoption of disease prevention approaches.</p> <p>8. Health promotion interventions aimed at people who have not been diagnosed with the condition to increase the adherence of disease prevention approaches.</p> <p>9. Knowledge transfer interventions directed to health practitioners to increase the level of understanding of osteoarthritis preventive measures available to people at risk.</p> <p>10. Knowledge transfer interventions directed to public health policy-makers to improve the quality and availability of education tools and information on preventive measures.</p>
<p>TOPIC 3: Increase the level and quality of communication</p>	<p>11. Communication interventions to increase the level and quality of communication of inter-professional teams involved in treating osteoarthritis patients.</p> <p>12. Communication interventions to improve the quality and level of communication between osteoarthritis patients and their health care providers.</p>
<p>TOPIC 4: Prevent the progression of osteoarthritis in patients with early-stage osteoarthritis</p>	<p>13. Non-pharmacologic interventions to prevent the progression of osteoarthritis in patients with early-stage osteoarthritis.</p> <p>14. Pharmacologic interventions to prevent the progression of osteoarthritis in patients with early-stage osteoarthritis.</p> <p>15. Complementary and alternative therapies to prevent the progression of osteoarthritis in patients with early-stage osteoarthritis.</p>
<p>TOPIC 5: Reduce inequities in waiting times for osteoarthritis surgery</p>	<p>16. Health systems interventions to reduce inequities in waiting times at a national level for joint replacement surgery in people with osteoarthritis.</p> <p>17. Health systems interventions to reduce barriers to surgery in disadvantaged groups of people with osteoarthritis.</p> <p>18. Knowledge transfer interventions aimed at health care practitioners to reduce the gaps in knowledge about issues associated with delays in surgery specific to disadvantaged groups of people with osteoarthritis.</p> <p>19. Knowledge transfer interventions aimed at policy-makers to reduce the gaps in knowledge about issues associated with delays in surgery specific to disadvantaged groups of people with osteoarthritis.</p> <p>20. Knowledge transfer interventions aimed at disadvantaged groups of people with osteoarthritis to reduce the gaps in knowledge about issues associated with delays in surgery as a treatment option.</p>
<p>TOPIC 6: Reduce decisional conflict about timing for joint replacement</p>	<p>21. Decision-aid interventions to reduce health care practitioner conflict about timing of joint replacement in treating people with osteoarthritis.</p> <p>22. Decision-aid interventions to aid health practitioners discuss options with people with OA who are having decisional conflict about joint replacement surgery</p> <p>23. Decision-aid interventions to reduce patient decisional conflict about timing of joint replacement in treating osteoarthritis</p> <p>24. Decision support interventions to increase patient participation in the decision-making process to develop and implement a treatment plan for people with osteoarthritis. (Increase patient participation in the decision-making process</p>
<p>TOPIC 7: Psychosocial impact of osteoarthritis in people living with the</p>	<p>25. Population health interventions to reduce the psychosocial impact of osteoarthritis in people living with the condition.</p> <p>26. Peer support interventions for communication between consumers to</p>

condition	<p>reduce the psychosocial impact of osteoarthritis in people living with the condition.</p> <p>27. Skills training interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition.</p> <p>28. Social support interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition.</p> <p>29. Information provision interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition.</p> <p>30. Cross-sectoral interventions to reduce the psychosocial impact of osteoarthritis in people living with the condition.</p>
TOPIC 8: Economic impact of osteoarthritis in people living with the condition	<p>31. Lifestyle-related interventions to reduce the economic burden of osteoarthritis in people living with the condition.</p> <p>32. Cross-sectoral interventions (interventions where the science, technology, engineering and medicine sectors collaborate with member of the humanities, arts and social sciences) to reduce the economic burden of osteoarthritis in people living with the condition.</p> <p>33. Workplace interventions to reduce the economic burden of osteoarthritis in people living with the condition.</p>
TOPIC 9: Weight management for people with osteoarthritis	<p>34. Weight management for the treatment of osteoarthritis</p> <p>35. Weight management as a risk reduction strategy for osteoarthritis</p> <p>36. Weight management as a preventive measure for those at high-risk of developing osteoarthritis</p> <p>37. Obesity reduction versus other non-pharmacologic treatments in treating osteoarthritis</p>
TOPIC 10: Effectiveness of osteoarthritis interventions according to osteoarthritis patient preferences	<p>38. Methods for incorporating patient preference in the measurement of intervention effectiveness for treating osteoarthritis.</p>
TOPIC 11: Increase knowledge transfer to patients of treatment options available for treating osteoarthritis	<p>39. Knowledge dissemination interventions to improve the quality and accessibility of information on treatment options available to people with osteoarthritis.</p> <p>40. Health promotion interventions to increase knowledge transfer to patients of treatment options available in treating people with osteoarthritis</p> <p>41. Knowledge dissemination interventions to improve the quality and accessibility of information on the level of effectiveness of treatment options available to people with osteoarthritis.</p>
TOPIC 11: Increase knowledge transfer (amongst health practitioners and to patients) of positive and negative side effects of drugs used to treat people with osteoarthritis	<p>42. Educational interventions to increase the quality and level of awareness and understanding in health practitioners of the desirable and undesirable side effects of drugs used to treat people with osteoarthritis.</p> <p>43. Knowledge dissemination interventions to increase the quality and level of awareness and understanding in people with osteoarthritis of the desirable and undesirable side effects of drugs used to treat the condition.</p>

As noted in figure 4.9 below (specific steps circled in red), in accordance with the original GEM methods, only the research topics identified through workshops were converted into research questions. The research topics identified through consultations with experts were not converted into research questions. This was done in accordance with the original GEM methods. In the original GEM methods, data drawn from consultations with experts did not feed into the final list of priority research questions because it was only used as a tool to inform the mapping workshops. Although we agreed to

follow the original GEM methods and not include the topics drawn from consultations with experts in the list of priority research topics, as a result of discussions with the CMSG team, we decided to add a new step to the process. This new step required that we systematically interview experts and document priority research topics from the perspective of experts. The objective was to use the new data to make recommendations for future GEM exercises. The CMSG team was specifically interested in recommendations as to how to incorporate the priorities identified through the consultations into the priority setting process and how to assess the potential value added to the process. As agreed, both, the 31 research topics and the top 6 priorities identified by clinicians were systematically collected and stored in the database. The recommendations put forward to the CMSG team are included in Chapter 7, Section 7.1.1.2.

**Figure 4. 9 Step 3: Converting Topics into Research Questions**



### 4.1.7.3. 1 “Map of Evidence” with priority research questions

What is the Osteoarthritis Map of Evidence?							
<p><i>This map outlines key areas where effort is required to improve the overall quality of life of people living with osteoarthritis.</i></p> <p><i>The intent is to use the map as a tool to assist in the identification of priority research topics on which to base upcoming systematic reviews</i></p>							
		Well Community		People with osteoarthritis (and families and carers)			
		Reduce Risk	Find the Condition Early	Have the best care and support in the <u>early stages</u>	Have the best care and support for <u>acute episodes</u>	Have the best care and support for the <u>long-term management</u>	Have the best care and support in the <u>advanced stages</u>
The needs of people who have or are at risk of osteoarthritis What are the optimal person or patient-centred services?							
People's needs							
Optimal services							
2	What is happening now? Gaps in current care - Current practice in meeting peoples needs and providing optimal services						
Access to Care and Support						* Health systems interventions to reduce inequities in waiting times at a national level for joint replacement surgery in people with osteoarthritis (16) - Health systems interventions to reduce barriers to surgery in disadvantaged groups of people with osteoarthritis (17)	
Pharmacologic/Drug Therapies				- Pharmacologic interventions to prevent the progression of osteoarthritis in patients with early-stage osteoarthritis (14)			
Non-pharmacologic/Drug therapies (including self management interventions) - applicable to one stage of the condition	- Weight management as a risk reduction strategy for osteoarthritis (35) - Weight management as a preventive measure for those at high-risk of developing osteoarthritis (36)			- Non-pharmacologic interventions to prevent the progression of osteoarthritis in patients with early-stage osteoarthritis (13) - Complementary and alternative therapies to prevent the progression of osteoarthritis in patients with early-stage			

			osteoarthritis (15)			
Non-pharmacologic therapies (including self management interventions) - applicable to more than one stage of the condition			<ul style="list-style-type: none"> <li>- Weight management for the treatment of osteoarthritis (34)</li> <li>- Obesity reduction versus other non-pharmacologic treatments in treating osteoarthritis (37)</li> </ul>			
Lifestyle changes - applicable to one stage of the condition	* Lifestyle-related interventions aimed at people who have not been diagnosed with the condition to reduce the risk of developing osteoarthritis (6)					
Support for high-quality services. Examples: information and communications technology, communication with patients, information and support for carers, decision support systems, etc. - applicable to one stage of the condition.	- Knowledge transfer interventions directed to health practitioners to increase the level of understanding of osteoarthritis preventive measures available to treat people at risk (9)				<ul style="list-style-type: none"> <li>* Communication interventions directed to patients to increase awareness of long-term self-management approaches in treating osteoarthritis (1)</li> </ul>	<ul style="list-style-type: none"> <li>- Knowledge transfer interventions aimed at health care practitioners to reduce the gaps in knowledge about issues associated with delays in surgery specific to disadvantaged groups of people with osteoarthritis (18)</li> <li>- Knowledge transfer interventions aimed at policy-makers to reduce the gaps in knowledge about issues associated with delays in surgery specific to disadvantaged groups of people with osteoarthritis (19)</li> <li>- Knowledge transfer interventions aimed at disadvantaged groups of people with osteoarthritis to reduce the gaps in knowledge about issues associated with delays in surgery as a treatment option (20)</li> <li>* Decision-aid interventions to reduce health care practitioner conflict about timing of joint replacement in treating people with osteoarthritis (21)</li> <li>- Decision-aid interventions to aid health practitioners discuss options with</li> </ul>

						people with OA who are having decisional conflict about joint replacement surgery (22) - Decision-aid interventions to reduce patient decisional conflict about timing of joint replacement in treating osteoarthritis (23)
Support for high-quality services. Examples: information and communications technology, communication with patients, information and support for carers, decision support systems, etc. - applicable to more than one stage of the condition.						<ul style="list-style-type: none"> <li>* Communication interventions to increase the level and quality of communication of inter-professional teams involved in treating osteoarthritis patients (11)</li> <li>* Communication interventions to improve the quality and level of communication between osteoarthritis patients and their health care providers (12)</li> <li>* Decision support interventions to increase patient participation in the decision-making process to develop and implement a treatment plan for people with osteoarthritis. (Increase patient participation in the decision-making process (24)</li> <li>- Peer support interventions for communication between consumers to reduce the psychosocial impact of osteoarthritis in people living with the condition (26)</li> <li>- Information provision interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition (29)</li> <li>- Cross-sectoral interventions to reduce the psychosocial impact of osteoarthritis in people living with the condition (30)</li> <li>- Methods for incorporating patient preference in the measurement of intervention effectiveness for treating osteoarthritis (38)</li> <li>- Knowledge dissemination interventions to improve the quality and accessibility of information on treatment options available to people with osteoarthritis (39)</li> <li>- Knowledge dissemination interventions to improve the quality and accessibility of information on the level of effectiveness of treatment options available to people with osteoarthritis (41)</li> <li>- Educational interventions to increase the quality and level of awareness and understanding in health practitioners of the desirable and undesirable side effects of drugs used to treat people with osteoarthritis (42)</li> <li>- Knowledge dissemination interventions to increase the quality and level of awareness and understanding in people with osteoarthritis of the desirable and undesirable side effects of drugs used to treat the condition (43)</li> </ul>
<b>3 What are the priorities for improving care? Where do the gaps between current and optimal services matter?</b>						
Critical intervention points where practical and significant health gains and service improvements can be made						* Educational interventions to change the behavior in patients to increase adherence to long-term self-management approaches in treating osteoarthritis (4)
<b>4 What actions across sectors are needed for change to occur? Social, educational, legal interventions required?</b>						

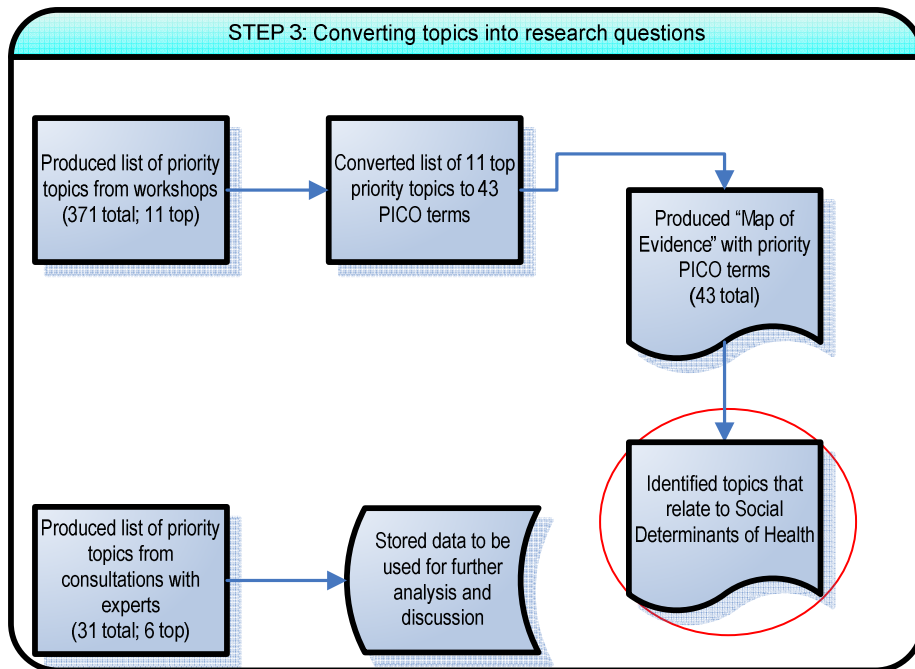
<p>Social determinants of health - applicable to a particular stage of the condition</p>	<ul style="list-style-type: none"> <li>- Health promotion interventions aimed at people who have not been diagnosed with the condition to increase the adoption of disease prevention approaches (7)</li> <li>- Health promotion interventions aimed at people who have not been diagnosed with the condition to increase the adherence of disease prevention approaches (8)</li> <li>- Knowledge transfer interventions directed to public health policy-makers to improve the quality and availability of education tools and information on preventive measures (10)</li> </ul>				<p>* Educational interventions to change the behavior in patients to increase the level of understanding of long-term self-management approaches in treating osteoarthritis (2)</p>	
<p>Social determinants of health - applicable to more than one stage of the condition</p>			<ul style="list-style-type: none"> <li>* Educational interventions to change the behavior in patients to increase the uptake of self-management approaches in treating osteoarthritis (3)</li> <li>* Educational interventions directed to osteoarthritis patients to increase the level of understanding of the need for continual &amp; on-going treatment (5)</li> <li>- Population health interventions to reduce the psychosocial impact of osteoarthritis in people living with the condition (25)</li> <li>- Skills training interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition (27)</li> <li>- Social support interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition (28)</li> <li>- Lifestyle-related interventions to reduce the economic burden of osteoarthritis in people living with the condition (31)</li> <li>- Cross-sectoral interventions (interventions where the science, technology, engineering and medicine sectors collaborate with member of the humanities, arts and social sciences) to reduce the economic burden of osteoarthritis in people living with the condition (32)</li> <li>- Workplace interventions to reduce the economic burden of osteoarthritis in people living with the condition (33)</li> <li>- Health promotion interventions to increase knowledge transfer to patients of treatment options available in treating people with osteoarthritis (40)</li> </ul>			

#### 4.1.7.3.2 Identified topics that relate to Social Determinants of Health

As indicated in Figure 4.10, the last activity of step 3 of the process was to analyze the 43 research questions that resulted from the broad research topics, in order to identify those that relate to social determinants of health. This exercise was important given that one of the main objectives of this thesis

was to incorporate the social determinants of health in the prioritization exercise. Details on the process that was followed to identify research questions that relate to the social determinants of health are explained in detail in Chapter 6 of this thesis.

**Figure 4. 10 Step 3: Converting Topics into Research Questions**



#### 4.1.7.4 Prioritizing the top ten research questions

As indicated in figure 4.10, step four of the process was to identify the top research questions to be worked on next. This was important given that not all 43 research questions developed in the previous step could be addressed at once. Consequently, the main objective of this step was to determine what research questions should be addressed by the CMSG until the next prioritization exercise is carried out.

Figure 4. 11 Five High-Level Steps of the Adapted GEM Methods

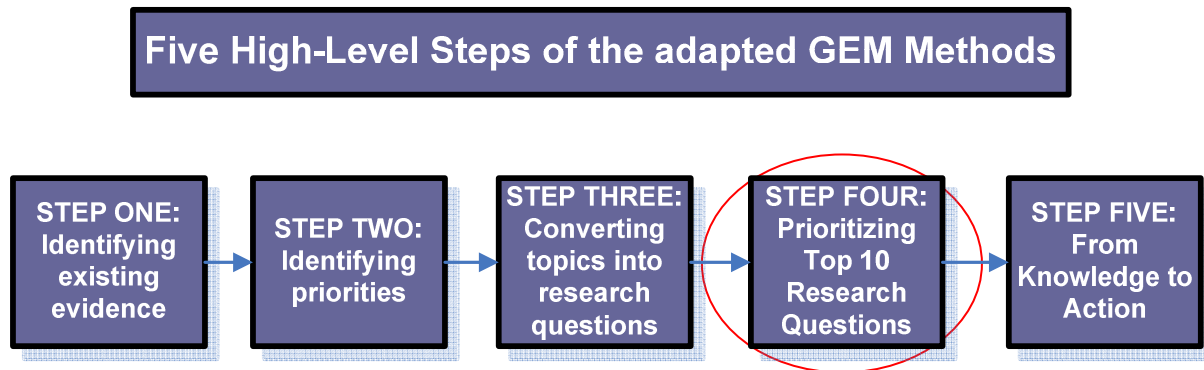


Figure 4.12 Step 4: Prioritizing top 10 Research Topics

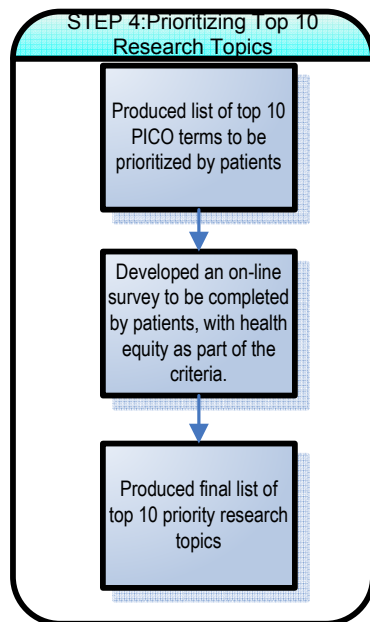


Figure 4.11 describes step 4 in more detail. As indicated in this figure, the number of top research questions to identify was established at 10. This number was calculated based on two pieces of information. First, in consultation with the research group and the CMSG it was concluded that the prioritization exercise would likely have to be repeated once every one to two years in order to keep the listing current. Second, the chief editors of the CMSG estimated that 10 systematic reviews would provide sufficient work for their team for one to two years, depending on the complexity and volume of the literature.

In order to identify the top 10 research questions, we first referred back to the list of broad research topics that were identified during the mapping workshops. From the list we were able to select the topics that were the top priorities based on the number of red dots assigned by workshop participants. Five broad topics had the highest number of red dots:

- Self management approaches
- Level and quality of communication
- Reduce risk in the well community
- Reduce inequities in waiting times for osteoarthritis surgery
- Reduce decisional conflict about timing for joint replacement

As a group, we decided to include at least one research question from each broad research topic. The results of this exercise are presented in table 4.7 below. Column A describes the broad research topic as it was worded during the mapping workshops. Column B provides the number of red dots that workshop participants assigned to the topic. Column C provides the total number of research questions that were developed from the broad research topic. And finally, Column D identifies the number of research questions that were incorporated into the top 10.

**Table 4. 7 Identifying the top 10 research questions**

A	B	C	D
Priority Research Topic	# Red Dots	# Resulting Research Questions	# Questions included in top 10
Self management approaches	10	5	4
Level and quality of communication	10	2	2
Reduce risk in the well community	9	5	1
Reduce inequities in waiting times for osteoarthritis surgery	9	5	1
Reduce decisional conflict about timing for joint replacement	9	4	2
Psychosocial impact of osteoarthritis in people living with the condition	8	6	0
Economic impact of osteoarthritis in people living with the condition	8	3	0
Weight management for people with osteoarthritis	7	4	0
Effectiveness of osteoarthritis interventions according to osteoarthritis patient preferences	5	1	0
Increase knowledge transfer to patients of treatment options available for treating osteoarthritis	5	3	0
Prevent the progression of osteoarthritis in patients with early-stage	4	3	0

Increase knowledge transfer (amongst health practitioners and to patients) of positive and negative side effects of drugs used to treat people with osteoarthritis	4	2	0
<b>Total Research Questions</b>		<b>43</b>	<b>10</b>

Once the top 10 questions were selected, we developed a survey that would be completed by patients to rank the top 10 research questions. A copy of the survey is included in Annex 4.

After the survey was designed, keeping in mind that it would be completed by patients, we met with the patient representative within the CMSG to review the survey to gather more information re the suitability of the wording. Feedback provided by the patient representative was minor and related mainly to the wording of one particular question. Once all feedback was addressed, we invited patients to participate in the survey through a letter, a copy of which is contained in Annex 1. Participants were also provided with a copy of the “Participant Information Sheet and Consent Form”, a copy of which is provided in Annex 2. Participants that agreed to participate were given the option to complete the survey in electronic format or in paper format.

The survey asked patients to rank the top 10 (ten) research questions. As part of the instructions to complete the survey, patients were informed we were interested in their personal point of view. For each research question listed in the survey participants were asked to rank each one of the questions for two dimensions: importance and equity.

<i>Importance: How important is this question?</i>
<i>Equity/ Social Determinants: To what degree does the question address the health needs of populations across different social gradients as defined by the PROGRESS framework (i.e. <u>P</u>lace of residence; <u>R</u>ace, ethnicity, and culture; <u>O</u>ccupation; <u>G</u>ender; <u>R</u>eligion; <u>E</u>ducation; <u>S</u>ocioeconomic status; and <u>S</u>ocial capital)?</i>

The ranking from used a scale from 1 to 4 and it was interpreted as follows:

- 1 = not at all
- 2 = a little
- 3 = a moderate amount
- 4 = high

In order to prioritize the questions, we collated the data from the ranking done by each patient for the two dimensions, importance and equity, and calculated an average. The survey was sent to 95 patients with osteoarthritis. We received a response from 51. The table below summarizes the results of

the survey by question, by dimension and sorted from top priority to lowest priority as ranked by the patients.

**Table 4. 8 Ranking of top 10 research questions from top priority to lowest priority**

A	B	C	D
Question	Importance	Equity	Average
Communication interventions to improve the quality and level of communication between osteoarthritis patients and their health care providers.	3.69	3.18	3.435
Health systems interventions to reduce inequities in waiting times at a national level for joint replacement surgery in people with osteoarthritis.	3.53	3.25	3.39
Decision support interventions to increase patient participation in the decision-making process to develop and implement a treatment plan for people with osteoarthritis.	3.59	3.1	3.345
Educational interventions to change the behaviour in patients to increase adherence to long-term self-management approaches in treating osteoarthritis.	3.55	3.1	3.325
Educational interventions to change the behaviour in patients to increase the uptake of self-management approaches in treating osteoarthritis.	3.61	2.98	3.295
Communication interventions to increase the level and quality of communication of inter-professional teams involved in treating osteoarthritis patients.	3.55	2.88	3.215
Educational interventions directed to osteoarthritis patients to increase the level of understanding of the need for continual & on-going treatment.	3.49	2.92	3.205
Communication interventions directed to patients to increase awareness of long-term self-management approaches in treating osteoarthritis.	3.43	2.94	3.185
Lifestyle-related interventions aimed at people who have not been diagnosed with the condition to reduce the risk of developing osteoarthritis.	3.39	2.86	3.125
Decision-aid interventions to reduce health care practitioner conflict about timing of joint replacement in treating people with osteoarthritis.	3.25	2.78	3.015

#### 4.1.7.5 From Knowledge to Action

After the list of top priority topics was produced, three activities were carried out in order to help take the new knowledge produced through this research into action:

- 1) Determine ownership of topics
- 2) Determine what topics from the 43 priority research questions are directly linked to social determinants of health
- 3) From those topics that are deemed as directly linked to social determinants of health, identify a level of analysis on health equity that could be incorporated into the systematic reviews.

Activity 1 is described below in detail. Activities 2 and 3 are summarized below and described in detail in Chapter 6, Section 6.2.5

ACTIVITY 1: We met with two other Cochrane Review Groups to determine ownership of the topics: Consumer and Communications Review Group and the Cochrane Effective Practice and Organization of Care (EPOC) Group. We contacted these groups based on a brief analysis conducted on the 43 priority research topics. The objective was to first check which topics (if any) were already being done. Then for the ones not yet being done, we would list these topics on the CMSG website as priority topics and actively seek volunteers to do them.

We presented each one of the Cochrane Review Groups with a copy of the final map of evidence containing the 43 priority research questions and asked them to answer the following questions:

1. How many of these topics in this box and in the other boxes too, fit best with your Review Group?
2. Do they need more splitting /lumping?
3. Is it your impression that some /many of these are already covered generically across all conditions that you feel are generic so we do not need a new review but maybe can pull out the musculoskeletal ones in the existing reviews?
4. If not already on the Cochrane Library is it your preference to run these through your group –or would you prefer that we do with your assistance?
5. Other thoughts?

The responses of the two groups are summarized below:

- Several of the topics may have been reviewed for medicines use. Further analysis is required.
- Many of the cells in the map of evidence describe interventions that are in broad categorical terms, e.g. knowledge transfer. The term might be suitable to a systematic review but for practice relevant information it would need to be broken down. And for searching for relevant reviews which already exist, it may need to be defined more clearly or more specifically.
- If new systematic reviews are needed for OA, RA or arthritis generally, then the expectation is they would be picked up by the CMSG. However, something to consider is whether 52 information

provision reviews are needed. Sometimes it might be justified and sometimes not. It may depend on how many trials are expected or whether the disease impacts on someone's life in a different way. So that is an issue what would need some discussion by the CRGs at the editorial stage.

- There is strong interest on the issue of how information from reviews that are generic to patients (e.g. use of internet) could be used by health professionals for things like advice on how to communicate more effectively with patients. How is evidence from such reviews applied to specific disease advice? Particularly if the population in question is not included in the review, which is not being dealt with currently.

ACTIVITY 2: We applied the Social Determinants of Health conceptual framework developed by the CSDH to systematically classify priority review topics that relate to social determinants of health. Using the framework we concluded that from 43 priority topics identified through this priority setting exercise, 25 could be classified under the social determinants of health. This allowed us to verify the methods had been successful in incorporating the social determinants of health into the decision-making process.

ACTIVITY 3: We applied the five-level framework developed by the Priority Public Health Conditions Knowledge Network to assign a level of health equity analysis for future systematic reviews. This framework provided a practical way of continuing to move the health equity agenda forward. By applying the framework we concluded all systematic review topics conducted by the Cochrane Collaboration could incorporate a level of analysis on health equity and social determinants of health.

## **4.2 The top priority research questions for osteoarthritis**

In the previous section of this chapter (4.1 Adapted Methods) we described the priority setting methodology that resulted from the adaptations made to the GEM methods. These modifications were made in order to meet the research objectives of sustainability and of including the social determinants of health and health equity in setting priorities. As mentioned in Chapter 3, after the methods were developed, we piloted the methods with the Cochrane Musculoskeletal Group to set priorities in Osteoarthritis. In this section (4.2 Priority Research Questions) the priority osteoarthritis research questions that resulted from this exercise are presented.

Table 4.9 below provides a listing of the top 10 questions from top priority to the lowest priority as ranked by patients.

**Table 4. 9 Top Research Questions for Osteoarthritis**

Ranking	Osteoarthritis Research Questions
1	Communication interventions to improve the quality and level of communication between osteoarthritis patients and their health care providers.
2	Health systems interventions to reduce inequities in waiting times at a national level for joint replacement surgery in people with osteoarthritis.
3	Decision support interventions to increase patient participation in the decision-making process to develop and implement a treatment plan for people with osteoarthritis.
4	Educational interventions to change the behaviour in patients to increase adherence to long-term self-management approaches in treating osteoarthritis.
5	Educational interventions to change the behaviour in patients to increase the uptake of self-management approaches in treating osteoarthritis.
6	Communication interventions to increase the level and quality of communication of inter-professional teams involved in treating osteoarthritis patients.
7	Educational interventions directed to osteoarthritis patients to increase the level of understanding of the need for continual & on-going treatment.
8	Communication interventions directed to patients to increase awareness of long-term self-management approaches in treating osteoarthritis.
9	Lifestyle-related interventions aimed at people who have not been diagnosed with the condition to reduce the risk of developing osteoarthritis.
10	Decision-aid interventions to reduce health care practitioner conflict about timing of joint replacement in treating people with osteoarthritis.

## 4.3 Assessing the methods and the research objectives

### 4.3.1 Application of the Framework for Successful Priority Setting to evaluate the results

The Framework for Successful Priority Setting was applied to evaluate the priority setting exercise. The evaluation is broken down in two steps: evaluating the process and evaluating the outcomes. The two tables below present the results of the evaluation. The 5 criteria applied to evaluate

the process and related results are included in table 4.10 below. The 5 criteria applied to evaluate the outcomes and related results are included in table 4.11 below.

In order to objectively assess the results, we quantified the results by assigning the following numeric value to the possible responses:

Yes = Yes, met the requirement (1 point)

No = No, did not meet the criteria (0 points)

Partially = Only part of the criteria was met (0.5 points)

At the bottom of each table the results of the evaluation are quantified.

**Table 4. 10 Evaluating the Process**

EVALUATING THE PROCESS			
Description of the criteria	Yes/No/Partially	Results of the Assessment	Potential areas of improvement
<p><b>Stakeholder Engagement:</b> effectively identified and engaged all relevant stakeholders in the process.</p>	Yes	An effort was made to engage all different types of stakeholders: patients, researchers, clinicians, decision-makers and policy-makers. All but policy-makers were ultimately involved in the process.	At the beginning of the process, identify a champion within a government organization responsible for developing relevant policy that could commit resources to participate in the process. This would help with knowledge sharing efforts to inform policy and program decision-making.
<p><b>Information Management:</b> identified relevant information that was shared and information that was lacking. All relevant information was tailored to specific audiences and disseminated through different communication tools.</p>	Yes	An effort was made to ensure that the different data was tailored to the specific audience that was meant to reach. In terms of relevant information that was shared, an example is the map of evidence shared with clinical experts to collect their input on priorities. Throughout the process clinicians indicated they found the map of evidence to be quite useful in terms of summarizing evidence that they could refer to in preventing and treating osteoarthritis and suggested continuing to keep it up to date as new systematic reviews related to osteoarthritis are published. In terms of	At the beginning of the process select a representative from each stakeholder group. Set up a meeting to present them with a list of relevant information that will be shared at each one of the different stages of the process and ask for their input in terms of identifying additional points in the process where reporting back to their stakeholder groups would be useful and also, input in terms of the format/content of the data to be shared. Limited resources available to produce this additional communication

		information that was lacking, an explanation on how the broad research topics were converted into research questions should have been shared with all stakeholders at the different stages of conversion.	tools might be of concern so we recommend defining a criterion up front to include/not include the feedback provided by stakeholder representatives participating in this discussion.
<b>Explicit Process:</b> the process was explained not only to those participating in the process but also to stakeholders not participating and the level of understanding of the process was verified.	Partially	The process was explained only to those stakeholders participating and/or involved in the priority-setting process. Communications did not include the broader community that ultimately will be impacted by the priority setting exercise. However, for those that were involved and/or participated in the process, the level of understanding was verified and recommendations put forward to improve the level of understanding for patients.	Identify organizations that you could partner with (e.g. The Arthritis Society) to establish a relationship and a commitment to jointly communicate relevant information (e.g. the process to set priorities) to the broader community. Examples of resources that could be incorporated are: web postings, web cross-posting, co-production of project-specific material,
<b>Consideration of Context &amp; Values:</b> Reasons for selecting priorities were grounded in clear value choices, and reasons and values were made explicit.	Yes	The process for selecting priorities was explicit: importance and equity were the dimensions applied to rank the top priority research questions. Context was also taken into account by allocating time to discuss contextual issues and the social determinants of health in the mapping workshops.	At the beginning of the mapping workshops, share with workshop participants the values that are guiding the priority setting exercise. Allow room for questions and answers.
<b>Revision or Appeals Mechanism:</b> a process to review decisions and resolve disagreements was in place and made explicit to internal and external stakeholders.	No	A process to review decisions was not explicitly incorporated into the process.	
<b>Subtotal Process Evaluation: 3.5 points</b>			

Table 4. 11 Evaluating the Outcomes

EVALUATING THE OUTCOMES			
Description of the criteria	Yes/No/Partially	Results of the Assessment	Potential areas of improvement
<b>Improved stakeholder understanding:</b> stakeholders gained knowledge on the priority setting process itself and/or on the organization	Yes	The Cochrane Collaboration, the CMSG, the Global Evidence Map Initiative, the Campbell and Cochrane Equity Methods Group all confirmed they gained knowledge throughout the process.	Establish learning objectives for each group at the beginning of the process and assess results against the criteria once the project is completed. This would allow for a more objective assessment of the knowledge transfer outcome.
<b>Shifted priorities/Reallocation of resources:</b> effort resulted in a clear action/change in the organization linked to the identified priorities	Yes	The results of the priority setting exercise will be posted onto the CMSG website and the intent is to work next on the systematic reviews that address the research questions listed in the top 10 and in the order defined with patients' input.	Obtain written agreement upfront from the Cochrane Review Group to dedicate resources to work on the priority research questions. Our agreement was only verbal.
<b>Improved Decision Making Quality:</b> greater consistency and quality in decision making was obtained in the organization	Partially	The quality was improved given that priorities are no longer set on personal interest but rather resulted from an objective priority-setting process. The impact on decision-making can only be assessed over time, as the CMSG picks topics to work on next.	The impact on decision-making can only be assessed over time. Incorporating a longer period of evaluation into the process would allow capturing more information in order to provide a more detailed assessment.
<b>Stakeholder Acceptance &amp; Satisfaction:</b> stakeholders are willing to continue to participate in the process	Yes	Stakeholders have confirmed they wish to continue participating in future priority-setting exercises.	Feedback from stakeholders was captured informally. The process could be improved by developing a questionnaire to capture feedback on a more structure manner.
<b>Positive Externalities:</b> external outcomes resulted from this exercise that could be interpreted as indicatives of success	Yes	We have received positive media coverage within the Cochrane Collaboration (e.g. mention in newsletters) and peers have started requesting more information in order to emulate the process.	Develop a template to formally capture positive externalities as the process is carried out.
<b>Subtotal Outcomes Evaluation: 4.5 points</b>			

In sum, the methods are sustainable and effectively incorporate the social determinants of health and health equity into the process. As in most processes, there is room for improvement in each one of these points and recommendations are put forward in “Chapter 7: Conclusions”.

### 4.3.2 Evaluating Sustainability and the Ability to Effectively Incorporate the Social Determinants of Health and Health Equity in the Process

In addition to assessing the level of success of the methods through an existing framework (Section 4.3.1) we also assessed whether the research objectives that relate to sustainability and the social determinants of health, and health equity, were in fact met or not.

- 1) To assess the sustainability of the methods, we developed a definition of sustainability for this context and compared the methodology against that definition. A “sustainable process” was defined as a process that is repeatable, that takes into account the characteristics and mandate of the Cochrane Collaboration and that makes an efficient use of resources so that it can be executed on a regular basis. The methodology that we carried out meets this definition, thus, we conclude the methods are sustainable.
- 2) To assess the ability to effectively include the social determinants of health (SDH) we analyzed the 43 priority research questions using the SDH conceptual framework. Through the framework we identified the research questions that relate to SDH. As part of the evaluation criteria defined upfront, we agreed that if at least one research question could be classified as a question that relates to the social determinants under the SDH conceptual framework then we would deem the methods effectively incorporated SDH into the priority setting exercise. In setting priorities for osteoarthritis, more than 50% of the 43 research questions that were developed were classified under the SDH, thus, we conclude the methods effectively incorporated the social determinants of health. The final results surpassed our initial expectations: historically, only 5 – 10 % of review topics addressed by a CRG relate to SDH. The final list of priority topics produced through this exercise had more than 50% of the topics relating to SDH.
- 3) To assess the ability to effectively include health equity in the process we reviewed the priority topics to identify those that explicitly address health equity issues. As part of the evaluation criteria defined upfront, we agreed that if at least one research question explicitly addressed equity then we would deem health equity was effectively incorporated into the priority setting process. From the 43 research questions that were developed, at least 1 explicitly addresses equity issues, thus, we conclude the methods effectively incorporated health equity. Furthermore, as the process evolved the research group agreed to include equity as one of the dimensions for patients to apply when ranking the top 10 research questions. This was another way in which health equity was incorporated into the process.

In sum, the methods are sustainable and effectively incorporate the social determinants of health and health equity into the process. As in most processes, there is room for improvement in each one of these points and recommendations are put forward in “Chapter 7: Conclusions”.

## Chapter 5: DISCUSSION

This chapter will begin with an overview of the results and main conclusions reached. Following this overview, a discussion on how to increase the sustainability of the methodology will be presented. Next, the top three strengths of our methodology will be reviewed along with a short discussion on how to further strengthen these activities. The potential risks associated to the implementation of these methods will be discussed next along with methodological issues and limitations of this study. Finally, what this thesis added to the state of knowledge and research is presented.

### 5.1 Overview of Results and Main Conclusions Reached

The research objectives of this study were three: 1) to develop a sustainable priority setting method that effectively incorporated the social determinants of health and health equity into the process; 2) to pilot the methods, and 3) to evaluate the methods. From the data that was presented in Chapter 4 we were able to conclude all three research objectives were met. Below we identify the sections in this report where details.

- Research objective 1: based on the evaluation criteria developed by the research group we were able to establish that the research objectives of sustainability and health equity and social determinants of health were met. A detailed description on how these results were reached is provided in Chapter 4, section 4.3.2.
- Research objective 2: The priority setting methodology was effectively tested to set priorities for Osteoarthritis in collaboration with the Cochrane Musculoskeletal Group, thus meeting the second research objective that required we test the methods. The top 10 research questions for Osteoarthritis are presented in Chapter 4, section 4.2.
- Research objective 3: The priority setting methodology was effectively evaluated with an independent evaluation tool, thus meeting the third research objective that required we evaluate the methods. The results of the evaluation are presented in Chapter 4, section 4.3.1.

Even though we were able to conclude all three research objectives were met, there are clearly limitations to this study and risks associated to the future implementation of the methods. The sections below describe such limitations and risks and provide high-level recommendations as to how to address such concerns.

## 5.2 Top 3 Methodological Strengths

### 5.2.1 Top Strength 1: Using the map of evidence to inform the process

Contrary to the original GEM methods that build a map of evidence at the end of the priority setting exercise, we created a map of evidence at the beginning of the priority setting exercise and we used it to inform the process. From a methodological perspective, the map of evidence was created in two steps: first, we developed a framework to capture all the key areas, inside and outside of the healthcare system, where effort is required to improve the quality of life of those suffering from a particular condition. The resulting product was a table/grid with key areas that span across the different stages of the disease. Second, we incorporated into the table all systematic reviews that had been published to date in those key areas. A copy of the map of evidence for osteoarthritis is provided in Appendix 4.5.

Three benefits were drawn from utilizing the map of evidence: First, it allowed us to apply a holistic approach when setting priorities, beyond clinical treatment and more in alignment with *patient needs*. Second, it allowed us to overcome the operational limits set by the way the Cochrane Collaboration is organized and operates, thus, allowing us to better meet the *needs of those that use the information* produced by Cochrane. Third, we were able to provide *those that are outside of the Cochrane system* with a practical tool to understand and use the information that is being produced by Cochrane.

#### 5.2.1.1 A holistic approach that better meets the needs of patients

The holistic approach was integrated into the process by asking clinicians to review the map of evidence before identifying priority topics. Also, as we went through the mapping workshops, we asked participants to think of priority topics in each one of the key areas included in the map. The resulting list of 43 priority research topics covers a variety of research areas that go beyond clinical treatment and surgery, which patients identified as being more in alignment with their needs. These priority topics include social determinants of health, clinical treatment, and other type of factors that can influence the quality of life of patients.

**Recommendation 1:** Develop tools to set priorities based on the needs of patients including both, clinical treatments and social determinants of health. The map of evidence for osteoarthritis is an example of such type of tool.

### 5.2.1.2 Focus on the needs of those that require the information regardless of how Cochrane operates

After the list of priority topics was analyzed by the research group, we came to the conclusion that more than one Cochrane Review Group will have to be involved in working through the priority topics. Thus, an unintended benefit had been attained by utilizing the map: we avoided being limited by the way the Cochrane Collaboration is organized and operates. This is an important difference from previous priority setting exercises where priority topics were limited by the scope of work of the Cochrane review Group leading the priority setting exercise. In brief, the way the Cochrane Collaboration operates did not interfere with the priority setting exercise, thus, allowing us to be more aligned with Cochrane's mandate of meeting information needs of decision-makers.

**Recommendation 2:** Develop tools to set priorities based on the needs of those that require the information and not limited by the way the Cochrane Collaboration operates. The map of evidence for osteoarthritis is an example of such type of tool.

### 5.2.1.3 A tool to help contextualize the information for those that are outside of the Cochrane Collaboration

Another unintended benefit was identified by clinicians and patients that are not normally involved with Cochrane activities. This group indicated the map provided them with a single source of summarized data in a context that made sense to them, which encouraged them to continue to access Cochrane for their personal information needs. This group of patients and clinicians inquired whether the map of evidence would continue to be updated after the priority setting exercise was completed as they would be interested in receiving regular updates.

In addition to helping patients and clinicians that are not normally involved with Cochrane, the map of evidence can be used to assist guideline developers in the selection of topics and research questions in the following ways:

- By identifying areas of knowledge where systematic reviews already exist – thus, ready to develop clinical guidelines if they do not exist.
- By identifying areas of knowledge where gaps exist = no systematic reviews available – thus, identify new areas where systematic reviews can be conducted.
- By providing a list of priority research questions (PICO format) that can be addressed by any evidence based center, not only Cochrane.

**Recommendation 3:** In setting priorities, develop tools that assist those that are not normally involved with Cochrane activities, to easily understand the information produced by Cochrane Groups. This will encourage them to participate in the process and continue to access Cochrane as a source of information. The map of evidence for osteoarthritis is an example of such type of tool.

### 5.2.2 Top Strength 2: Patients as champions of the process

An essential part of the success of the priority setting exercise was to have a “trusted” patient within the patient community that championed the research project. As explained in chapter 4, two activities were developed specifically to obtain patient input: a patient-only mapping workshop and a survey to rank the top 10 research topics. Obtaining buy-in a priori from patients was essential to ensure their participation. In both situations, our champion discussed with patients the importance of their participation in this research effort before we got involved. Because they trusted this person, when we approached them to ask whether they would be interested in participating they unequivocally agreed to participate.

**Recommendation 4:** Before initiating the priority setting exercise identify a patient that is willing to act as a champion for the research project. This person should be trusted by his/her peers and should genuinely believe the patient community will benefit from participating in the research. This person should be able to effectively communicate such message to the patient community.

### 5.2.3 Top Strength 3: Patient/Clinician Overlap Analysis

Two components that were added to the original GEM methods were a patient only mapping workshop and formal interviews with clinical experts. When analyzing the results it became clear there is an overlap between what clinicians and patients identify as a priority. There are two points on which they agree should be considered a priority in research: prevention and self management approaches, mainly diet and exercise. Clinicians and patients also agreed there is a need to consider exercise and diet as a formal treatment with dosages, timing of dosage and expected health outcomes. Exercise and diet they propose should be handled as a formal treatment just as it is done with drugs. Three out of the top 10 priority topics relate to self-management approaches. The patient/clinician overlap in priorities provides more information as to the type of self management approaches that are preferred by patients and clinicians.

**Recommendation 5:** When setting priorities incorporate activities that allow you to capture patient and clinician input separately. Identifying potential priority overlaps between these two groups allows the

research group to 1) validate the results produced by the priority setting exercise and 2) capture more information on patient and clinician preferences.

## **5.3 Methodological limitations and Recommendations for future applications of the methods**

In this section, the main methodological challenges and limitations of the study will be discussed. Five methodological issues have been identified:

- 1) Lack of involvement of disadvantaged groups of the population
- 2) Lack of validation of data captured under the equity dimension
- 3) Lack of understanding of the blanks in the map of evidence of osteoarthritis
- 4) Lack of validation of research questions derived from broad research topics
- 5) Lack of clarity of ownership of priority topics

### **5.3.1 Lack of involvement of disadvantaged groups of the population**

Although patients from different parts of the globe were involved in the priority setting exercise, it was a challenge to involve patients from low and middle income countries due to the lack of contacts in those countries. Even a greater challenge was to involve patients from disadvantaged groups of the population because they had neither the resources to travel to the location where the mapping workshops took place nor were connected to people that would be able to put them in touch with our research team. Patients that were involved in this process had been previously involved with Cochrane as volunteers in research activities and/or as reviewers of systematic reviews. This is a major issue given that in order to ensure health equity is in fact being addressed participation of disadvantaged countries and disadvantaged groups of the populations is required. Otherwise we risk addressing the needs only of those groups of the population that have the means and contacts to participate in Cochrane activities and consequently, have the power to influence decisions made by Cochrane.

Not tapping into the disadvantaged groups in society was a glaring omission of this study. Two ways in which future studies can incorporate the needs of disadvantaged groups of the population are:

- 1) By having patients from disadvantage groups of the population participate in the priority setting process. In order to ensure their participation, Cochrane will have to secure funds to obtain buy-in from patients and to pay for their related expenses throughout the process.
- 2) As suggested by the five-level framework developed by the Priority Public Health Conditions Knowledge Network, another way to address the needs of disadvantaged groups of the population is to incorporate a health equity dimension to all reviews conducted by Cochrane. Commitment

from senior management will be required to promote this approach across the CRGs, to develop appropriate techniques to incorporate equity into the standard methods and to evaluate the results in order to continue to improve the methods. Further details on how Cochrane can incorporate equity into systematic reviews are provided in Chapter 6.

**Recommendation 6:** In order to ensure health equity issues are addressed, secure funds and develop processes to incorporate patients from low and middle income countries and from disadvantaged groups of the population in the priority setting exercise.

### 5.3.2 Lack of validation of data captured under the equity dimension

Even when we were dealing with patients that had been previously involved with Cochrane, the concept of health equity was difficult for them to understand. The patients that participated in our process were above average in terms of their knowledge of systematic reviews and of the research process followed by Cochrane, yet when they were asked to complete the prioritization questionnaire several patients requested we explain what the concept of health equity meant. Furthermore, when analyzing the results we noted that the dimension of equity scored lower than the dimension of importance for every question for every survey that was completed. So, although we initially assumed that patients would be able to understand the concept of health equity based on the definition provided in the questionnaire, after responding to their questions and concerns in completing the on-line survey, we came to following conclusions:

- 1) The patients might not have understood the concept of health equity
- 2) The methodology lacked a process to verify whether patients understood the concept of health equity or not
- 3) If the patients did not understand the concept of health equity, the results generated through the survey could potentially be inaccurate

Some questions that were left outstanding at the end of the process were:

- What are the potential reasons for having the majority of patients score the dimension of equity lower than the dimension of importance?
- Did the patients understand the concept of health equity?
- Was the health equity dimension correctly captured in the on-line survey?

- Is it possible that the equity dimension scored lower due to the fact that the patients that participated in the process were not part of disadvantaged groups of the population and therefore, could not relate to the concept?

**Recommendation 7:** Validate that patients understand the concept of health equity before the prioritization survey is completed.

### 5.3.3 Lack of understanding of the blanks in the Map of Evidence for Osteoarthritis

At the end of the priority setting exercise there were some sections within the map of evidence that did not contain any priority topics. Two potential reasons for the lack of topics in these sections are:

- 1) Those that participated in the priority-setting exercise did not consider there were any “priority” topics in those areas
- 2) Those areas in the map were not clearly explained in the map of evidence, therefore, making it difficult for participants to identify priority topics in those sections.

Future priority setting exercises should consider validating with participants that they understand the scope of each section contained in the map of evidence. Thus, validating that priority topics are not being missed due to a lack of understanding by participants of the scope of topics contained within a particular section in the map of evidence.

**Recommendation 8:** Validate that participants understand the scope of research topics contained within each section of the map. This will help ensure priority topics are not being missed due to lack of comprehension.

### 5.3.4 Lack of validation of research questions derived from broad research topics

Converting the data collected in the brainstorming sessions into research terms (i.e. PICO terms) that could be used by Cochrane Review groups proved to be challenging. It was also a highly laborious and resource intensive task, consuming 1048 hours of effort. The difficulty lied in meeting the following two requirements:

- 1) Develop PICO terms that are consistent with the research topics and issues raised by participants at mapping workshops
- 2) Develop PICO terms that can be understood by the Cochrane Review Group that will carry out the systematic reviews

As we were trying to translate the input provided by patients into research questions we concluded it was easy to get deviated from the topic initially proposed, thus, requiring a step to validate that the research questions derived from the broad research topics reflect the original idea.

**Recommendation 9:** Validate research questions (i.e. PICO terms) derived from the broad research topics are in alignment with the original topic raised at a mapping workshop and are in terms that can be understood by the Cochrane Review Group that will carry out the systematic reviews.

### 5.3.5 Lack of clarity of ownership of priority topics

Demonstrating the impact that identified priorities have on the research work is essential in maintaining participants' involvement. However, after we met with Cochrane Review Groups to discuss who would own the priority topics that were identified through this exercise we concluded some topics would be left unaddressed. As a result, it will be difficult for the CMSG to maintain participants' involvement in the long term. In trying to identify the source of this issue, we realized that although the map of evidence provides a holistic view focused on the needs of patients with a particular condition (i.e. osteoarthritis) to help participants identify priorities, the Cochrane collaboration is not prepared to address research questions in this format. The Cochrane Review Groups that we met indicated they would not take ownership of the topics unless the wording of the research question was further modified. This should be done in order to make it consistent with their scope of work. The limited scope of work of the different Cochrane review groups limits the ownership of topics.

**Recommendation 10:** In order to ensure that the priority setting process is sustainable in the long term, when converting broad research topics into questions, involve other Cochrane Review Groups that could potentially be involved in owning the priority topics. This will increase the possibility of assigning ownership of each research topic to a CRG.

## 5.4 Thesis Contributions

The outcome of this research has both theoretical and practical importance.

From a theoretical perspective, it was important to include the social determinants of health and health equity into a priority setting process specifically designed for systematic review topics. This research work is different from previous priority setting exercises within Cochrane in that it explicitly attempts to contribute to reducing health inequity.

Another theoretical contribution is the "Map of evidence for Osteoarthritis", which was developed to inform the process by capturing existing evidence that related to both, the treatment of the condition and the social determinants of health that impact the condition. This map captured all

existing systematic reviews and identified the gaps in evidence. The analysis was conducted independently from the way in which Cochrane entities are organized in order to focus on the needs of those suffering of the condition and avoid introducing bias by trying to identify topics based on Cochrane's organizational structure. This approach is different from past work, which limited priority setting exercises to topics that would be of interest to one particular Cochrane Review Group. The map of evidence allows for a holistic view of the condition and the needs of decision-makers independently from the way in which the Cochrane Collaboration entities are organized.

We also incorporated health equity into the prioritization criteria which allowed us to test the feasibility of its usage by patients that were asked to rank the top 10 research questions. Several recommendations as to how the ranking process can be improved are included in this study. Finally, in terms of theoretical importance, the empirical validation of the following three conceptual frameworks contributed to the development of the underlying conceptual theories:

4. The Social Determinants of Health conceptual framework developed by the CSDH was used to systematically classify priority review topics that relate to social determinants of health. Using the framework we concluded that from 43 priority topics identified through this priority setting exercise, 25 could be classified under the social determinants of health. This allowed us to verify the methods had been successful in incorporating the social determinants of health into the decision-making process.
5. The five-level framework developed by the Priority Public Health Conditions Knowledge Network was used to suggest a level of health equity analysis for future systematic reviews. This framework provided a practical way of continuing to move the health equity agenda forward. By applying the framework we concluded all systematic review topics conducted by the Cochrane Collaboration could incorporate a level of analysis on health equity and social determinants of health. Thus, we recommend this to be incorporated as best practices in the Cochrane manual.
6. The "Framework for Successful Priority Setting",<sup>68</sup> was used to evaluate the process and the outcomes of our priority setting exercise. This framework provided a high-level analysis of the process but lacked input as to ways of dealing with what the evaluation framework identified as an issue. The evaluation process would be of more value if it offered suggestions to address the issues identified.

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<sup>68</sup> Sibbald SL, Singer PA, Upshur R, Martin DK. Priority setting: what constitutes success? A conceptual framework for successful priority setting. *BMC Health Serv Res* 2009; 9:43.

From a practical standpoint, we propose a sustainable priority setting method that can be utilized by all Cochrane Review groups to set priorities for systematic reviews on a continuous basis. Specific recommendations to streamline the priority setting method, such as converting broad research topics at the mapping workshops and not afterwards, are included in this study in order to increase the likelihood of its usage amongst all Cochrane entities.

#### **5.4.1 Applying the methods outside of Cochrane and the healthcare system**

The methods are portable to other organizations dedicated to producing systematic reviews, inside and outside of healthcare systems. For example, the Campbell collaboration dedicated to producing systematic reviews in education, crime and justice, and social welfare. Campbell currently has five Coordination groups: social welfare, crime and justice, educations, methods and the users group. The methods could help these Campbell groups identify existing reviews and priority topics. The concept of inequity (i.e. perspective of disadvantaged groups of the population) is still an important consideration in the topics addressed by the Campbell Collaboration.

## Chapter 6: EQUITY AND THE SOCIAL DETERMINANTS OF HEALTH (SDH)

### 6.1 Why develop a priority setting methodology for the Cochrane Collaboration that incorporates the Social Determinants of Health?

In August 2008, the final report published by the WHO Commission on the Social Determinants of Health (CSDH) suggested that underlying factors, or social determinants of health, such as level of income and level of education, can have an impact on the health of populations across the world. The CSDH, defines the social determinants of health as “the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices.” Because SDH factors originate from outside the boundaries of the healthcare system, health authorities will require the cooperation of institutions, organizations, and stakeholders outside of the health care sector to address the impact of these factors on ill health. The report of the CSDH also suggests that the social determinants of health are primarily responsible for health inequities, which are defined as the unfair and avoidable differences in health status seen within and between countries and amongst sub-groups of the population. An example of such situation is the continued development in low and middle income countries of a flexible workforce, which from an economic competitiveness perspective is seen as a good model, but from the perspective of those that are employed in it, there is a greater risk of having ill health consequences. Non-fixed term temporary contracts, being employed with no contract, and part-time work are examples of the terms offered to those employed in a flexible workforce<sup>69</sup>. Evidence indicates that mortality is significantly higher among these flexible workers compared to permanent workers.<sup>70</sup> As this scenario exemplifies, when looking to treat people with a particular condition, we should also analyze what is happening outside of the healthcare system in order to have a more complete picture of the situation and ultimately be able to intervene more effectively. Given the evidence suggesting that global health inequities are growing, the CSDH provided advice on addressing these inequities. The three broad recommendations were:

1. Improve daily living conditions
2. Tackle the inequitable distribution of power, money, and resources
3. Measure and understand the problem and assess the impact of action

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<sup>69</sup> Benach J & Muntaner C (2007). Precarious employment and health: developing a research agenda. *Journal of Epidemiology and Community Health*, 61:276-277.

<sup>70</sup> Kivimäki M et al. (2003). Temporary employment and risk of overall and cause-specific mortality. *American Journal of Epidemiology*, 158:663-668.

In their detailed recommendations, the CSDH encouraged both research and academic communities to provide support to the government and the public sector in taking action to measure and understand what social determinants impact the health of people and provide solutions as to how the inequities that are being generated can be addressed. In alignment with the recommendations put forward by the CSDH, in 2009 the World Health Assembly established that there is a global need to improve our understanding and development of policy to reduce inequities in health.<sup>71</sup> The Assembly also recognized the need to generate new, or make use of existing, research methods and evidence, tailored to national contexts. This nation-level knowledge would provide policy-makers with the data that they require to develop policy that addresses health inequities within their countries. The World Health Assembly also concluded, “there is little guidance available internationally to assist policy-makers and practitioners to act on the full range of social determinants,” and called upon the international community, urging WHO Member States to tackle health inequities within and across countries. Action is required both, at a national and an international level, in order to effectively address health inequity.

One objective of this thesis is to respond to the CSDH recommendations and the World Health Assembly call for action, by accomplishing the following three directives:

- 1) Understand the current status of existing systematic reviews for a particular condition as it refers to the social determinants of health
- 2) Develop a methodology for the Cochrane Collaboration to identify research priorities for systematic reviews that takes into account the social determinants of health
- 3) Help bridge the gap between the new knowledge generated from this thesis and the action that needs to be taken by Cochrane decision-makers. This will be done by suggesting a practical way of incorporating health equity into the systematic review topics that were prioritized.

## **6.2 How were the social determinants of health and health equity incorporated into the methods?**

The methodology developed for this thesis incorporates the social determinants of health and health equity in several ways.

1. It provides a framework to identify any existing systematic reviews on the social determinants of health that impact the condition.

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<sup>71</sup> Kelly PM et al. *The social determinants of health: developing an evidence base for political action*. Final Report of the Measurement and Evidence Knowledge Network to the Commission on Social Determinants of Health. Geneva, World Health Organization, 2007.

2. When conducting the priority setting workshops, the method forces a discussion on social determinants of health and health equity issues related to the condition.
3. It incorporates health equity into the final prioritization criteria.
4. It analyses and classifies priority topics based on the Social Determinants of Health conceptual framework developed by the CSDH.
5. It suggests a level of analysis of health equity to be incorporated when conducting future systematic reviews on the priority topics identified through this research effort.

Figure 6.1(below) provides a visual representation of steps one through five (listed above) that represent the main activities carried out to identify research priorities. The methods were piloted with the Cochrane Musculoskeletal Review Group (CMSG) and Osteoarthritis was the medical condition used to test the methods. Details on how the review group and the condition were selected are provided in Chapter 3, Section 3.2 Selecting a Collaborative Review Group and a Medical Condition to Test the Methods. The five sections below (6.2.1 – 6.2.5) will provide details on how the social determinants of health and health equity were incorporated in each one of the five main steps of this methodology.

### **6.2.1 Identifying Existing Evidence**

As indicated in Figure 6.1, the first step in this process was to discover existing evidence. The main objective of this step was to inform the priority setting process by identifying all existing systematic reviews relevant to osteoarthritis and to present the information in a way that would be meaningful for individuals participating in the process. In order to accomplish this objective, we first searched the literature for existing frameworks that provided a blueprint to improve the quality of life of people living with osteoarthritis. We found only one framework that was specific for Osteoarthritis and that incorporated a holistic view of the condition from both, a patient and a health systems perspective. Also, the comprehensive design of the framework made it relatively simple to add the social determinants of health. We called this framework the “Map of Evidence for Osteoarthritis”. Chapter 4, section 4.1.7.1.1 Building the Map of Evidence for Osteoarthritis describes how the map was built and provides a copy of the resulting map.

The resulting map of evidence included a section on social determinants of health for all the stages of the condition (population at risk of developing osteoarthritis to the advanced stages of osteoarthritis), which allowed us to classify in a section of its own, previous systematic reviews that addressed social determinants of health for Osteoarthritis. After the literature search was completed, the map of evidence contained three systematic reviews classified under lifestyle changes that somewhat relate to social determinants of health. However, we did not find any systematic reviews that

specifically addressed topics on social determinants of health for Osteoarthritis; therefore, this section of the map was left blank.

## **6.2.2 Identifying Priorities**

As indicated in figure 6.1 (below), the second step in this process was to identify priority research topics. The objective was two-fold: 1) to brainstorm to identify topics of interest and 2) to identify the top priority research topics. In order to accomplish this we first conducted two “mapping workshops” and then consulted with twelve clinical experts on osteoarthritis. The social determinants of health were incorporated both into the mapping workshops and into the consultations with experts. The process followed to incorporate the social determinants of health into the consultations with experts is explained in section 6.2.2.1 (below) and into the mapping workshops is explained in section 6.2.2.2 (below).

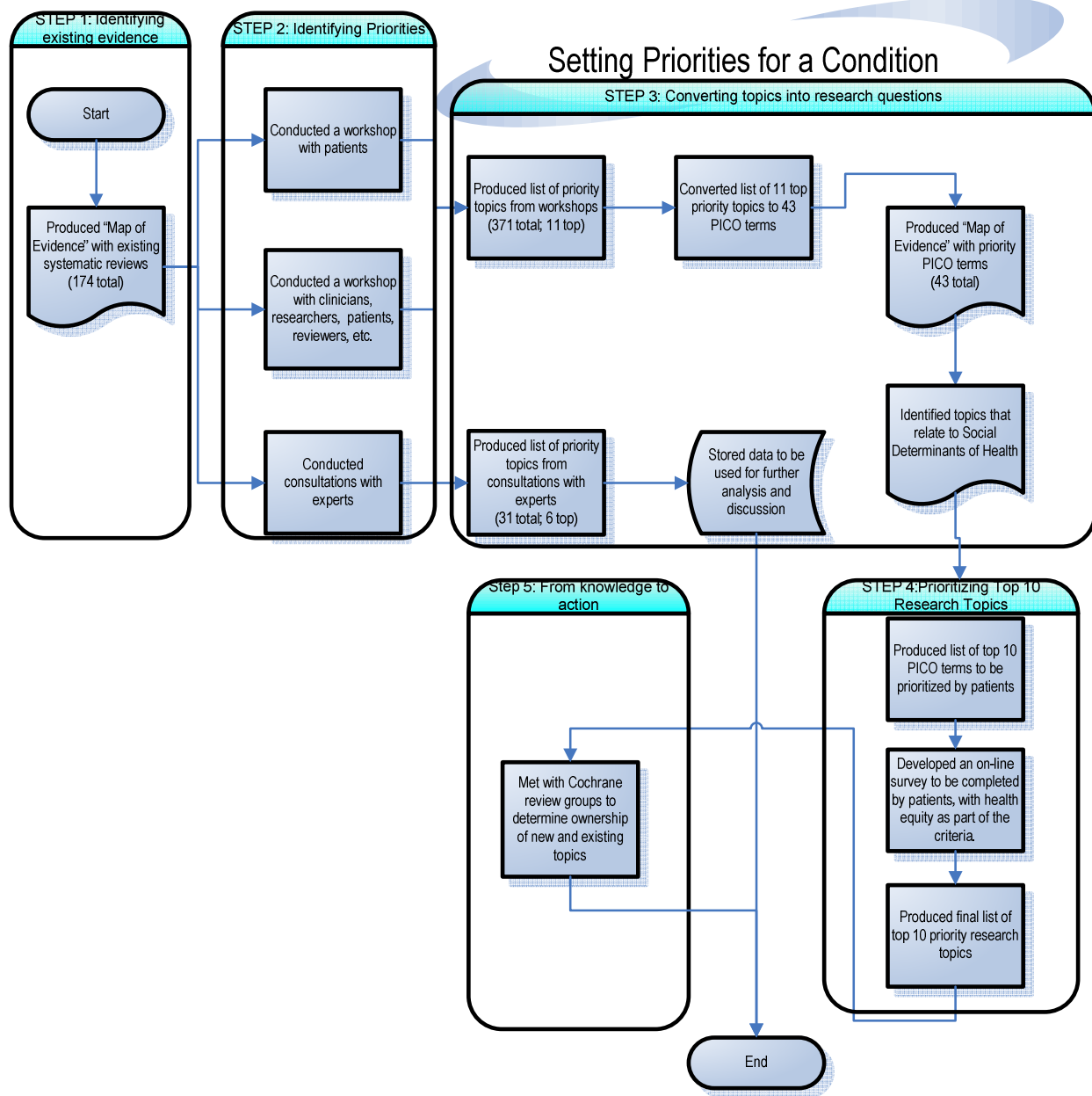
### **6.2.2.1 Incorporating the SDH into the Consultations with Experts**

The social determinants of health were incorporated into the consultations by providing the experts with a copy of the Map of Evidence for Osteoarthritis. This map provided a visual representation of existing systematic reviews on osteoarthritis and of the gaps in literature, such as the section on social determinants of health. Experts were asked to review the Map of Evidence for Osteoarthritis and determine, based on their personal point of view, the top three research topics that the CMSG should work on next. A total of twelve (12) experts in osteoarthritis were consulted, who identified thirty-one (31) priority topics. From the thirty-one (31) research topics raised by clinical experts, two (2) were identified as top priority by at least 4 experts. The two topics are:

- Exercise: as a preventive measure and as a formal treatment plan for people with OA (including dosage, types, etc.)
- Risk reduction among the well: Social economic factors impacting OA; what are the most significant ones? What are the main lifestyle changes that need to be done to have an impact on prevention?

The wording used to describe these two research topics reflects the wording used by clinicians during the consultations. The research topics were not converted into any particular research format. Chapter 4, Section 4.1.7.2.2 Consultations with Experts, provides details on the process that was followed when consulting with clinical experts and provides a detailed list of all priority topics identified through the consultations.

Figure 6. 1 Representation of the Priority Setting Methodology



### 6.2.2.2 Incorporating the SDH into the Workshops

Two workshops were conducted during the 2009 Cochrane Colloquium to identify research priorities for osteoarthritis. The first workshop was exclusively for patients. The second workshop incorporated input from researchers, clinicians, and patients. Seven (7) patients participated in the “patient-only” workshop, while twenty-one (21) participants attended the second workshop.

In order to ensure all stages of the conditions were covered when proposing research topics, the two brainstorming sessions were guided by a facilitator. The facilitator asked participants to provide

priority topics for each stage of the development of Osteoarthritis, starting with “Reducing Risk in the well community,” and ending with the “Advanced Stages of Osteoarthritis.” All the stages of Osteoarthritis were taken from the map of evidence that was developed. The map of evidence is described in Chapter 4, Section 4.1.3 Map of Evidence for Osteoarthritis including Social Determinants of Health. To ensure participants considered the social determinants of health during the workshops, the facilitator stimulated a discussion regarding contextual factors, in which participants were asked to specify what factors would influence the feasibility, interventions, outcomes, or other aspects of care (for example, rural or urban location, socioeconomic status, distance, availability of services). This information was documented as the sessions were being conducted.

Participants were encouraged to identify as many priority topics as they considered necessary based on their personal judgement. After the brainstorming session, all research topics were organized on the board by broad topics and by stage of the condition. Subsequently, participants were asked to identify with a red dot those that they considered were the top priorities. Following the original GEM methods, participants were only given five red dots each to identify the top priorities. During the two workshops, 371 priority research topics were identified; however, only eleven were identified as top priorities. Chapter 4, Section 4.1.7.2.1 Mapping Workshops provides a detailed explanation on how the mapping workshops were conducted.

### 6.2.3 Converting Topics into Research Questions

The top eleven broad research topics identified at the workshops were then converted into research questions with the assistance of the Cochrane Musculoskeletal Group and a consumer/patient representative. The main objective of this conversion was to take the information that was provided by participants during the workshops on the post it notes and during the discussions, and to put it in a format that could be used by the Cochrane Musculoskeletal Group to conduct the systematic review. The format that was used is referred to as PICO format, which stands for Population, Intervention, Comparison, and Outcome Measured. Details on the conversion process and those that took part in the process are provided in Chapter 4, Section 4.1.7.3 Converting topics into research questions. A total 43 research questions were derived from the top 11 priority topics. The complete list containing the 43 research questions is contained in Table 6.1 below.

**Table 6. 1 Listing of 43 Research Questions**

Research Questions
1. Communication interventions directed to patients to increase awareness of long-term self-management approaches in treating osteoarthritis.
2. Educational interventions to change the behaviour in patients to increase the level of understanding

of long-term self-management approaches in treating osteoarthritis.

3. Educational interventions to change the behaviour in patients to increase the uptake of self-management approaches in treating osteoarthritis.
4. Educational interventions to change the behaviour in patients to increase adherence to long-term self-management approaches in treating osteoarthritis.
5. Educational interventions directed to osteoarthritis patients to increase the level of understanding of the need for continual & on-going treatment.
6. Lifestyle-related interventions aimed at people who have not been diagnosed with the condition to reduce the risk of developing osteoarthritis.
7. Communication interventions to increase the level and quality of communication of inter-professional teams involved in treating osteoarthritis patients.
8. Communication interventions to improve the quality and level of communication between osteoarthritis patients and their health care providers.
9. Health promotion interventions aimed at people who have not been diagnosed with the condition to increase the adoption of disease prevention approaches.
10. Health promotion interventions aimed at people who have not been diagnosed with the condition to increase the adherence of disease prevention approaches.
11. Knowledge transfer interventions directed to health practitioners to increase the level of understanding of osteoarthritis preventive measures available to people at risk.
12. Knowledge transfer interventions directed to public health policy-makers to improve the quality and availability of education tools and information on preventive measures.
13. Non-pharmacologic interventions to prevent the progression of osteoarthritis in patients with early-stage osteoarthritis.
14. Pharmacologic interventions to prevent the progression of osteoarthritis in patients with early-stage osteoarthritis.
15. Complementary and alternative therapies to prevent the progression of osteoarthritis in patients with early-stage osteoarthritis.
16. Health systems interventions to reduce inequities in waiting times at a national level for joint replacement surgery in people with osteoarthritis.
17. Health systems interventions to reduce barriers to surgery in disadvantaged groups of people with osteoarthritis.
18. Knowledge transfer interventions aimed at health care practitioners to reduce the gaps in knowledge about issues associated with delays in surgery specific to disadvantaged groups of people with osteoarthritis.
19. Knowledge transfer interventions aimed at policy-makers to reduce the gaps in knowledge about issues associated with delays in surgery specific to disadvantaged groups of people with osteoarthritis.
20. Knowledge transfer interventions aimed at disadvantaged groups of people with osteoarthritis to reduce the gaps in knowledge about issues associated with delays in surgery as a treatment option.
21. Decision-aid interventions to reduce health care practitioner conflict about timing of joint replacement in treating people with osteoarthritis.
22. Decision-aid interventions to aid health practitioners discuss options with people with OA who are having decisional conflict about joint replacement surgery
23. Decision-aid interventions to reduce patient decisional conflict about timing of joint replacement in treating osteoarthritis
24. Decision support interventions to increase patient participation in the decision-making process to develop and implement a treatment plan for people with osteoarthritis. (Increase patient participation in the decision-making process

25. Population health interventions to reduce the psychosocial impact of osteoarthritis in people living with the condition.
26. Peer support interventions for communication between consumers to reduce the psychosocial impact of osteoarthritis in people living with the condition.
27. Skills training interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition.
28. Social support interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition.
29. Information provision interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition.
30. Cross-sectoral interventions to reduce the psychosocial impact of osteoarthritis in people living with the condition.
31. Lifestyle-related interventions to reduce the economic burden of osteoarthritis in people living with the condition.
32. Cross-sectoral interventions (interventions where the science, technology, engineering and medicine sectors collaborate with member of the humanities, arts and social sciences) to reduce the economic burden of osteoarthritis in people living with the condition.
33. Workplace interventions to reduce the economic burden of osteoarthritis in people living with the condition.
34. Weight management for the treatment of osteoarthritis
35. Weight management as a risk reduction strategy for osteoarthritis
36. Weight management as a preventive measure for those at high-risk of developing osteoarthritis
37. Obesity reduction versus other non-pharmacologic treatments in treating osteoarthritis
38. Methods for incorporating patient preference in the measurement of intervention effectiveness for treating osteoarthritis.
39. Knowledge dissemination interventions to improve the quality and accessibility of information on treatment options available to people with osteoarthritis.
40. Health promotion interventions to increase knowledge transfer to patients of treatment options available in treating people with osteoarthritis
41. Knowledge dissemination interventions to improve the quality and accessibility of information on the level of effectiveness of treatment options available to people with osteoarthritis.
42. Educational interventions to increase the quality and level of awareness and understanding in health practitioners of the desirable and undesirable side effects of drugs used to treat people with osteoarthritis.
43. Knowledge dissemination interventions to increase the quality and level of awareness and understanding in people with osteoarthritis of the desirable and undesirable side effects of drugs used to treat the condition.

During the first analysis of the results of the mapping workshops, we were able to identify that a majority of these 43 research questions related to non-clinical aspects of Osteoarthritis and/or in order to address them it would be necessary to go outside the boundaries of the health care system. The next step was to confirm, in an objective way, whether the questions were in fact related to social determinants of health or not, which we did only once the entire priority setting exercise was completed. The verification process consisted of comparing each question against the conceptual

framework developed by the CSDH. Section 6.2.5.1 later on in this chapter, provides a detailed explanation of the framework and on how the comparison and verification process was conducted. The results of this analysis demonstrated that 25 out of the 43 questions were in fact related to social determinants of health. Below is the distribution of research questions that relate to the Social Determinants of Health (SDH) per stage of the condition and from the highest number to the lowest number of questions:

- 16 SDH research questions were identified that apply **across all stages** of OA
- 4 SDH research questions were identified relate to **reducing risk/preventing** OA
- 3 SDH research questions were identified that relate to the **advanced stages** of OA

2 SDH research questions were identified that relate to the **long term management** of OA

Once the 43 questions were drafted in PICO format, we incorporated them into the Map of Evidence to be able to classify the data. The “Map of Evidence” containing the 43 research questions, including those that relate to social determinants of health, is presented and explained in Chapter 4, Section 4.1.7.3. 1 Map of Evidence with priority research questions.

### 6.2.4 Prioritizing the Top 10 Research Questions

Step four of the process was to identify the top 10 research questions to be worked on next and prioritize them. This was important given that not all 43 research questions developed in the previous step could be addressed at once. Chapter 4, “Section 4.1.7.4 Prioritizing the top ten research questions”, provides a detailed explanation on how the top ten topics were identified. The method applied followed a similar structure as the mapping workshops by selecting topics that were identified as the highest priority by patients. Once the top 10 questions were selected, we developed a survey that was completed by patients to rank the top 10 research questions in order of priority. Patients were asked to rank each one of the questions for two dimensions: 1) importance and 2) equity. The questions are included in table 6.2 below.

**Table 6. 2 Questions asked in on-line patient questionnaire**

<b>Importance:</b> <i>How important is this question?</i>
<b>Equity/ Social Determinants:</b> <i>To what degree does the question address the health needs of populations across different social gradients as defined by the <b>PROGRESS</b> framework (i.e. <b>P</b>lace of residence; <b>R</b>ace, ethnicity, and culture; <b>O</b>ccupation; <b>G</b>ender; <b>R</b>eligion; <b>E</b>ducation; <b>S</b>ocioeconomic status; and <b>S</b>ocial capital)?</i>

The list of top 10 research questions and the quantitative results of the ranking exercise (in a scale from 1 to 4, with 1 being the lowest and 4 being the highest number) are included in table 6.3 below. Column B in the table includes the average level of importance as identified by patients for each particular question. Column C includes the level to which patients considered the question was addressing the needs of the population across different social gradients and column D includes an average of the two results for each question. The questions were ranked from the highest combined ranking (level of importance and level of equity) to the lowest. Important to note is that the second highest ranking question is related to health inequities experienced by osteoarthritis patients in accessing joint replacement surgery.

**Table 6. 3 Top 10 Research Questions**

A	B	C	D
Question	Importance	Equity	Average
1. Communication interventions to improve the quality and level of communication between osteoarthritis patients and their health care providers.	3.69	3.18	3.435
2. Health systems interventions to reduce inequities in waiting times at a national level for joint replacement surgery in people with osteoarthritis.	3.53	3.25	3.39
3. Decision support interventions to increase patient participation in the decision-making process to develop and implement a treatment plan for people with osteoarthritis.	3.59	3.1	3.345
4. Educational interventions to change the behaviour in patients to increase adherence to long-term self-management approaches in treating osteoarthritis.	3.55	3.1	3.325
5. Educational interventions to change the behaviour in patients to increase the uptake of self-management approaches in treating osteoarthritis.	3.61	2.98	3.295
6. Communication interventions to increase the level and quality of communication of inter-professional teams involved in treating osteoarthritis patients.	3.55	2.88	3.215

A	B	C	D
Question	Importance	Equity	Average
7. Educational interventions directed to osteoarthritis patients to increase the level of understanding of the need for continual & on-going treatment.	3.49	2.92	3.205
8. Communication interventions directed to patients to increase awareness of long-term self-management approaches in treating osteoarthritis.	3.43	2.94	3.185
9. Lifestyle-related interventions aimed at people who have not been diagnosed with the condition to reduce the risk of developing osteoarthritis.	3.39	2.86	3.125
10. Decision-aid interventions to reduce health care practitioner conflict about timing of joint replacement in treating people with osteoarthritis.	3.25	2.78	3.015

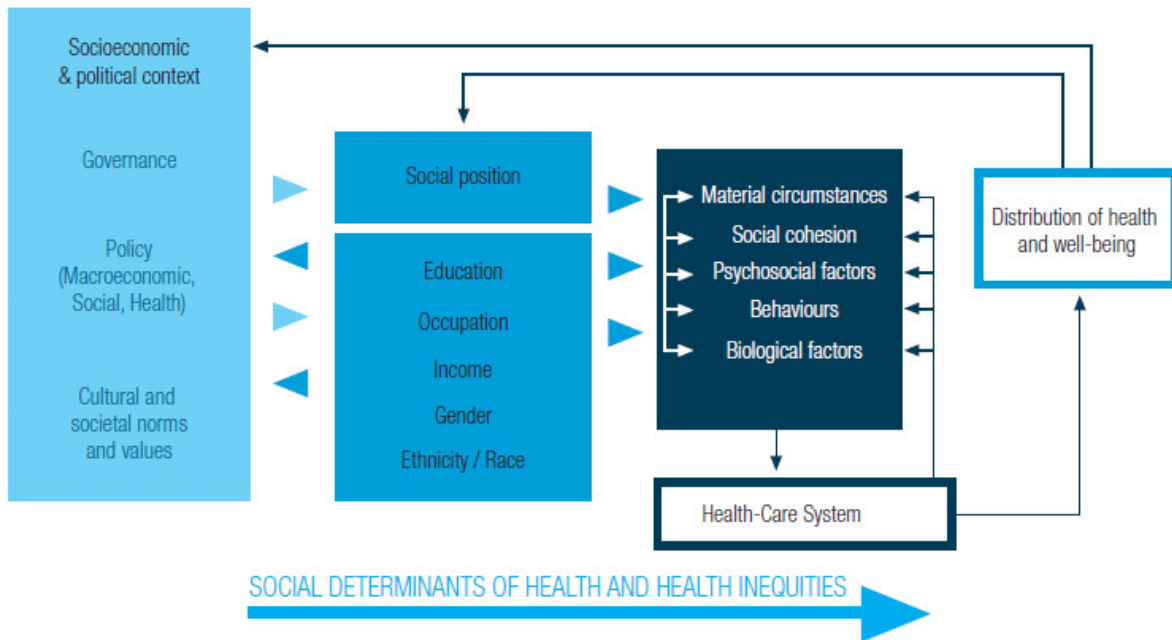
### 6.2.5 From Knowledge to Action

In order to help move forward the agenda on social determinants of health, in this section we propose an objective and systematic way of classifying research questions under the social determinants of health and a method to incorporate health equity into future systematic reviews.

#### 6.2.5.1 Identifying research questions that fall under the social determinants of health

The conceptual framework developed by the SDHC (Figure 2, below) was used as a basis to determine whether a research question should be classified or not under the social determinants of health. Each research question, and any additional information provided by research participants during the workshops, was compared against the conceptual framework. The purpose of the comparison was to identify those topics that related to one or more of the underlying factors identified in the conceptual framework. If a topic required data on at least one of the underlying factors identified in the conceptual framework to answer the question, then it would be classified under the social determinants of health. For example, when analyzing the question: “Lifestyle-related interventions aimed at people who have not been diagnosed with the condition to reduce the risk of developing osteoarthritis”, we concluded the following underlying factors would need to be addressed in order to address the question: “social position, education, occupation, income, gender, ethnicity/race”, therefore, the question would be classified as a question that relates to social determinants of health.

Figure 6. 2 Commission on Social Determinants of Health Conceptual Framework



Source: CSDH (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health.* Geneva, World Health Organization.

Table 6.4 below contains a listing of all the 25 questions that were classified under the social determinants of health. Column A provides the wording of the research question and Column B provides a listing of the underlying factors that relate to the question.

Table 6. 4 List of Priority Topics that relate to the Social Determinants of Health

Column A	Column B
Priority Topics	CSDH Conceptual Framework
1. Health promotion interventions aimed at people who have not been diagnosed with the condition to increase the adoption of disease prevention approaches	Social position: education, occupation, income, gender, ethnicity/race
2. Health promotion interventions aimed at people who have not been diagnosed with the condition to increase the adherence of disease prevention approaches	Social position: education, occupation, income, gender, ethnicity/race
3. Knowledge transfer interventions directed to public health policy-makers to improve the quality and	Socioeconomic and political context: Policy

<b>Column A</b>	<b>Column B</b>
<b>Priority Topics</b>	<b>CSDH Conceptual Framework</b>
availability of education tools and information on preventive measures	(macroeconomic, social, health)
4. Lifestyle-related interventions aimed at people who have not been diagnosed with the condition to reduce the risk of developing osteoarthritis	Social position: education, occupation, income, gender, ethnicity/race
5. Educational interventions to change the behaviour in patients to increase the level of understanding of long-term self-management approaches in treating osteoarthritis	Education + behaviours
6. Educational interventions to change the behaviour in patients to increase adherence to long-term self-management approaches in treating osteoarthritis	Education + behaviours
7. Knowledge transfer interventions aimed at health care practitioners to reduce the gaps in knowledge about issues associated with delays in surgery specific to disadvantaged groups of people with osteoarthritis	Health-care system
8. Knowledge transfer interventions aimed at policy-makers to reduce the gaps in knowledge about issues associated with delays in surgery specific to disadvantaged groups of people with osteoarthritis	Socioeconomic and political context: Policy (macroeconomic, social, health)
9. Knowledge transfer interventions aimed at disadvantaged groups of people with osteoarthritis to reduce the gaps in knowledge about issues associated with delays in surgery as a treatment option	Social position: education, occupation, income, gender, ethnicity/race + health-care system
10. Educational interventions to change the behavior in patients to increase the uptake of self-management approaches in treating osteoarthritis	Education + behaviours

<b>Column A</b>	<b>Column B</b>
<b>Priority Topics</b>	<b>CSDH Conceptual Framework</b>
11. Educational interventions directed to osteoarthritis patients to increase the level of understanding of the need for continual & on-going treatment	Education + behaviours
12. Population health interventions to reduce the psychosocial impact of osteoarthritis in people living with the condition	Social cohesion + psychosocial factors
13. Skills training interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition	Social cohesion + psychosocial factors
14. Social support interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition	Social cohesion + psychosocial factors
15. Cross-sectoral interventions to reduce the psychosocial impact of osteoarthritis in people living with the condition	Socioeconomic and political context: Policy (macroeconomic, social, health)+ Psychosocial factors + social cohesion
16. Lifestyle-related interventions (e.g. diet, exercise, or diet plus exercise) to reduce the economic burden of osteoarthritis in people living with the condition	Behaviours
17. Cross-sectoral interventions (interventions where the science, technology, engineering and medicine sectors collaborate with member of the humanities, arts and social sciences) to reduce the economic burden of osteoarthritis in people living with the condition	Socioeconomic and political context: Policy (macroeconomic, social, health)
18. Workplace interventions to reduce the economic burden of osteoarthritis in people living with the	Income + material circumstances

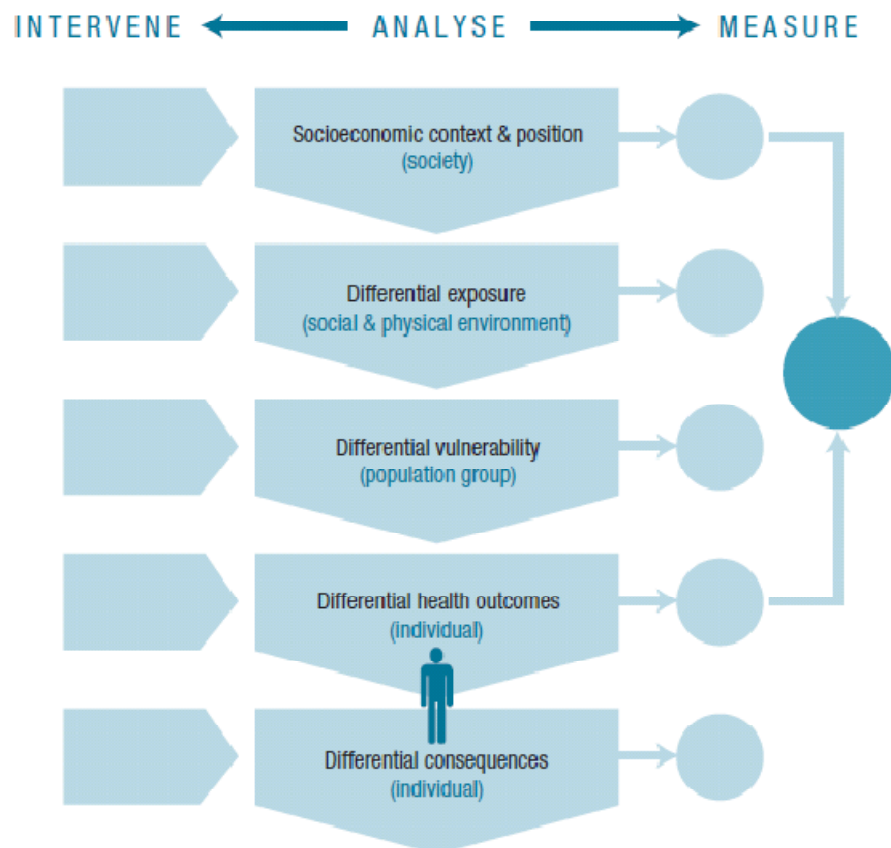
<b>Column A</b>	<b>Column B</b>
<b>Priority Topics</b>	<b>CSDH Conceptual Framework</b>
condition	
19. Health promotion interventions to increase knowledge transfer to patients of treatment options available in treating people with osteoarthritis	Education
20. Decision support interventions to increase patient participation in the decision-making process to develop and implement a treatment plan for people with osteoarthritis. (Increase patient participation in the decision-making process).	Health-care system
21. Methods for incorporating patient preference in the measurement of intervention effectiveness for treating osteoarthritis	Health-care system
22. Health systems interventions to reduce inequities in waiting times at a national level for joint replacement surgery in people with osteoarthritis	Health-care system
23. Health systems interventions to reduce barriers to surgery in disadvantaged groups of people with osteoarthritis	Health-care system
24. Peer support interventions for communication between consumers to reduce the psychosocial impact of osteoarthritis in people living with the condition	Psychosocial factors + social cohesion
25. Information provision interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition	Psychosocial factors + social cohesion

### 6.2.5.2 Suggesting Next Steps for Future Systematic Reviews

After we identified questions that could be classified under social determinants of health, we used the five-level framework, developed by the Priority Public Health Conditions Knowledge Network, to analyze the topics and propose a level of analysis to be incorporated into each systematic review. A visual representation of the five-level framework developed by the Priority Public Health Conditions Knowledge Network is contained in Figure 3 (below). The framework proposes three dimensions of activity (analyze, intervene and measure) and five levels of analysis. Each level of analysis is described below, including an action plan for each.

1. **Socio-economic context and position (structure of society):** Social position exerts a powerful influence on the type, magnitude, and distribution of health in societies. The **health care sector** should aim to gain a better understanding of stratification in order to effectively reduce health inequities.

Figure 6. 3 Five-level framework developed by the Priority Public Health Conditions Knowledge Network



2. **Differential exposure (environment):** Exposure to most risk factors (material, psychosocial, and behavioural) is inversely related to social position. Health programs that differentiate and analyze **risk factors by socioeconomic group**, in order to understand “the causes behind the causes” should be promoted.
3. **Differential vulnerability (population groups):** In addition to socioeconomic causes, there are amplifying factors, which are **other social, cultural, and economic environments and cumulative life course factors** that impact health. These amplifying factors are present in low-income populations and marginalized groups. The proposed course of action is to reduce or eliminate the amplifying factors by identifying appropriate entry-points for breaking the vicious cycles found in vulnerable populations.

4. **Differential healthcare outcomes (individual):** Everyone in need of care should **receive it in the most appropriate form regardless of their social position or social circumstances**. Systematic differences in health outcomes between different socioeconomic groups should be reduced in a way that allows all individuals to enjoy the health of the most advantaged.
5. **Differential consequences (individual):** Poor health may have several **social and economic consequences**, including loss of earnings, loss of ability to work, and social isolation or exclusion. Disadvantaged individuals in ill-health might suffer further socioeconomic degradation, crossing the poverty line, and accelerating in a downward spiral that further damages health. The proposed course of action is to identify appropriate entry-points for breaking the vicious cycles in which both, **ill-health and vulnerable populations**, find themselves trapped.

Each one of the questions that was classified under the social determinants of health was analyzed to determine what level of health equity analysis was best suited for the research question. Section 6.2.5.3 below provides a the results of such analysis.

### 6.2.5.3 List of Questions that Relate to SDH and Proposed Course of Action for Future Systematic Reviews

Table 6.4 (below) summarizes the research questions that relate to social determinants by stage of the condition, the classification of each question under the CSDH conceptual framework, and the proposed level of analysis to be incorporated into the systematic reviews based on the Five-level framework. A key finding from this exercise is the empirical validation of the five-level framework. By applying the framework we were able to propose a practical way of incorporating an equity analysis into all the systematic reviews identified through this exercise. The summary of this analysis was presented to the CMSG, who considered this to be an important part of the exercise as it provided a practical way of moving forward with the health equity agenda.

**Table 6. 5 Recommended Level of Analysis to address Health Equity in Future Systematic Reviews**

Column A	Column B	Column C
Priority Topics	CSDH Conceptual Framework	Recommended Level of Analysis
<b>Social determinants of health - applicable to a particular stage of the condition</b>		
<b>Stage: Reduce Risk</b>		
1. Health promotion interventions aimed at people who have not been diagnosed	Social position: education, occupation,	Differential exposure & differential vulnerability

Column A	Column B	Column C
Priority Topics	CSDH Conceptual Framework	Recommended Level of Analysis
with the condition to increase the adoption of disease prevention approaches	income, gender, ethnicity/race	
2. Health promotion interventions aimed at people who have not been diagnosed with the condition to increase the adherence of disease prevention approaches	Social position: education, occupation, income, gender, ethnicity/race	Differential exposure & differential vulnerability
3. Knowledge transfer interventions directed to public health policy-makers to improve the quality and availability of education tools and information on preventive measures	Socioeconomic and political context: Policy (macroeconomic, social, health)	Socioeconomic context and position
4. Lifestyle-related interventions aimed at people who have not been diagnosed with the condition to reduce the risk of developing osteoarthritis	Social position: education, occupation, income, gender, ethnicity/race	Socio-economic context and position; differential exposure; differential vulnerability;
<b>Stage: Long-term Management</b>		
5. Educational interventions to change the behaviour in patients to increase the level of understanding of long-term self-management approaches in treating osteoarthritis	Education + behaviours	Differential healthcare outcomes
6. Educational interventions to change the behaviour in patients to increase	Education + behaviours	Differential healthcare outcomes

Column A	Column B	Column C
Priority Topics	CSDH Conceptual Framework	Recommended Level of Analysis
adherence to long-term self-management approaches in treating osteoarthritis		
<b>Stage: Advanced Stages</b>		
7. Knowledge transfer interventions aimed at health care practitioners to reduce the gaps in knowledge about issues associated with delays in surgery specific to disadvantaged groups of people with osteoarthritis	Health-care system	Socioeconomic context and position & differential vulnerability
8. Knowledge transfer interventions aimed at policy-makers to reduce the gaps in knowledge about issues associated with delays in surgery specific to disadvantaged groups of people with osteoarthritis	Socioeconomic and political context: Policy (macroeconomic, social, health)	Socioeconomic context & differential vulnerability
9. Knowledge transfer interventions aimed at disadvantaged groups of people with osteoarthritis to reduce the gaps in knowledge about issues associated with delays in surgery as a treatment option	Social position: education, occupation, income, gender, ethnicity/race + health-care system	Differential consequences
<b>Social determinants of health - applicable to more than one stage of the condition</b>		
10. Educational interventions to change the behavior in patients to increase the uptake of self-management approaches in treating osteoarthritis	Education + behaviours	Differential healthcare outcomes

<b>Column A</b>	<b>Column B</b>	<b>Column C</b>
<b>Priority Topics</b>	<b>CSDH Conceptual Framework</b>	<b>Recommended Level of Analysis</b>
11. Educational interventions directed to osteoarthritis patients to increase the level of understanding of the need for continual & on-going treatment	Education + behaviours	Differential healthcare outcomes
12. Population health interventions to reduce the psychosocial impact of osteoarthritis in people living with the condition	Social cohesion + psychosocial factors	Differential consequences
13. Skills training interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition	Social cohesion + psychosocial factors	Differential consequences
14. Social support interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition	Social cohesion + psychosocial factors	Differential consequences
15. Cross-sectoral interventions to reduce the psychosocial impact of osteoarthritis in people living with the condition	Socioeconomic and political context: Policy (macroeconomic, social, health)+ Psychosocial factors + social cohesion	Differential consequences
16. Lifestyle-related interventions (e.g. diet, exercise, or diet plus exercise) to reduce the economic burden of osteoarthritis in people living with the condition	Behaviours	Differential consequences:

Column A	Column B	Column C
Priority Topics	CSDH Conceptual Framework	Recommended Level of Analysis
<p>17. Cross-sectoral interventions (interventions where the science, technology, engineering and medicine sectors collaborate with member of the humanities, arts and social sciences) to reduce the economic burden of osteoarthritis in people living with the condition</p>	<p>Socioeconomic and political context: Policy (macroeconomic, social, health)</p>	<p>Differential consequences:</p>
<p>18. Workplace interventions to reduce the economic burden of osteoarthritis in people living with the condition</p>	<p>Income + material circumstances</p>	<p>Differential consequences:</p>
<p>19. Health promotion interventions to increase knowledge transfer to patients of treatment options available in treating people with osteoarthritis</p>	<p>Education</p>	<p>Differential healthcare outcomes</p>
<p>20. Decision support interventions to increase patient participation in the decision-making process to develop and implement a treatment plan for people with osteoarthritis. (Increase patient participation in the decision-making process</p>	<p>Health-care system</p>	<p>Differential healthcare outcomes</p>
<p>21. Methods for incorporating patient preference in the measurement of intervention effectiveness for treating osteoarthritis</p>	<p>Health-care system</p>	<p>Differential healthcare outcomes</p>

Column A	Column B	Column C
Priority Topics	CSDH Conceptual Framework	Recommended Level of Analysis
22. Health systems interventions to reduce inequities in waiting times at a national level for joint replacement surgery in people with osteoarthritis	Health-care system	Differential healthcare outcomes
23. Health systems interventions to reduce barriers to surgery in disadvantaged groups of people with osteoarthritis	Health-care system	Differential healthcare outcomes
24. Peer support interventions for communication between consumers to reduce the psychosocial impact of osteoarthritis in people living with the condition	Psychosocial factors + social cohesion	Differential consequences
25. Information provision interventions directed to the consumer to reduce the psychosocial impact of osteoarthritis in people living with the condition	Psychosocial factors + social cohesion	Differential consequences

### 6.3 Conclusions reached from incorporating Health Equity and Social Determinants of Health into the prioritization exercise

Throughout this chapter we explained how this thesis incorporated the social determinants of health and health equity as we established research priorities for osteoarthritis. There were five key modifications made to the methods in order to do so. The five bullet points below summarize the methodological pieces that were added to the original GEM methods in order to address health equity and the results obtained through the priority setting exercise as we piloted the methods for osteoarthritis.

1. In order to inform the process we developed a framework, called map of evidence for osteoarthritis, to identify and classify existing systematic reviews that related to social determinants of health. The resulting map of evidence showed no systematic reviews on social determinants of health existed.
2. When conducting the priority setting workshops, the method forced a discussion on social determinants of health and health equity issues related to the condition. This information was captured in order to develop (later on) research questions from each broad research topic and to determine whether the question related to social determinants of health or not. See point 4 below for further details.
3. We incorporated health equity as prioritization criteria in the on-line survey that was used by patients to rank the top 10 research questions. Patients were asked to rank questions depending on what they thought was the level to which the question addressed the needs of populations across different social gradients. The higher the level, the higher the ranking the question received. The CMSG will work first on the highest ranking research question, which allows us to conclude that the level of health equity of the question actively influenced the process.
4. We analyzed and classified priority topics based on the Social Determinants of Health conceptual framework in order to objectively and systematically identify research questions that resulted from the prioritization exercise and that related to social determinants of health. From a total of 43 research questions that were developed as part of this prioritization exercise, 25 related to social determinants of health.
5. Using the five-level framework developed by the Priority Public Health Conditions Knowledge Network, we suggested a level of health equity analysis to be incorporated when conducting systematic reviews on the topics identified through this research effort. The CMSG found this to be very useful as it provided a practical way of moving the health equity agenda forward.

Although we are able to conclude based on this five points above that the process effectively incorporated the social determinants of health and health equity in setting research priorities for osteoarthritis, two recommendations can be made to improve the process:

- 1) In order to ensure health equity issues are addressed, secure funds and develop processes to incorporate patients from low and middle income countries and from disadvantaged groups of the population in the priority setting exercise
- 2) Validate that patients understand the concept of health equity before the prioritization survey is completed

Further details on these two recommendations are provided in Chapter 5, Section 5.3.

## **6.3.1 Forging ahead with SDH**

### **6.3.1.1 Beyond Healthcare Interventions**

The Cochrane Collaboration had historically focused on the production of systematic reviews of the effectiveness of medical, surgical, and pharmacological interventions. However, over the last few years they have expanded the scope of the reviews to other areas such as, counseling, consumer behaviours, best practices, public health approaches, educational tools, etc. After the report from the WHO Commission on Social Determinants of Health was published, the importance of addressing factors outside of the healthcare system became more apparent. Cochrane's commitment to address those factors that impact health and originate outside of the health care system is ongoing. This is proven by the fact that at the end of the research project we obtained commitment from Cochrane to conduct systematic reviews in all areas that were identified as a priority – even if they fell outside of typical health interventions.

### **6.3.1.2 Beyond Randomized Controlled Trials (RCTs)**

Traditionally randomized controlled trials were the main type of evidence considered for Cochrane systematic reviews. This was done because RCTs were considered to be the highest quality of evidence. However, Cochrane has recognized the limitations of such approach and has created a Non-randomized Studies Methods Groups with the mandate of looking at how to incorporate non-RCTs quality evidence into the systematic reviews. This is part of Cochrane's effort to move away from the concept of the 'hierarchy' or 'pyramid' approach toward using the concept of 'fit-for-purpose', which matches the study designs to consider in the review to the question. For example, if a systematic review is addressing a policy question on social determinants of health, then it is very unlikely an RCT will be able to address the question. In this type of situation, Cochrane Review Groups are developing approaches to incorporate other types of studies (beyond RCTs) to address the research question. In order to search for new types of studies, the librarian scientists in Cochrane and Cochrane have developed a strategy to incorporate search terms (i.e. MeSH terms) associated with social determinants. This is important as some of the SDH priority research questions identified through this research will likely require incorporating non-RCT studies.

In addition to considering studies that are not RCTs, given that the topic on SDH is relatively new, there might be relatively few underlying studies that combine clinical and social aspects. Thus there is a danger that the resulting systematic review can end up being based on weak evidence or not

being feasible. In these situations, we recommend communicating the importance of this topic to the research community and encouraging funding in those research areas.

## Chapter 7: CONCLUSIONS

The three research objectives of this study were met: we developed a sustainable priority setting method that effectively incorporated the social determinants of health and health equity into the process, we piloted the methods, and we evaluated the methods.

Even though we were able to conclude all three research objectives were met, there are clearly limitations to this study and risks associated to the future implementation of the methods. Ten high-level recommendations were put forward to address such concerns are as follows:

**Recommendation 1:** Develop tools to set priorities based on the needs of patients including both, clinical treatments and social determinants of health. The map of evidence for osteoarthritis is an example of such type of tool.

**Recommendation 2:** Develop tools to set priorities based on the needs of those that require the information and not limited by the way the Cochrane Collaboration operates. The map of evidence for osteoarthritis is an example of such type of tool.

**Recommendation 3:** In setting priorities, develop tools that assist those that are not normally involved with Cochrane activities, to easily understand the information produced by Cochrane Groups. This will encourage them to participate in the process and continue to access Cochrane as a source of information. The map of evidence for osteoarthritis is an example of such type of tool.

**Recommendation 4:** Before initiating the priority setting exercise identify a patient that is willing to act as a champion for the research project. This person should be trusted by his/her peers and should genuinely believe the patient community will benefit from participating in the research. This person should be able to effectively communicate such message to the patient community.

**Recommendation 5:** When setting priorities incorporate activities that allow you to capture patient and clinician input separately. Identifying potential priority overlaps between these two groups allows the research group to 1) validate the results produced by the priority setting exercise and 2) capture more information on patient and clinician preferences.

**Recommendation 6:** In order to ensure health equity issues are addressed secure funds and develop processes to incorporate patients from low and middle income countries and from disadvantaged groups of the population in the priority setting exercise.

**Recommendation 7:** Validate that patients understand the concept of health equity before the prioritization survey is completed.

**Recommendation 8:** Validate that participants understand the scope of research topics contained within each section of the map. This will help ensure priority topics are not being missed due to lack of comprehension.

**Recommendation 9:** Validate research questions (i.e. PICO terms) derived from the broad research topics are in alignment with the original topic raised at a mapping workshop and are in terms that can be understood by the Cochrane Review Group that will carry out the systematic reviews.

**Recommendation 10:** In order to ensure that the priority setting process is sustainable in the long term, when converting broad research topics into questions, involve other Cochrane Review Groups that could potentially be involved in owning the priority topics. This will increase the possibility of assigning ownership of each research topic to a CRG.

The impact of this method is mainly in the appropriateness and relevance of selection of topics and research questions as determined by the key stakeholders groups involved. Given the constraints of medical/scientific resources worldwide this is essential in ensuring that efforts invested into producing evidence-based medicine are relevant to those that will use the information.

**Annex 1. 1 Comparison of Priority-Setting Approaches**

Frameworks	Accountability for Reasonableness (Norman Daniels, Doug Martin and Peter Singer)	The James Lind Alliance (JLA)	Health Sector Wide Disease Based Model (HsW – DBM)	The Global Evidence Mapping (Scoping studies)	The Combined Approach Matrix (CAM)	Evidence Based Public Health Policy and Practice
<p><b>Characteristics</b></p> <p><b>1. Objective of priority-setting</b></p>	<p>To offer a framework for legitimate and fair priority setting that can be applied in a variety of situations.</p>	<p>To assist in setting research agendas for publicly funded research by identifying uncertainties about the effects of treatments that are sufficiently important to be addressed in systematic reviews of existing research evidence or additional primary research.</p>	<p>To assist health planners in achieving the optimal mix of health services for a population by:</p> <p>(1) Identifying highly cost-effective interventions and</p> <p>(2) recommending desirable resource shifts to enhance net community welfare.</p>	<p>To build evidence maps, which define, retrieve, evaluate and summarise research evidence addressing a range of clinical questions in a particular disease area. The process will also enable the identification of evidence gaps.</p>	<p>To classify, organize, summarize and present the large body of information that enters into the priority-setting process.</p>	<p>To identify a list of prioritised topics for Cochrane reviews.</p>
<p><b>2. Focus at the global or national level?</b></p>	<p>Both</p>	<p>Applied at national. Feasible at global</p>	<p>Applied at national. Feasible at global</p>	<p>Applied at national Feasible at global</p>	<p>Both</p>	<p>Applied at global Feasible at national</p>
<p><b>3. Strategies or principles (a belief that is accepted as a reason for acting in a particular way)</b></p>	<p>Fairness Transparency Justice (with an emphasis on democratic deliberations.)</p>	<p>Patient engagement Public engagement<sup>2</sup> Greater uptake<sup>3</sup></p>	<p>Cost-benefit assessment<sup>4</sup></p>	<p>Evidence-based</p>	<p>Economic dimension Institutional dimension</p>	<p>Evidence-based Global public health agencies engagement Developing countries needs</p>

Frameworks	Accountability for Reasonableness (Norman Daniels, Doug Martin and Peter Singer)	The James Lind Alliance (JLA)	Health Sector Wide Disease Based Model (HsW – DBM)	The Global Evidence Mapping (Scoping studies)	The Combined Approach Matrix (CAM)	Evidence Based Public Health Policy and Practice
<b>4. Criteria for priority setting</b>	Flexible - involved parties agree on the grounds for decision to be made.	Flexible - each participant suggests priority ranking based on personal criteria: values, opinions, beliefs, etc. A disease area is selected in conjunction with new Working Partnerships before the process is initiated. 'Burden of disease' is not used as a criteria for priority-setting.	Performance ratios (outcome of the cost-utility analysis). A disease area is selected by stakeholders before the process is initiated. 'Burden of disease' is not a criteria for priority-setting.	Fixed - based on: <sup>27</sup> (1) Clinical importance (2) Novelty (3) Controversy A disease area is selected by stakeholders before the process is initiated. <sup>28</sup> 'Burden of disease' is not a criteria for priority-setting.	The CAM tool assists with priority setting but it is not a priority-setting process in itself. Measured by DALYs (number of years of health disease) or other appropriate indicators.	Flexible - each participant suggests priority ranking based on personal criteria: values, opinions, beliefs, etc. Considered
<b>4.1 Burden of disease</b>	Flexible - involved parties are to decide whether 'burden of disease' is to be used as a criteria or not.	Not considered	Not considered	Not considered	Not considered	Not considered
<b>4.1.1 Equity</b>	Flexible - involved parties decide whether to include equity or not in the criteria. Flexible - involved parties choose determinants.	The process is conducted for a specific disease area. 'Analysis of determinants of disease burden' is not a criteria for priority-setting.	The process is conducted for a specific disease area. 'Analysis of determinants of disease burden' is not a criteria for priority-setting.	The process is conducted for a specific disease area. 'Analysis of determinants of disease burden' is not a criteria for priority-setting.	Considered	
<b>4.2 Analysis of determinants of disease burden</b>						

Frameworks Characteristics	Accountability for Reasonableness (Norman Daniels, Doug Martin and Peter Singer)	The James Lind Alliance (JLA)	Health Sector Wide Disease Based Model (Hsw – DBM)	The Global Evidence Mapping (Scoping studies)	The Combined Approach Matrix (CAM)	Evidence Based Public Health Policy and Practice
<b>4.2.1 Equity</b>	Flexible - involved parties decide whether to include equity or not in the criteria.	Not considered	Not considered	Not considered	Not considered	Not considered
<b>4.3 Cost-effectiveness of interventions</b>	Flexible - involved parties decide whether to include or not cost-effectiveness of interventions as a criteria. <sup>6</sup>	Not considered	Cost/utility value in terms of QALYs.	Not considered	Cost-effectiveness measured in terms of DALYs saved for a given cost.	Not considered
<b>4.3.1 Equity</b>	Flexible - involved parties decide whether to include equity or not in the criteria.	Not considered	Not considered	Not considered		Not considered
<b>5. Institutions that participate in the process</b>	Various institutions	Various institutions <sup>7</sup>	Various institutions <sup>8</sup>	Various institutions	Various institutions <sup>30</sup>	Various institutions <sup>31</sup>
<b>6. People that make the decisions</b>	Clinicians Consumers <sup>9</sup> Patients Managers	Clinicians Consumers Patients Researchers Academics <sup>10</sup> Managers	Clinicians Consumers Researchers Academics An Advisory Panel <sup>11</sup>	Clinicians Consumers Patients Carers Policymakers <sup>26</sup>	Not defined	Academics Researchers Policymakers

Frameworks Characteristics	Accountability for Reasonableness (Norman Daniels, Doug Martin and Peter Singer)	The James Lind Alliance (JLA)	Health Sector Wide Disease Based Model (HsW – DBM)	The Global Evidence Mapping (Scoping studies)	The Combined Approach Matrix (CAM)	Evidence Based Public Health Policy and Practice
<p><b>7. The factors they consider (things that cause or influence the decision-making process)</b></p>	<p>(1) Relevance (2) Publicity (3) Appeal mechanism (4) Enforcement</p>	<p>(1) Identifying important questions (2) Assessing whether they really are ‘uncertainties’ or whether there is already existing research on them (3) If genuine uncertainty exists, which of the ‘questions’ should be prioritized<sup>12</sup></p>	<p>Relative performance of interventions based on cost/utility analysis</p>	<p>The process covers only clinical questions that could be usefully informed by research evidence</p>	<p>Not defined</p>	<p>(1) Burden of disease, magnitude of problem, urgency (2) Importance to developing countries (3) Avoidance of duplication (4) Opportunity for action</p>
<p><b>8. The reasons for the decision</b></p>	<p>Variable<sup>13</sup> based on: (1) context (2) participants (3) decision to be made</p>	<p>Variable based on: (1) context (2) participants (3) target disease</p>	<p>Variable based on: (1) context (2) participants (3) target disease</p>	<p>Variable based on: (1) context (2) participants (3) target disease</p>	<p>Not defined</p>	<p>Not defined.</p>

<p><b>Frameworks</b></p> <p><b>Characteristics</b></p>	<p><b>Accountability for Reasonableness (Norman Daniels, Doug Martin and Peter Singer)</b></p>	<p><b>The James Lind Alliance (JLA)</b></p>	<p><b>Health Sector Wide Disease Based Model (HsW – DBM)</b></p>	<p><b>The Global Evidence Mapping (Scoping studies)</b></p>	<p><b>The Combined Approach Matrix (CAM)</b></p>	<p><b>Evidence Based Public Health Policy and Practice</b></p>
<p><b>9. The process of decision-making</b></p>	<p>Three-step process:<sup>14</sup>  (1) Conduct case study research to describe priority setting  (2) Conduct interdisciplinary research to evaluate the description using the “accountability for reasonableness” framework  (3) Apply action research to improve the process</p>	<p>Three-step process:  (1) Populate the Database of Effects of Uncertainties of Treatments (DUETs) with uncertainties of the disease in question;  (2) Develop methods for prioritizing these uncertainties into a short list of 20 – 30,  (3) Conduct a final workshop at which members of the Working Partnerships (which in theory should include patients and clinicians) agree on their top ten shared priorities from the short list. (See Appendix A for more details)</p>	<p>Six-step process:  (1) Select the disease<sup>5</sup>  (2) Gain an understanding of the disease and the options for reducing disease burden  (3) Determine a common outcome measure  (4) Select interventions to be analyzed<sup>15</sup>  (5) Conduct cost-utility analyses and compare interventions.  (6) Draw conclusions</p>	<p>Four-step process:  (1) Identification, development and prioritisation of clinical research questions<sup>29</sup>  (2) Identification of relevant studies and study selection  (3) Data extraction  (4) Identification of evidence gaps</p>	<p>Not defined</p>	<p>Five-step process:  (1) Development and use of a taskforce of individuals to identify and nominate global research needs  (2) Identification of gaps in the current systematic review literature  (3) Production of a list of useful review topics for decision making within public health agencies globally  (4) Prioritisation of the nominated review topics, using an a priori set of criteria  (5) Communication and dissemination of the list of prioritised review topics to achieve completed reviews</p>

Frameworks Characteristics	Accountability for Reasonableness (Norman Daniels, Doug Martin and Peter Singer)	The James Lind Alliance (JLA)	Health Sector Wide Disease Based Model (HsW – DBM)	The Global Evidence Mapping (Scoping studies)	The Combined Approach Matrix (CAM)	Evidence Based Public Health Policy and Practice
10. Publicity condition (decisions and their rationale must be publicly accessible)	Considered	Partially considered <sup>19</sup>	Considered <sup>21</sup>	Partially considered	Recommended	Partially considered
11. Relevance condition (rationales must rest on evidence, reasons, and principles that all fair-minded parties agree are relevant)	Considered	Partially considered <sup>20</sup>	Partially considered <sup>22</sup>	Considered	Recommended	Considered
12. Appeal mechanism for challenging decisions (there must be an avenue for appealing these decisions and their rationales)	Considered	Not considered <sup>18</sup>	Not considered	Not considered	Not considered	Not considered

Frameworks Characteristics	Accountability for Reasonableness (Norman Daniels, Doug Martin and Peter Singer)	The James Lind Alliance (JLA)	Health Sector Wide Disease Based Model (HsW – DBM)	The Global Evidence Mapping (Scoping studies)	The Combined Approach Matrix (CAM)	Evidence Based Public Health Policy and Practice
<p><b>13. Enforcement</b> (There must be some means, either voluntary or regulatory, of ensuring that the publicity condition, relevance condition and appeals condition are met.)</p>	<p>Considered</p>	<p>Not considered</p>	<p>Not considered</p>	<p>Not considered</p>	<p>Not considered</p>	<p>Not considered</p>
<p><b>14. Techniques for deciding</b></p>	<p>Not considered</p>	<p>* Nominal group technique * Delphi, * Diamond 9</p>	<p>Techniques employed to select the interventions for the cost-utility analysis: (1) Literature review<sup>16</sup> (2) Group discussions (3) Transfer to utility technique (TTU)<sup>17</sup></p>	<p>* Consultations with clinical experts * Surveys * Coding data * Literature review * Mapping workshops * International Classification of Functioning, Disability and Health * Systematic review methods for identifying and selecting studies</p>	<p>Not considered</p>	<p>Teleconferences Email communication Consultations</p>

<p><b>Frameworks</b></p> <p><b>Characteristics</b></p>	<p><b>Accountability for Reasonableness (Norman Daniels, Doug Martin and Peter Singer)</b></p> <p>Some assumptions are:</p> <ul style="list-style-type: none"> <li>• The parties involved are working towards a common goal.</li> <li>• The parties involved will come to an agreement on the evidence, reasons, and principles that are relevant for the decision-making process.</li> <li>* The parties involved agree to pursue their diverse needs on terms they can justify to each other.</li> </ul>	<p><b>The James Lind Alliance (JLA)</b></p> <p>Some assumptions are:</p> <ul style="list-style-type: none"> <li>• Consensus is to be sought on the importance of the priority areas of uncertainty about treatment effects – and nothing else.</li> <li>• Making priority decisions does not create new knowledge, but reviews existing evidence of uncertainty.</li> <li>• Best use will be made of the information available in DUEs, and the existing knowledge base/experience of participants.</li> <li>• Strong disagreement, as well as strong agreement will be acknowledged and recorded</li> <li>• A broad range of perspectives in</li> </ul>	<p><b>Health Sector Wide Disease Based Model (HsW – DBM)</b></p> <p>Some assumptions are:</p> <ul style="list-style-type: none"> <li>* A useful criteria for selecting a subset of interventions for the conduct of economic evaluations can be developed</li> <li>* A single outcome measure that will support comparisons across a wide range of modalities and health services can be defined</li> <li>* A cost-effective estimate based on objective evidence is available for each intervention</li> <li>* It is possible to draw conclusions about desirable resource shifts</li> <li>* A disease can be selected prior</li> </ul>	<p><b>The Global Evidence Mapping (Scoping studies)</b></p> <p>Some assumptions are:</p> <ul style="list-style-type: none"> <li>* The study team has access to the custom relational databases that are used for data extraction purposes.</li> <li>* Before commencing a new mapping exercise, the study team will have access to the "Compendium of Methods and Protocols". This document reports on the methodologies employed by the Global Evidence Mapping Initiative in 2008, when conducting a mapping exercise on Traumatic Brain Injury and Spinal</li> </ul>	<p><b>The Combined Approach Matrix (CAM)</b></p> <p>Some assumptions:</p> <ul style="list-style-type: none"> <li>* The CAM matrix will be used to capture that data that enters into a priority-setting process.</li> </ul> <p>However, the priority-setting process is flexible.</p>	<p><b>Evidence Based Public Health Policy and Practice</b></p>
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**15. Prior assumptions**

		<p>patients and clinicians, likely to be experienced among patients and clinicians, is necessary in the last face to face part of the process</p> <ul style="list-style-type: none"> <li>• Time will be limited, so it must be used efficiently.</li> </ul> <p>* The disease area can be selected at the time new Working Partnerships are established (i.e. the UK Asthma Working Partnership will focus on prioritizing research topics for asthma treatments).</p>	to applying the framework	Cord Injury.		
<p><b>16. Degree to which it can be adapted to Cochrane and Campbell review groups</b></p>			Low degree <sup>23</sup>			
<p><b>17. Countries where the process has been conducted</b></p>	<p>Canada, Tanzania, United States</p>	<p>United Kingdom</p>	<p>Australia</p>	<p>Australia</p>	<p>India, Pakistan</p>	<p>Global approach participants from: USA, Australia, Switzerland, South Africa, Philippines, United Kingdom.</p>

Frameworks Characteristics	Accountability for Reasonableness (Norman Daniels, Doug Martin and Peter Singer)	The James Lind Alliance (JLA)	Health Sector Wide Disease Based Model (HsW – DBM)	The Global Evidence Mapping (Scoping studies)	The Combined Approach Matrix (CAM)	Evidence Based Public Health Policy and Practice
<p><b>18. Key References</b></p>	<p>* Daniels Norman and Sabin James (1998). The Ethics of Accountability in Managed Care Reform. Health Affairs, Vol.17 Number 5.            * Martin Doug, Giacomini Mita, Singer Peter (2001). Fairness, accountability for reasonableness, and the views of priority setting decision-makers. Health Policy 61; 279-290.            * Martin Doug and Singer Peter (2003). A Strategy to Improve Priority Setting in Health Care Institutions. Health Care Analysis, Vol. 11, No. 1.            * Mshana Simon et. al. (2007). What do District Health Planners in Tanzania think about</p>	<p>* Oliver S, Gray J (2006). A bibliography of research reports about patients', clinicians' and researchers' priorities for new research. London: James Lind Alliance.            * Crowe S, (2006). Priority Setting Approaches for James Lind Alliance (JLA) Working Partnerships.</p>	<p>* Segal L, Day S, Champan A, Osborne R, Monash University, Centre for Health Economics (2006). Priority Setting in Osteoarthritis. Research Paper.</p>	<p>* The Global Evidence Mapping Initiative (2008). Preliminary Evidence Mapping Report: Rehabilitation, subacute &amp; Long-term care of patients with traumatic brain injury or spinal cord injury.            Russell Gruen &amp; Emma Tavander - Mgmt Group.</p>	<p>* Global Forum for Health Research (2004). The Combined Approach Matrix, a priority-setting tool for health research. Edited by Abdul Ghaffar, Andres de Francisco and Stephen Matlin.</p>	<p>* Doyle J, Waters E, Yach D, McQueen D, De Francisco A, Stewart T (2005). Global priority setting for Cochrane systematic reviews of health promotion and public health research. J. Epidemiol Community Health; 59:193-197.</p>

improving priority  
setting using  
'Accountability for  
Reasonableness?  
BioMedCentral  
Health Services  
Research 7:180

## Annex 4. 1 Invitation Letter to Participate in the Research Project



uOttawa

University of Ottawa

Institute of Population Health

Date

**Invitation to participate in the research project titled:**

**“Priority-setting for health research: an enhanced method that incorporates ‘health equity’ and the ‘social determinants of health’ into the decision-making process”**

Dear ,

You are being asked to participate in the research project titled: **Priority-setting for health research: An enhanced method that incorporates ‘health equity’ and the ‘social determinants of health’ into the decision-making process”**.

One of the key aspects of the project is to identify the research topics on which to base upcoming research and systematic reviews in the field of osteoarthritis. As an expert in the field, your participation will help us to identify all relevant (established and emerging) research topics in Osteoarthritis.

The research participants will include a cross section of health professionals, researchers and patients interested, for whom osteoarthritis care is of importance in their lives. The research project comprises two main activities; brainstorming to identify new research topics of interest and completing an on-line survey to prioritise the research topics identified by the group.

If you would like to participate in the project, please contact Alejandra Jaramillo (*REMOVED PERSONAL INFORMATION*).

If you are unable to participate, feel free to forward this letter to a work colleague who might be interested in contributing. This research project has been approved by the Ottawa Hospital Research Ethics Board. Patient Information Sheets describing this activity in more detail are attached to this letter and additional copies are available upon request. If you have any queries regarding this activity, you can contact the Principal Investigator, Professor Peter Tugwell at (*REMOVED PERSONAL INFORMATION*).

Your perspectives on osteoarthritis care and willingness to contribute to this research project will be of great value in shaping our evidence maps. Thank you for taking the time to consider this matter.

Yours sincerely,

Peter Tugwell  
Professor University of Ottawa  
Canada Research Chair in Health Equity



Université d'Ottawa  
Institut de recherche  
sur la santé des  
populations

University of Ottawa  
Institute of Population  
Health

## PARTICIPANT INFORMATION SHEET

Name of Research Project: **Priority-setting for health research: An enhanced method that incorporates 'health equity' and the 'social determinants of health' into the decision-making process"**

You are being asked to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve.

### 1. What is the purpose of the study?

Cochrane systematic reviews are documents that provide the evidence for and against the various treatments, medications, surgery, education, and other health interventions for a specific medical condition. The purpose of this study is to assist the Cochrane Musculoskeletal Group identify review topics for Osteoarthritis.

### 2. Why have I been chosen?

You are being asked to participate in this study because you are considered a key stakeholder in the process of setting research priorities for osteoarthritis. The following stakeholder groups are being asked to participate: Clinicians, researchers, patients/consumers, and policy-makers/decision-makers.

### 3. Do I have to take part?

Participation is optional. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw from the study at any time.

### 4. What is expected from me if I decide to take part in the study?

Should you chose to take part in the study, you will be required to perform one of the following three tasks:

- 1) Mapping workshop.  
When participating in a mapping workshop, you will be asked to identify Osteoarthritis research topics that you consider to be the most important ones. "Most important" is defined for the purposes of this study, as the topic that from your perspective will have the biggest impact, for example on outcomes or resources. It will take approximately 1 hour to complete this task. You should keep in mind there is no right or wrong answer. We are interested in your personal point of view.

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Canada

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2) Consultation.

When participating in a consultation, you have the choice of doing it via teleconference or in person at a location of your choice, whichever is more convenient for you. It will take approximately 10 to 15 minutes to complete this task. Before the consultation, you will be asked to review the "Osteoarthritis Map of Evidence", which outlines key areas where effort is required to improve the overall quality of life of people living with osteoarthritis. In the map you will find a listing of relevant systematic reviews conducted in the field of osteoarthritis - classified by stage of the condition and by key area. The map allows you to visually identify areas where gaps in evidence exist (i.e. areas where systematic reviews haven't been conducted).

Then you will be asked to respond to the following question:

*From your perspective, list at least three (3) new research topics from Osteoarthritis that need to be addressed. Please consider all stages of the condition - from prevention to long-term care.*

You can use the map as a tool to assist you in identifying new priority research topics on which to base upcoming reviews. You should keep in mind there is no right or wrong answer. We are interested in your personal point of view.

3) Participate in a broader prioritization exercise, which will consist of completing a survey. In this step of the process, you will be provided with the cumulative list of research questions and asked to rank each question on a scale of 1 to 4, where:

- 1 = not at all
- 2 = a little
- 3 = a moderate amount
- 4 = high

For the following two dimensions:

- Dimension 1 - Importance: How clinically important is this topic?
- Dimension 2 - Equity: Would you say the topic addresses the health needs of populations across different social gradients as illustrated by the PROGRESS concept (i.e. place of residence; race, ethnicity, and culture; occupation; sex; religion; education; socioeconomic status; and social capital)?

**6. What are the possible disadvantages and risks of taking part?**

There are no physical or financial risks to taking part in the study. Only your time and commitment is required to review the documentation and participate in a brief teleconference.

**7. What are the possible benefits of taking part?**

This study will give you a chance to offer your insights and experiences to improve our understanding of osteoarthritis and to define research priorities in this area.

**8. Will my taking part in this study be kept confidential?**

Any personal information collected during the course of the research will be kept

confidential. Results will be compiled at the aggregate level. The information will be kept electronically in a password-protected computer.

The Ottawa Hospital Research Ethics Board and the Ottawa Hospital Research Institute may review your relevant study records, under the supervision of Dr. Peter Tugwell's staff for audit purposes.

The study records will be kept for 15 years after termination of the study. The information will be destroyed after 15 years. Electronic files will be deleted.

#### **9. What will happen to the results of the research study?**

The results of this study will help us improve the process of priority-setting within the Cochrane Collaboration. The study results will be submitted and likely published in an academic journal. You can ask to be notified when the results of the study are published. No personal identifying details will be published.

#### **10. Who is funding the research?**

This study is funded in part by the Social Sciences and Humanities Research Council in the form of a scholarship for Alejandra Jaramillo, who is undertaking this research project as her master's thesis.



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## PARTICIPANT CONSENT FOR RESEARCH PROJECT

Name of Research Project:

**“Priority-setting for health research: an enhanced method that incorporates ‘health equity’ and the ‘social determinants of health’ into the decision-making process”.**

I have read the 4-page Patient Information Sheet (or have had this document read to me), and have had an opportunity to ask any questions I had about the study.

My questions and/or concerns have been answered to my satisfaction and I agree to participate in this study. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

The main purpose of this study is to assist the Cochrane Musculoskeletal Group identify priority research topics for Osteoarthritis. I understand that withdrawing my consent will not affect my normal involvement in Cochrane Musculoskeletal Group activities or the care I receive.

The research project comprises two main activities; brainstorming to identify new research topics of interest and completing an on-line survey to prioritize the research topics identified by the group.

A copy of the Information Sheet and/or Consent Form will be provided to me should I want to review the information at a later date, if I need to contact someone about the study or my participation in the study, or simply for my records.

There are two copies of this consent form, one of which I may keep.

If I have any questions about the conduct of the research project, I may contact: Alejandra Jaramillo, Project Co-Investigator at (*REMOVED PERSONAL INFORMATION*)

Interviewer's Name (print): \_\_\_\_\_

Interviewer's Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Participant's Name (print) : \_\_\_\_\_

Participant's Signature: \_\_\_\_\_

Date: \_\_\_\_\_

#### Annex 4. 3 Invitation email for consultations with experts

**Subject of email:**

**CONSULTATION WITH EXPERTS: PRIORITY-SETTING IN OSTEOARTHRITIS**

**Invitation to participate in the pilot project titled:**

**Priority-setting for Osteoarthritis**

**Date: Tuesday, October 20th, 2009**

**Time: Your preferred time between 7am and 7pm**

**Duration of consultation: 15 minutes**

As part of the ACR 2009 Annual Scientific Meeting taking place in Philadelphia, **Peter Tugwell** and the **Cochrane Musculoskeletal Group** would like to invite you to participate in a project titled: **Priority-setting for Osteoarthritis**.

One of the key aspects of the project is to identify the research topics on which to base upcoming systematic reviews in the field of **osteoarthritis**. As an expert in the field, your participation will help us to identify relevant emerging research topics.

Experts consulted will include a cross section of health professionals, researchers, decision-makers and consumers/patients for whom osteoarthritis care is of importance in their lives. The research project comprises two main activities; brainstorming to identify new research topics of interest and prioritising the research topics.

Should you choose to participate in this project you will be asked to review a **map of evidence for osteoarthritis**. The map outlines key areas to improve the overall quality of life of people living with the condition and provides a listing of systematic reviews in each area. As part of the consultation, you will be asked to use the map as a tool to note areas where gaps in evidence exist and to identify new priority research topics. **The consultation will take less than 15 minutes.**

If you would like to be consulted, please email Alejandra Jaramillo at (*REMOVED PERSONAL INFORMATION*) to confirm your interest to participate and to kindly provide a preferred time for the consultation. In an attempt to be as flexible as possible to meet your availability, we are booking 15-minute consultations from 7 am to 7 pm. If you have any queries regarding this activity, please contact Alejandra Jaramillo.

Your perspectives on osteoarthritis care and willingness to contribute to this research project will be of great value in shaping our evidence maps. Thank you for taking the time to consider this invitation.

Yours sincerely,

**Dr. Peter Tugwell**

MD, MSc, FRCPC, FCAHS

Director, Centre for Global Health

Professor, Faculty of Medicine

Institute of Population Health

University of Ottawa

Annex 4. 4 Prioritization Survey

**Prioritization survey**

**Project Name:** “Priority-setting for health research: an enhanced method that incorporates health equity and the social determinants of health into the decision-making process”.

**Instructions:** We are interested in your personal point of view. For each topic listed below, please rank each dimension on a scale from 1 to 4, where:

- 1 = not at all
- 2 = a little
- 3 = a moderate amount
- 4 = high

- **Dimension 1 - Importance:** How important is this question?
- **Dimension 2 – Equity/ Social Determinants:** To what degree does the question address the health needs of populations across different social gradients as defined by the PROGRESS framework (i.e. Place of residence; Race, ethnicity, and culture; Occupation; Gender; Religion; Education; Socioeconomic status; and Social capital)?

**Topics to prioritize:**

**1. Communication interventions directed to patients to increase awareness of long-term self-management approaches in treating osteoarthritis.**

	<i>Not at all</i>	<i>A little</i>	<i>A moderate amount</i>	<i>High</i>
<i>Importance: How important is this question?</i>	1	2	3	4
<i>Equity/ Social Determinants: To what degree does the question address the health needs of populations across different social gradients as defined by the PROGRESS framework (i.e. <u>P</u>lace of residence; <u>R</u>ace, ethnicity, and culture; <u>O</u>ccupation; <u>G</u>ender; <u>R</u>eligion; <u>E</u>ducation; <u>S</u>ocioeconomic status; and <u>S</u>ocial capital)?</i>	1	2	3	4

**2. Educational interventions to change the behavior in patients to increase the uptake of self-management approaches in treating osteoarthritis.**

	<i>Not at all</i>	<i>A little</i>	<i>A moderate amount</i>	<i>High</i>
<i>Importance: How important is this question?</i>	1	2	3	4
<i>Equity/ Social Determinants: To what degree does the question address the health needs of populations across different social gradients as defined by the PROGRESS framework (i.e. <u>P</u>lace of residence; <u>R</u>ace, ethnicity, and culture; <u>O</u>ccupation; <u>G</u>ender; <u>R</u>eligion; <u>E</u>ducation; <u>S</u>ocioeconomic status; and <u>S</u>ocial capital)?</i>	1	2	3	4

**3. Educational interventions to change the behavior in patients to increase adherence to long-term self-management approaches in treating osteoarthritis.**

	<i>Not at all</i>	<i>A little</i>	<i>A moderate amount</i>	<i>High</i>
<i>Importance: How important is this question?</i>	1	2	3	4
<i>Equity/ Social Determinants: To what degree does the question address the health needs of populations across different social gradients as defined by the PROGRESS framework (i.e. <u>P</u>lace of residence; <u>R</u>ace, ethnicity, and culture; <u>O</u>ccupation; <u>G</u>ender; <u>R</u>eligion; <u>E</u>ducation; <u>S</u>ocioeconomic status; and <u>S</u>ocial capital)?</i>	1	2	3	4

**4. Educational interventions directed to osteoarthritis patients to increase the level of understanding of the need for continual & on-going treatment.**

	<i>Not at all</i>	<i>A little</i>	<i>A moderate amount</i>	<i>High</i>
<i>Importance: How important is this question?</i>	1	2	3	4
<i>Equity/ Social Determinants: To what degree does the question address the health needs of populations across different social gradients as defined by the PROGRESS framework (i.e. <u>P</u>lace of residence; <u>R</u>ace, ethnicity, and culture; <u>O</u>ccupation; <u>G</u>ender; <u>R</u>eligion; <u>E</u>ducation; <u>S</u>ocioeconomic status; and <u>S</u>ocial capital)?</i>	1	2	3	4

**5. Lifestyle-related interventions aimed at people who have not been diagnosed with the condition to reduce the risk of developing osteoarthritis.**

	<i>Not at all</i>	<i>A little</i>	<i>A moderate amount</i>	<i>High</i>
<i>Importance: How important is this question?</i>	1	2	3	4
<i>Equity/ Social Determinants: To what degree does the question address the health needs of populations across different social gradients as defined by the PROGRESS framework (i.e. <u>P</u>lace of residence; <u>R</u>ace, ethnicity, and culture; <u>O</u>ccupation; <u>G</u>ender; <u>R</u>eligion; <u>E</u>ducation; <u>S</u>ocioeconomic status; and <u>S</u>ocial capital)?</i>	1	2	3	4

**6. Communication interventions to increase the level and quality of communication of inter-professional teams involved in treating osteoarthritis patients.**

	<i>Not at all</i>	<i>A little</i>	<i>A moderate amount</i>	<i>High</i>
<i>Importance: How important is this question?</i>	1	2	3	4
<i>Equity/ Social Determinants: To what degree does the question address the health needs of populations across different social gradients as defined by the PROGRESS framework (i.e. <u>P</u>lace of residence; <u>R</u>ace, ethnicity, and culture; <u>O</u>ccupation; <u>G</u>ender; <u>R</u>eligion; <u>E</u>ducation; <u>S</u>ocioeconomic status; and <u>S</u>ocial capital)?</i>	1	2	3	4

**7. Communication interventions to improve the quality and level of communication between osteoarthritis patients and their health care providers.**

	<i>Not at all</i>	<i>A little</i>	<i>A moderate amount</i>	<i>High</i>
<i>Importance: How important is this question?</i>	1	2	3	4
<i>Equity/ Social Determinants: To what degree does the question address the health needs of populations across different social gradients as defined by the PROGRESS framework (i.e. <u>P</u>lace of residence; <u>R</u>ace, ethnicity, and culture; <u>O</u>ccupation; <u>G</u>ender; <u>R</u>eligion; <u>E</u>ducation; <u>S</u>ocioeconomic status; and <u>S</u>ocial capital)?</i>	1	2	3	4

**8. Health systems interventions to reduce inequities in waiting times at a national level for joint replacement surgery in people with osteoarthritis.**

	<i>Not at all</i>	<i>A little</i>	<i>A moderate amount</i>	<i>High</i>
<i>Importance: How important is this question?</i>	1	2	3	4
<i>Equity/ Social Determinants: To what degree does the question address the health needs of populations across different social gradients as defined by the PROGRESS framework (i.e. <u>P</u>lace of residence; <u>R</u>ace, ethnicity, and culture; <u>O</u>ccupation; <u>G</u>ender; <u>R</u>eligion; <u>E</u>ducation; <u>S</u>ocioeconomic status; and <u>S</u>ocial capital)?</i>	1	2	3	4

**9. Decision-aid interventions to reduce health care practitioner conflict about timing of joint replacement in treating people with osteoarthritis.**

	<i>Not at all</i>	<i>A little</i>	<i>A moderate amount</i>	<i>High</i>
<i>Importance: How important is this question?</i>	1	2	3	4
<i>Equity/ Social Determinants: To what degree does the question address the health needs of populations across different social gradients as defined by the PROGRESS framework (i.e. <u>P</u>lace of residence; <u>R</u>ace, ethnicity, and culture; <u>O</u>ccupation; <u>G</u>ender; <u>R</u>eligion; <u>E</u>ducation; <u>S</u>ocioeconomic status; and <u>S</u>ocial capital)?</i>	1	2	3	4

**10. Decision support interventions to increase patient participation in the decision-making process to develop and implement a treatment plan for people with osteoarthritis.**

	<i>Not at all</i>	<i>A little</i>	<i>A moderate amount</i>	<i>High</i>
<i>Importance: How important is this question?</i>	1	2	3	4
<i>Equity/ Social Determinants: To what degree does the question address the health needs of populations across different social gradients as defined by the PROGRESS framework (i.e. <u>P</u>lace of residence; <u>R</u>ace, ethnicity, and culture; <u>O</u>ccupation; <u>G</u>ender; <u>R</u>eligion; <u>E</u>ducation; <u>S</u>ocioeconomic status; and <u>S</u>ocial capital)?</i>	1	2	3	4

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Annex 4. 5 Map of Evidence for Osteoarthritis

<p><b>What is the Osteoarthritis Map of Evidence?</b>                      This map outlines key areas where effort is required to improve the overall quality of life of people living with osteoarthritis. In the map you will find a listing of relevant systematic reviews conducted in the field of Osteoarthritis - classified by stage of the condition and by key area. The map allows you to visually identify areas where gaps in evidence exist (i.e. areas where systematic reviews haven't been conducted). The intent is to use the map as a tool to assist in the identification of priority research topics on which to base upcoming reviews.</p>					
<p>People with the condition (and families and carers)</p>					
Well Community (some of whom are more at risk than others)	Find the condition early	Early Stages	Acute Episodes	Long-term Management	Advanced stages
Stage of the Condition	Reduce the Risk	Early Stages	Acute Episodes	Long-term Management	Advanced stages
<p>What are the optimal person or patient-centred services for the conditions?                      The needs of people who have or are at risk of the condition.</p>					
People's needs					
Optimal services					
<p>What is happening now? Current practice in meeting peoples needs and providing optimal services</p>					
Access to Care and Support					
Pharmacologic therapies per stage of the condition			(1) Evidence-based data on pain relief with antidepressants <sup>1</sup>	(2) Glucosamine long-term treatment and the progression of knee osteoarthritis: systematic review of randomized controlled trials <sup>2</sup> (3) Longterm efficacy of topical nonsteroidal antiinflammatory drugs in knee osteoarthritis: metaanalysis of randomized placebo controlled clinical trials <sup>3</sup>	
<p>Therapies that could potentially apply to all stages of the condition: Early, Acute, Long-term, and Advanced stages of OA                      STUDY POPULATION NOT SUBDIVIDED</p>					
Pharmacologic therapies not specific to one stage of the condition	N/A	N/A	<p>(4) Acetaminophen for osteoarthritis<sup>4</sup>                      (5) Rofecoxib for osteoarthritis<sup>5</sup>                      (6) Tramadol for osteoarthritis<sup>6</sup>                      (7) Chondroitin for osteoarthritis<sup>7</sup>                      (8) Doxycycline for osteoarthritis of the knee or hip<sup>8</sup>                      (9) Oral or transdermal opioids for osteoarthritis of the knee or hip<sup>9</sup>                      (10) S-Adenosylmethionine for osteoarthritis of the knee or hip<sup>10</sup>                      (11) Efficacy of topical non-steroidal anti-inflammatory drugs in the treatment of osteoarthritis: meta-analysis of randomised controlled trials<sup>11</sup>                      (12) A meta-analysis of controlled clinical studies with diacerein in the treatment of osteoarthritis<sup>12</sup>                      (13) Structural and symptomatic efficacy of glucosamine and chondroitin in knee osteoarthritis: a comprehensive meta-analysis<sup>13</sup>                      (14) S-Adenosyl-L-Methionine (SAMe) for Depression, Osteoarthritis, and Liver Disease<sup>14</sup>                      (15) Intra-articular hyaluronic acid in treatment of knee osteoarthritis: a meta-analysis<sup>15</sup>                      (16) Glucosamine therapy for treating osteoarthritis<sup>16</sup>                      (17) Chloroquines for the treatment of osteoarthritis<sup>17</sup>                      (18) Glucosamine and chondroitin for treatment of osteoarthritis: a systematic quality assessment and meta-analysis<sup>18</sup>                      (19) A comparison of the efficacy and safety nonsteroidal antiinflammatory agents acetaminophen in the treatment of osteoarthritis: a meta-analysis<sup>19</sup>                      (20) Cyclooxygenase-2 selective non-steroidal anti-inflammatory drugs (etodolac, meloxicam, celecoxib, rofecoxib, etoricoxib, valdecoxib and lumiracoxib) for osteoarthritis and rheumatoid arthritis: a systematic review and economic evaluation<sup>20</sup>                      (21) Devil's Claw (Harpagophytum procumbens) as a treatment for osteoarthritis: a review of efficacy and safety<sup>21</sup></p>		

- (22) Does paracetamol (acetaminophen) reduce the pain of osteoarthritis: a meta-analysis of randomised controlled trials<sup>22</sup>
- (23) Dose-effect relationships of nonsteroidal anti-inflammatory drugs: a literature review<sup>23</sup>
- (24) Effect of therapeutic exercise for hip osteoarthritis pain: results of a meta-analysis<sup>24</sup>
- (25) The effectiveness of topically applied capsaicin: a meta-analysis<sup>25</sup>
- (26) Efficacy and safety of opioids for osteoarthritis: a meta-analysis of randomized controlled trials<sup>26</sup>
- (27) Efficacy and safety of viscosupplementation with Hylan G-F 20 for the treatment of knee osteoarthritis: a systematic review<sup>27</sup>
- (28) Efficacy of topical NSAIDs in the treatment of osteoarthritis: a meta-analysis of randomized controlled trials<sup>28</sup>
- (29) Glucosamine and arthritis<sup>29</sup>
- (30) Glucosamine for pain in osteoarthritis: why do trial results differ?<sup>30</sup>
- (31) Glucosamine<sup>31</sup>
- (32) Harpagophytum procumbens for osteoarthritis and low back pain: a systematic review<sup>32</sup>
- (33) Hyaluronic acid injections for knee osteoarthritis: systematic review of the literature<sup>33</sup>
- (34) Hylian versus hyaluronic acid for osteoarthritis of the knee: a systematic review and meta-analysis<sup>34</sup>
- (35) Intra-articular hyaluronic acid for the treatment of osteoarthritis of the knee: systematic review and meta-analysis<sup>35</sup>
- (36) Intra-articular steroid injections for painful knees: systematic review with meta-analysis<sup>36</sup>
- (37) Intra-articular viscosupplementation for treatment of osteoarthritis of the knee<sup>37</sup>
- (38) A metaanalysis of chondroitin sulfate in the treatment of osteoarthritis<sup>38</sup>
- (39) Need for common internal controls when assessing the relative efficacy of pharmacologic agents using a meta-analytic approach: case study of cyclooxygenase 2-selective inhibitors for the treatment of osteoarthritis<sup>39</sup>
- (40) Nonsteroidal antiinflammatory drugs or acetaminophen for osteoarthritis of the hip or knee: a systematic review of evidence and guidelines<sup>40</sup>
- (41) Pennsaid therapy for osteoarthritis of the knee: a systematic review and metaanalysis of randomized controlled trials<sup>41</sup>
- (42) S-Adenosyl-L-methionine for treatment of depression, osteoarthritis, and liver disease<sup>42</sup>
- (43) Safety profile of nonprescription ibuprofen in the elderly osteoarthritis patient: a meta-analysis<sup>43</sup>
- (44) A systematic review of prolotherapy for chronic musculoskeletal pain<sup>44</sup>
- (45) A systematic review of randomised clinical trials of individualised herbal medicine in any indication<sup>45</sup>
- (46) Upper gastroduodenal ulceration in arthritis patients treated with celecoxib<sup>46</sup>
- (47) EULAR Recommendations 2003. An evidence based approach to the management of knee osteoarthritis: report of a Task Force of the Standing Committee for International Clinical Studies Including Therapeutic Trials (ESCISIT)<sup>47</sup>
- (48) Glucosamine therapy compared to ibuprofen for joint pain<sup>48</sup>
- (49) Herbal medicines for the treatment of osteoarthritis: a systematic review<sup>49</sup>
- (50) Hyaluronic acid injections relieve knee pain<sup>50</sup>
- (51) Symptomatic efficacy of avocado-soybean unsaponifiables (ASU) in osteoarthritis (OA) patients: a meta-analysis of randomized controlled trials<sup>51</sup>
- (52) A systematic review of randomized controlled trials of pharmacological therapy in osteoarthritis of the hip<sup>52</sup>
- (53) A systematic review of randomized controlled trials of pharmacological therapy in osteoarthritis of the knee, with an emphasis on trial methodology<sup>53</sup>
- (54) Therapeutic effects of hyaluronic acid on osteoarthritis of the knee: a meta-analysis of randomized controlled trials<sup>54</sup>
- (55) Topical treatments for osteoarthritis of the knee<sup>55</sup>
- (56) Tramadol for osteoarthritis: a systematic review and metaanalysis<sup>56</sup>
- (57) Diacerein for osteoarthritis<sup>57</sup>
- (58) Single dose oral celecoxib for acute postoperative pain in adults<sup>58</sup>
- (59) Topical rubefacients for acute and chronic pain in adults<sup>59</sup>
- (60) Single dose oral etodolac for acute postoperative pain in adults<sup>60</sup>
- (61) Single dose oral etoricoxib for acute postoperative pain in adults<sup>61</sup>
- (62) Corticosteroid injections for osteoarthritis of the knee: meta-analysis<sup>62</sup>
- (63) Efficacy, tolerability, and upper gastrointestinal safety of celecoxib for treatment of osteoarthritis and rheumatoid arthritis: systematic review of randomised controlled trials<sup>63</sup>
- (64) Meta-analysis: chondroitin for osteoarthritis of the knee or hip<sup>64</sup>
- (65) Risk of cardiovascular events and rofecoxib: cumulative meta-analysis<sup>65</sup>
- (66) Treatment of Primary and Secondary Osteoarthritis of the Knee<sup>66</sup>
- (67) Hyaluronate for temporomandibular joint disorders<sup>67</sup>
- (68) Intraarticular corticosteroid for treatment of osteoarthritis of the knee<sup>68</sup>
- (69) Viscosupplementation for the treatment of osteoarthritis of the knee<sup>69</sup>
- (70) Non-steroidal anti-inflammatory drugs, including cyclo-oxygenase-2 inhibitors, in osteoarthritic knee pain: meta-analysis of randomised placebo controlled trials<sup>70</sup>

<p>Non-pharmacologic therapies (including self-management therapies)</p>	<p>(71) Screening for Obesity in Adults<sup>1</sup>  (72) Treatment of acute scaphoid fractures: systematic review and meta-analysis<sup>72</sup>  (73) Hormone replacement therapy for osteoarthritis in peri-menopausal and post-menopausal women<sup>73</sup>  (74) Pharmacological and Surgical Treatment of Obesity<sup>74</sup>  (75) Osteoarthritis and the postmenopausal woman: epidemiological, magnetic resonance imaging, and radiological findings<sup>75</sup></p>	<p>(76) The efficacy of magnetic resonance imaging in the diagnosis of degenerative and inflammatory temporomandibular joint disorders: a systematic literature review<sup>76</sup></p>	<p>(77) Effectiveness of exercise therapy in patients with osteoarthritis of the hip or knee: a systematic review of randomized clinical trials<sup>77</sup></p>		<p>(78) Effectiveness of psychoeducational interventions in osteoarthritis<sup>78</sup>  (79) Long-term effectiveness of exercise therapy in patients with osteoarthritis of the hip or knee: a systematic review<sup>79</sup></p>	<p>(80) Braces and orthoses for treating osteoarthritis of the knee<sup>80</sup>  (81) Mobile bearing vs fixed bearing prostheses for total knee arthroplasty for post-operative functional status in patients with osteoarthritis and rheumatoid arthritis<sup>81</sup>  (82) Posterior versus lateral surgical approach for total hip arthroplasty in adults with osteoarthritis<sup>82</sup>  (83) Retention versus sacrifice of the posterior cruciate ligament in total knee replacement for treatment of osteoarthritis and rheumatoid arthritis<sup>83</sup>  (84) Metal versus non-metal backing of the tibial component for total knee replacement for osteoarthritis and/or rheumatoid arthritis<sup>84</sup>  (85) Computer assisted knee arthroplasty for osteoarthritis and other non-traumatic diseases<sup>85</sup>  (86) Minimally invasive surgical approaches for total hip arthroplasty in adults with osteoarthritis<sup>86</sup>  (87) Patella resurfacing in total knee arthroplasty<sup>87</sup>  (88) Patient outcomes following tricompartmental total knee replacement: a meta-analysis<sup>88</sup>  (89) Total knee replacement<sup>89</sup>  (90) Continuous passive motion following total knee arthroplasty<sup>90</sup>  (91) Effects of different bearing surface materials on aseptic loosening of total hip arthroplasty in patients with osteoarthritis and other non-traumatic diseases of the hip<sup>91</sup>  (92) Osteotomy for treating knee osteoarthritis<sup>92</sup>  (93) Intensity of exercise for the treatment of osteoarthritis<sup>93</sup>  (94) Pre-operative education for hip or knee replacement<sup>94</sup>  (95) Effectiveness of physiotherapy exercise after knee arthroplasty for osteoarthritis: systematic review and meta-analysis of randomised controlled trials<sup>95</sup>  (96) Effectiveness of hip prostheses in primary total hip replacement: a critical review of evidence and an economic model<sup>96</sup>  (97) Efficacy of continuous passive motion following total knee arthroplasty: a metaanalysis<sup>97</sup>  (98) Electrical muscle stimulation for osteoarthritis of the knee: biological</p>
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					<p>basis and systematic review<sup>98</sup></p> <p>(99) Meta-analysis of surgical treatments for temporomandibular articular disorders<sup>99</sup></p> <p>(100) Metal-on-metal total hip resurfacing arthroplasty<sup>100</sup></p> <p>(101) Patellar resurfacing in total knee arthroplasty for osteoarthritis: a systematic review<sup>101</sup></p> <p>(102) Patient outcomes following unicompartmental or bicompartamental knee arthroplasty: a meta-analysis<sup>102</sup></p> <p>(103) Retention versus removal of the posterior cruciate ligament in total knee replacement: a systematic literature review within the Cochrane framework<sup>103</sup></p> <p>(104) Surgical approach for total hip arthroplasty: direct lateral or posterior?<sup>104</sup></p> <p>(105) A systematic review of the clinical effectiveness and cost-effectiveness and economic modelling of minimal incision total hip replacement approaches in the management of arthritic disease of the hip<sup>105</sup></p> <p>(106) A systematic review of the effectiveness and cost-effectiveness of metal-on-metal hip resurfacing arthroplasty for treatment of hip disease<sup>106</sup></p> <p>(107) Surgery for thumb (trapeziometacarpal joint) osteoarthritis<sup>107</sup></p>
					<p><b>Potentially applicable across several stages of the condition: Early, Acute, Long-term, and Advanced stages of OA</b></p>
<p>Non-pharmacologic therapies not specific to one stage of the condition</p>	<p>N/A</p>	<p>N/A</p>	<p>(108) Acupuncture and osteoarthritis of the knee: a review of randomized controlled trials<sup>108</sup></p> <p>(109) Acupuncture as a symptomatic treatment of osteoarthritis: a systematic review<sup>109</sup></p> <p>(110) Acupuncture for osteoarthritis of the knee: a systematic review<sup>110</sup></p> <p>(111) Acupuncture for peripheral joint osteoarthritis: a systematic review and meta-analysis<sup>111</sup></p> <p>(112) Acupuncture for the pain management of osteoarthritis of the knee<sup>112</sup></p> <p>(113) Aerobic walking or strengthening exercise for osteoarthritis of the knee: a systematic review<sup>113</sup></p> <p>(114) Avocado-soybean unsaponifiables (ASU) for osteoarthritis: a systematic review<sup>114</sup></p> <p>(115) Clinical efficacy of low power laser therapy in osteoarthritis<sup>115</sup></p> <p>(116) Crenobalneartherapy for limb osteoarthritis: systematic literature review and methodological analysis<sup>116</sup></p> <p>(117) Do exercise and self-management interventions benefit patients with osteoarthritis of the knee: a metaanalytic review<sup>117</sup></p> <p>(118) Does the hip powder of Rosa canina (rosehip) reduce pain in osteoarthritis patients: a meta-analysis of randomized controlled trials<sup>118</sup></p> <p>(119) Effect of weight reduction in obese patients diagnosed with knee osteoarthritis: a systematic review and meta-analysis<sup>119</sup></p> <p>(120) The effectiveness of acupuncture for osteoarthritis of the knee: a systematic review<sup>120</sup></p> <p>(121) The effectiveness of exercise in the treatment of osteoarthritic knees: a critical review<sup>121</sup></p> <p>(122) Efficacy of aerobic exercises for osteoarthritis (part I): a meta-analysis<sup>122</sup></p> <p>(123) The efficacy of aerobic exercises for treating osteoarthritis of the knee<sup>123</sup></p> <p>(124) Efficacy of balneartherapy for osteoarthritis of the knee: a systematic review<sup>124</sup></p> <p>(125) Efficacy of strengthening exercises for osteoarthritis (part I): a meta analysis<sup>125</sup></p> <p>(126) The evidence for clinical efficacy of rose hip and seed: a systematic review<sup>126</sup></p> <p>(127) Feet insoles and knee osteoarthritis: evaluation of biomechanical and clinical effects from a literature review<sup>127</sup></p> <p>(128) Homeopathic remedies for the treatment of osteoarthritis: a systematic review<sup>128</sup></p>		

			<p>(129) Is exercise effective treatment for osteoarthritis of the knee?<sup>129</sup></p> <p>(130) Low level laser therapy for osteoarthritis and rheumatoid arthritis: a metaanalysis<sup>130</sup></p> <p>(131) Philadelphia Panel evidence-based clinical practice guidelines on selected rehabilitation interventions for knee pain<sup>131</sup></p> <p>(132) Pulsed electromagnetic energy treatment offers no clinical benefit in reducing the pain of knee osteoarthritis: a systematic review<sup>132</sup></p> <p>(133) Pulsed electromagnetic field therapy and osteoarthritis of the knee: synthesis of the literature<sup>133</sup></p> <p>(134) Pulsed electromagnetic fields for treating osteo-arthritis<sup>134</sup></p> <p>(135) Pulsed signal therapy and the treatment of osteoarthritis<sup>135</sup></p> <p>(136) A review of the literature on shortwave diathermy as applied to osteo-arthritis of the knee<sup>136</sup></p> <p>(137) Safety of acupuncture for osteoarthritis of the knee: a review of randomised controlled trials, focusing on specific reactions to acupuncture<sup>137</sup></p> <p>(138) Short-term efficacy of physical interventions in osteoarthritic knee pain: a systematic review and meta-analysis of randomised placebo-controlled trials<sup>138</sup></p> <p>(139) Splinting for osteoarthritis of the carpometacarpal joint: a review of the evidence<sup>139</sup></p> <p>(140) Ultrasound for osteo-arthritis of the knee: a systematic review<sup>140</sup></p> <p>(141) How efficacious is spa treatment: a systematic review of randomized studies<sup>141</sup></p> <p>(142) Efficacy of balneotherapy for rheumatoid arthritis: a meta-analysis<sup>142</sup></p> <p>(143) Efficacy of transcutaneous electrical nerve stimulation for osteoarthritis of the lower extremities: a meta-analysis<sup>143</sup></p> <p>(144) Integrated exercise and self-management programmes in osteoarthritis of the hip and knee: a systematic review of effectiveness<sup>144</sup></p> <p>(145) Tai chi for osteoarthritis: a systematic review<sup>145</sup></p> <p>(146) Therapeutic exercise for people with osteoarthritis of the hip or knee: a systematic review<sup>146</sup></p> <p>(147) Balneotherapy for osteoarthritis<sup>147</sup></p> <p>(148) Herbal therapy for treating osteoarthritis<sup>148</sup></p> <p>(149) Acupuncture for shoulder pain<sup>149</sup></p> <p>(150) Published trials of nonmedicinal and noninvasive therapies for hip and knee osteoarthritis<sup>150</sup></p> <p>(151) Arthroscopic debridement for knee osteoarthritis<sup>151</sup></p> <p>(152) Autologous cartilage implantation for full thickness articular cartilage defects of the knee<sup>152</sup></p> <p>(153) Aquatic exercise for the treatment of knee and hip osteoarthritis<sup>153</sup></p> <p>(154) Exercise for osteoarthritis of the hip<sup>154</sup></p> <p>(155) Exercise for osteoarthritis of the knee<sup>155</sup></p> <p>(156) Transcutaneous electrical nerve stimulation for knee osteoarthritis<sup>156</sup></p> <p>(157) Evaluation of acute knee pain in primary care<sup>157</sup></p> <p>(158) Electromagnetic fields for the treatment of osteoarthritis<sup>158</sup></p> <p>(159) Acupuncture for osteoarthritis<sup>159</sup></p> <p>(160) Therapeutic ultrasound for osteoarthritis of the knee<sup>160</sup></p> <p>(161) Arthroscopic lavage for osteoarthritis of the knee<sup>161</sup></p> <p>(162) Homeopathy for osteoarthritis<sup>162</sup></p> <p>(163) Meta-analysis: acupuncture for osteoarthritis of the knee<sup>163</sup></p> <p>(164) Traction for hip osteoarthritis<sup>164</sup></p> <p>(165) Interventions for the management of temporomandibular joint osteoarthritis<sup>165</sup></p> <p>(166) Frankincense: systematic review<sup>166</sup></p> <p>(167) Interventions for treating osteoarthritis of the big toe joint<sup>167</sup></p> <p>(168) Thermotherapy for treatment of osteoarthritis<sup>168</sup></p> <p>(169) Home versus center based physical activity programs in older adults<sup>169</sup></p> <p>(170) Progressive resistance strength training for improving physical function in older adults<sup>170</sup></p> <p>(171) Meta-analysis: chronic disease self-management programs for older adults<sup>171</sup></p>
<p>Lifestyle changes</p>	<p>(172) Behavioral Counseling in Primary Care to Promote a Healthy Diet<sup>172</sup></p> <p>(173) Behavioral Counseling in Primary Care to Promote Physical Activity<sup>173</sup></p> <p>(174) Patient education interventions in osteoarthritis and rheumatoid arthritis: a</p>		

	meta-analytic comparison with nonsteroidal antiinflammatory drug treatment. <sup>174</sup>					
Support for high-quality services						
<b>What are the priorities for improving care? Where do the gaps between current and optimal services matter?</b>						
Critical intervention points where practical and significant health gains and service improvements can be made						
<b>What cross-sectoral actions are needed for change to occur?</b>						
Social determinants of health that impact the condition. Interventions required at a local, jurisdictional and national level.						

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