

Effective stakeholder participation in setting research priorities using a Global Evidence Mapping approach

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Accepted 5 April 2012; Published online 18 July 2012

Abstract

Objective: We present a multistep process for identifying priority research areas in rehabilitation and long-term care of traumatic brain-injured (TBI) patients. In particular, we aimed to (1) identify which stakeholders should be involved; (2) identify what methods are appropriate; (3) examine different criteria for the generation of research priority areas; and (4) test the feasibility of linkage and exchange among researchers, decision makers, and other potential users of the research.

Study Design and Setting: Potential research questions were identified and developed using an initial scoping meeting and preliminary literature search, followed by a facilitated mapping workshop and an online survey. Identified research questions were then prioritized against specific criteria (clinical importance, novelty, and controversy). Existing evidence was then mapped to the high-priority questions using usual processes for search, screening, and selection. A broad range of stakeholders were then brought together at a forum to identify priority research themes for future research investment. Using clinical and research leaders, smaller targeted planning workshops prioritized specific research projects for each of the identified themes.

Results: Twenty-six specific questions about TBI rehabilitation were generated, 14 of which were high priority. No one method identified all high-priority questions. Methods that relied solely on the views of clinicians and researchers identified fewer high-priority questions compared with methods that used broader stakeholder engagement. Evidence maps of these high-priority questions yielded a number of evidence gaps. Priority questions and evidence maps were then used to inform a research forum, which identified 12 priority themes for future research.

Conclusion: Our research demonstrates the value of a multistep and multimethod process involving many different types of stakeholders for prioritizing research to improve the rehabilitation outcomes of people who have suffered TBI. Enhancing stakeholder representation can be augmented using a combination of methods and a process of linkage and exchange. This process can inform decisions about prioritization of research areas. © 2013 Elsevier Inc. All rights reserved.

Keywords: Prioritization; Traumatic brain injury; Research funding; Evidence mapping; Research gaps; Rehabilitation

1. Introduction

Health policy makers, health care organizations, and research funding bodies worldwide are faced with decisions of how to best allocate scarce resources. Priority setting is necessary in making choices about the funding for health services and treatments [1,2], research [3], health technology assessments [4], guideline development [5–7], and development of systematic reviews [8].

In prioritizing research spending, a variety of methods have been reported. Some rely heavily on quantitative data [4,6,7], whereas others depend more on the views of key stakeholders and end users [2]. Although there is little

evidence to support the use of one method over another, the consultative approach is thought by many to be more likely to reflect the values of the communities involved and to foster acceptance of the subsequent allocation decisions [2,9,10].

Critical to the process of research priority setting are who sets the priorities and what criteria are used to determine them [11]. Underlying values and assumptions about health problems may differ depending on who is consulted [9,12,13]. Inclusion of end users of research, in particular (e.g., patients, clinicians, policy makers, payers, and researchers), helps to ensure that research priorities reflect the concerns, needs, and values of all stakeholders [9,10]. Lomas's "listening model" highlights the importance of consultation with stakeholders and places particular emphasis on linkage and exchange between decision makers and the potential users of the research [9]. A number of health

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What is new?**Key findings**

- Priority setting methods relying solely on the views of clinicians and researchers without consumer or other input can narrow the focus of the prioritization and ultimately miss questions deemed as high priority by end users.

What this adds to what was known?

- Inclusion of all research end users helps to ensure that research priorities reflect the concerns, needs, and values of all stakeholders.

What is the implication and what should change now?

- Future prioritization should include all relevant stakeholders (e.g., patients, clinicians, policy makers, payers, and researchers) to ensure that the resulting priority areas reflect the values of the communities involved.

research organizations are actively involving stakeholders and end users to identify potential topics for research and review [11,14,15].

The Global Evidence Mapping (GEM) Initiative is a program of work funded by the Victorian Transport Accident Commission to: identify and prioritize research questions in traumatic brain injury (TBI) and spinal cord injury (SCI) research and then map the available research evidence for high-priority questions. The project has spanned 4 years, and the methods used for evidence mapping have been described [16]. The results have been a resource for clinicians, researchers, and policy makers.

In this article, we focus specifically on the processes to identify priority research areas, with four main aims: (1) to identify what stakeholders should be involved; (2) to identify what methods are appropriate; (3) to examine different criteria for the generation of research priority areas in any given field; and (4) to examine the feasibility of linkage and exchange among researchers, decision makers, and other potential users of research. Although the GEM Initiative spanned the acute rehabilitation and long-term care of TBI and SCI patients, for practical purposes, we limit the clinical domain of our discussion to setting research priorities in the postacute rehabilitation and long-term care of patients who have sustained a TBI [17].

2. Methods

We developed a four-step approach to identifying research priorities, in the field of neurotrauma. The first and

second steps are to generate and prioritize, the questions for which research could usefully inform decision making (i.e., what are the questions that need to be answered?). The third step is to map existing research to those questions (i.e., what answers exist for those questions?), and the fourth step is based on reflection about relative importance of individual questions and the quantity and quality of research that exists to answer each one; in order to identify priority areas for research investment (i.e., which questions are not adequately answered and which of these are most important?).

2.1. Step 1: Generating questions

Four methods were used to generate questions; these have been detailed elsewhere [16]. In short, they included:

1. An initial scoping meeting with clinical experts during which we consulted experts to define the research field and identify important clinical issues.
2. A preliminary literature search to identify recent review articles (systematic reviews or otherwise) or guidelines highlighting treatment and management issues that would contribute to articulating the questions.
3. A facilitated mapping workshop to generate issues or questions relating to clinical problems.

The mapping workshop consisted of a brainstorming session using a Nominal Group Technique [18], in which participants were asked to anonymously generate important issues or questions based on their experience of TBI care and record these on individual sticky notes. The nominal group technique uses a structured group process to generate and prioritize ideas, encouraging contributions from every member of the group, and minimizing dominance of the discussion by more vocal group members [18].

Issues could encompass diagnosis, prognosis, interventions, or service delivery and organization. This was followed by an open discussion of the information gathered to gain insight into other perspectives and stimulate further ideas. When time permitted, we explored the influence on clinical care of contextual factors, such as rural or urban location and socioeconomic status.

4. A structured online survey

Members of a purposeful sample of stakeholders (clinicians, researchers, managers, and patient/carer representatives) were asked what they considered to be the most important clinical problems relating to therapies and/or outcomes in rehabilitation care of TBI. Participants were requested to structure their responses in the PICO format (identifying the patient/population, intervention, comparator, and outcome) by specifying a problem, intervention (\pm comparison), and outcome.

From the mapping workshop and the online survey, we obtained fragments of ideas more often than fully formed

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