



Review Article

Patient engagement: What partnering with patient in research is all about



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ABSTRACT

The inclusion of patients on important decision related to healthcare has marked a significant ‘patient revolution’ during the last several decades. Patients now played active roles in personal health decisions, healthcare delivery and policy making, and the development of clinical practice guidelines. Such inclusion of patients’ values has resulted in largely positive effects. The next wave of this ‘patient revolution’ is active and meaningful engagement with patients in health related research. Similar to other aspects of healthcare, it is increasingly recognized that experienced patients, their families, and caregivers, have a wealth of knowledge that comes from living and experiencing a medical condition. By understanding and valuing this experience-based knowledge, research priority setting, research study design, trial conduct, analysis of results and knowledge dissemination can be positively influenced. Patients can challenge our assumptions, align research with the needs of patients, increase transparency and trust in research, and lead to research that has a greater impact on the ultimate care of patients. This new approach to research is timed well with a larger movement towards simple, pragmatic clinical trials better reflecting realistic patient care. While there is still much to be learned about the best methods and exact impacts of patient engagement in research, preliminary results are promising and future venous thromboembolism research will likely benefit from the adoption of patient engagement in research.

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Contents

| | |
|--|-----|
| 1. Introduction | 113 |
| 2. What is patient engagement in research? | 114 |
| 3. Evidence and justification of patient engagement in research | 114 |
| 4. Effective methods of engagement | 115 |
| 4.1. Selection of ‘patients’ | 115 |
| 4.2. Clearly defined patient engagement plan | 117 |
| 4.3. Training and ongoing support | 117 |
| 4.4. Mutual respect and valuing patients’ experiential based knowledge as expertise. | 117 |
| 4.5. Start early and continue throughout | 117 |
| 4.6. Include a plan of for evaluation | 117 |
| 5. Examples of patient engagement in research | 117 |
| 6. Patient engagement in venous thromboembolism research | 118 |
| 7. Hazards of patient engagement | 119 |
| 8. Conclusion and future direction | 119 |
| References | 119 |

1. Introduction

The last several decades have seen a revolution in healthcare delivery, with patients playing a much more active role in their care [1].

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This patient movement is best summed up by the World Health Organization declaration of Alma-Ata: “the people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare” [2]. Patient centred care and shared decision making has largely been accepted and adopted in most healthcare delivery models, with evidence that this leads to better health outcomes for

patients [3,4]. Similarly, healthcare improvement and policy making has shown important benefits from active patient engagement [5]. The importance of the patient perspective, and consideration for patient values and preference, is also reshaping how clinical practice guidelines are developed [6,7]. This patient 'revolution' has now entered the realm of research, with patients becoming active partners with clinicians and researchers [1,8–11], and patient engagement being described as the 'blockbuster drug of the century' [12].

The acceptance and uptake of patient engagement in research has occurred at a slower pace, however, than within healthcare delivery and policy making [10]. The need and importance of patient engagement in the research process is often met with skepticism about patients' ability to contribute, additional costs, and slowing down or interfering with the research process [10]. Too often, patients' role in research is merely symbolic, often referred to as 'tokenism', or to provide a false appearance of inclusiveness [10,13]. Nevertheless, the overall approach to clinical research is now changing, with a greater interest on patient centred outcomes research and pragmatic clinical trial designs, such as comparative effectiveness research [14–16]. The traditional model of clinical trials with strict inclusion/exclusion criteria and complicated protocols needs to be challenged. It is unacceptable for large, expensive, clinical trials to be conducted, but their findings not substantially contribute to clinical practice changes [17]. This often is because comparative arms of trials do not reflect the realities of actual clinical care, inclusion criteria are not generalizable to typical patients, and study outcome are not meaningful to patients [15,17]. Furthermore, existing research is frequently not aligned with the priorities of patients. The James Lind Alliance reported an analysis of 334 studies reporting research priorities for future research, and found most reported researchers' priorities and not those of patients [18]. The movement towards simple pragmatic trials and comparative effectiveness research has opened an opportunity for change, and this change should include patients.

2. What is patient engagement in research?

Patient engagement has been recognized and endorsed by national and international research funding institutes, but terminology and consensus on what exactly constitutes patient engagement is lacking [16,

19,20]. Some groups identify 'patients', while others use terms such as citizen, public, end-users, or stakeholder to encompass broader groups or any group that has a 'stake' in the outcomes of the research (including patients, clinicians, policy makers, payers, etc.) [21]. For the purpose of this review, the term 'patients' will refer to patients, family, and caregivers that have personal experience or have been affected by the health condition being addressed. The precise group of 'patients' to engage should be customized for each individual research context.

Likewise, terms such as 'engagement', 'involvement', 'representative' are used interchangeably in the literature [19,22–24]. For this paper, the term 'engagement' means when patients co-build research programs through meaningful and equal partnerships with clinicians, scientists and other research team members. This type of patient engagement should occur throughout the entire lifecycle of research (Fig. 1). The depth of the engagement with patients might reasonably vary between research scopes and a list of suggested definitions of levels of engagement that is in line with the work of others [11,23,25, 26] is included (Table 1).

The fundamental principle behind patient engagement stems from the realization that whereas clinicians, scientists, and healthcare professionals have disease specific expertise, patients have experience based expertise [5,27]. Experience based expertise is the skills and knowledge that is derived from personal experiences, such as living with a chronic illness and coping with the daily management required, and its impact on one's life. Meaningful patient engagement requires that experience based knowledge be valued and added to scientific knowledge as an approach to research [10].

3. Evidence and justification of patient engagement in research

The current movement towards patient engagement in research is driven by two complementary forces. The first is one of patient empowerment and justice; patients are the funders (through publicly funded research granting agencies), the participants, and the ultimate end-users of research, and they have a right to be part of the process [28]. This argument is often summarized by the phrase "nothing about me without me" [29]. This moral rationale for engaging patients in research argues that regardless of any direct changes (positive or negative) patient engagement might have on the research process, it is of intrinsic

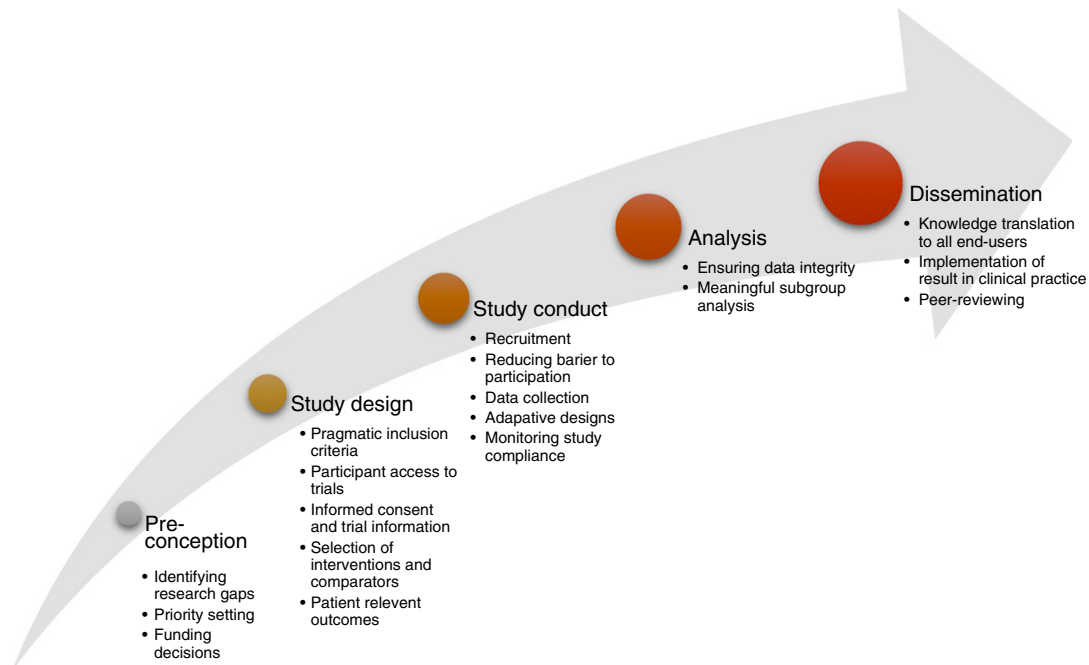


Fig. 1. Patient engagement throughout research.

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