

Active patient engagement: Long over-due in rehabilitation research

Harrison, S.L¹ and Brooks, D^{1,2}

¹ The Department of Respiratory Medicine, West Park Healthcare Centre, Toronto, Ontario, Canada.

² Department of Physical Therapy, University of Toronto, Toronto, ON, Canada.

Patients offer a valuable contribution to developing and improving clinical care. Current foundations and strategies, including the Canadian Foundation for Healthcare Improvement and Canada's Strategy for Patient-Oriented Research, are focused on ways to engage patients' in the development of health services. Furthermore, there is a body of literature reporting on engaging patients in decision-making and policies to promote care delivered across acute settings ¹. In comparison, patient engagement in research has received little attention ².

The concept of actively involving patients in research is more recent. Patients' role in research has evolved from one which is passive, representing a data point, to one which is active and involves contributing to the research process. According to the Canadian Institute of Health Research (CIHR), 'patient engagement' refers to the meaningful collaboration of patients in the conduct of research and is now a requirement of any application for funding ³. The CIHR recommends integrating the 'patient perspective' into every step of the research process ranging from conceptualization of a research idea and protocol development through to translation of the research findings into clinical practice.

Lessons regarding the involvement of patients in research can be gained from other countries. INVOLVE is a government funded program, supporting active patient engagement in health research across the UK ⁴. However, the description of how patients have contributed to the research process is usually only briefly described in published research papers, if at all and therefore the full impact of their involvement is seldom fully understood. Studies need to routinely report detailed information about the method of engaging patients in research and the impact of such engagement on outcomes and continuing research enquiry ³.

Very few published rehabilitation studies have included patients in the research process except as subjects ². In the US the National Institute on Disability and Rehabilitation has recognized the importance of involving patients with disabilities in rehabilitation research ⁴. A number of studies exist exploring the experience of living with a disability ^{5 6 7} and patients with disabilities have been included in program development ^{8;9}. Yet, patient involvement in testing rehabilitation interventions is still scarce ² and may contribute to the current challenges of developing, translating, disseminating and sustaining evidence-based rehabilitation interventions in clinical practice.

Why patient engagement is important

The benefits of actively involving patients in research exist at a number of levels: 1. the patient, 2. the researcher and, 3. the public and the wider community. At the patient level, studies which involve users in the selection of research topics result in the development of research protocols which are grounded in the day-to-day reality of patients' experiences, meaning research questions are more relevant to the needs of the population. An example of this is provided by Morgan and colleagues who recruited individuals who had a stroke as co-researchers in a study to assess the public's knowledge of stroke. As co-researcher, patients role included identifying and directing the aims of the study ¹⁰.

Actively involving patients can facilitate the research process at a number of stages including; development, recruitment, intervention and analysis. Firstly, involving patients during the development of the research protocol can identify patient important outcome measures ¹¹. Secondly, users can provide pragmatic criticism on the content of information sheets assisting in the process of obtaining informed consent ¹². Patient engagement has been shown to enhance participant recruitment and attrition. For example, Carroll et al involved patients in the delivery of a community-based intervention, consisting of one home visit and telephone calls, which was successful in promoting attendance to cardiac rehabilitation ¹³. Patients' insight can increase the chances of developing and delivering an intervention which is feasible, for example users improved the timing of delivering therapeutic massage for individuals with Parkinson disease ¹⁴.

Finally, patients have enhanced the depth of qualitative analysis by adding insight to interpretations ¹².

It has been suggested that the relationship between the community and researchers can be strengthened by patient engagement, improving on the ease of implementing research findings into the clinical service. More broadly, patient engagement builds communication with the community which may subsequently lead to the public's wider understanding of science and research ¹⁵.

How are patients engaged in research?

Identifying patients

According to a systematic review consisting of 142 studies convenience sampling is the strategy most often used, to identify patients to activity engage in research ¹. Some studies recruited patient volunteers from advertisements including posters and the hospital internet pages ¹. New media options such as Facebook, Instagram and Twitter may offer alternative options. Interestingly, recruitment via 'word of mouth' from peers or clinicians did not appear to be a strategy commonly described in the literature and yet, it may present opportunities. For this method to be successful it is important that healthcare professionals are educated with regards to patient engagement and are aware of what the role entails so they can offer accurate information to patients. A combination of different methods maybe the best approach to recruit a diverse sample of patient representatives.

Engaging patients

An active approach to patient engagement is to have patients serve on a research board or advisory council throughout the duration of the study period, in this capacity patients are often referred to as 'patient advisors' or 'patient experts'. The role of a 'patient advisor' may involve; attending research meetings, developing ideas for future research, reviewing study proposals and grant applications and assisting in the translation and implementation of research findings.

Implementation activities may include; writing articles for local newspapers and magazines in addition to scientific journals and, presenting at local events, clinical team meetings and research conferences ².

Patient engagement can be a substantial commitment and it is important that patients are aware of the role requirements from the outset. These can be presented in the form of a contract which the patient and researchers sign. Some institutions pay patients to contribute to research, although the amount varies. The National Institute for Health Research in the UK recommends a daily fee of £150 (\$300 CAD) plus expenses, for preparation, attendance at a research meeting and follow up activities. Payment for reviewing documents (i.e. project briefs) separate from the meeting varies depending on the level and length but ranges from £50 (\$100 CAD) to £200 pounds (\$400 CAD) ¹⁶.

To facilitate patients' ability to contribute to the research process in a meaningful way it is important to ensure adequate training in research methodologies is provided. When appropriate training has not been supplied, meetings can be dominated by patients' personal experience stories rather than suggestions for improvements to the study design ¹⁶. However, the amount of training offered is worth considering as the lines can become blurred between acting as a lay advisor and patients becoming a trained researcher ¹⁷. In fact, patients' role may be time limited; as over time patients become professionals themselves.

The benefits and challenges of patient engagement

A systematic review has described the personal benefits and negative consequences of engaging in research on the patients themselves ¹⁸. Patient engagement appeared to elicit feelings of empowerment and a sense of satisfaction from giving something back to the health and research community. The support and social interactions which stemmed from being part of a team were valued. Patient engagement seemed to contribute to improved disease management by developing disease-specific knowledge and coping strategies. Practical skills in research methodology and presentations were also achieved. Throughout the experience, patients gleaned a deeper trust of research findings and perceived research to be more valuable ¹⁸.

Other papers included in the review reported more negative effects, for example some patients described feeling overburdened, frustrated and marginalized¹⁸. As researchers there are a number of considerations we can make to reduce such negative consequences. Firstly, we need to be mindful of the burden imposed on a patient by their condition, both in terms of disability and the time taken up with health appointments. Such factors may contribute to the low attendance rates documented in research meetings¹⁷. It is important to be realist in our expectations of patients to fulfil their role in research. Offering training in research methodologies can reduce feelings of frustration by improving patients ability to contribute^{19;20}. Feelings of being dismissed and marginalized likely stem from patients perceptions of how researchers view their contribution. There have been concerns that patient engagement in research is tokenistic^{21 22}. Furthermore, community priorities have been shown to influence the scientific rigor of studies, perhaps offering an explanation for why researchers resist input from patients²². Hopefully, tokenistic views, held by researchers and patients, will dispense as the method and impact of patient engagement is more frequently reported in published studies.

Conclusion

In conclusion, patient engagement in rehabilitation research offers significant benefits, to patients, researchers and the community. A diverse group of patient representatives can be recruited through the use of multiple methods and these individuals should be actively involved throughout the research process. The role requirements of patient engagement must be clearly defined and training ought to be offered to enable patients to make a meaningful contribution. Applications for research funding need to include the cost of patient engagement. Involving patients in rehabilitation research is not without its challenges but by valuing the contribution of patients the quality of rehabilitation research can be significantly enhanced, ensuring the conduct of relevant, feasible research which can be more easily transferred to the clinical service.

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