

Editorial

Measuring the impact of patient and public involvement: the need for an evidence base

Over the last decade there has been increasing emphasis on patient and public involvement in different aspects of healthcare activity in the UK and internationally [1, 2]. The importance of involving patients and the public in the re-design of a patient-focused healthcare system has become emphasized and strengthened by recent international health policy [3] and the implementation of recent UK legislation (e.g. Local Involvement Networks [4]). Equally, the imperative of patient and public involvement as a central feature of health services research is being emphasized by its integral role in many research funding programmes and initiatives in the UK (e.g. the Health Technologies Assessment [5]).

Although the UK has experienced extensive patient and public involvement activity in the National Health Service, the international research evidence base underpinning this activity remains partial and lacks coherence. A range of difficulties exist, including poor conceptualization, variable and partial attempts at measurement, and the limited attention that has been placed on evaluating the impact or outcome of involvement [6,7]. Research in this area has often been found to be of poor quality [8], and there have been difficulties related to attributing change directly to patient involvement [9]. In addition, the focus on robust measurement of change and impact that exists in other areas, such as patient-reported health outcomes, has not yet emerged in this area, despite the need to measure the impact of patient and public involvement in a valid, reliable and responsive way. The area is also limited by the lack of an agreed set of criteria specifically designed for assessing the quality of studies. Researchers have to rely on more general quality checklists which may not assess important aspects of patient and public involvement.

These difficulties have hampered the development of an evidence base for patient and public involvement, which practitioners, clinicians, users or researchers can draw on to inform good practice and to develop instruments that can measure the impact of involvement. Instead, individuals undertaking involvement work have to rely on previous examples, intuition and an array of approaches that have not

always been evaluated for a particular setting. While these approaches can often be successful in many ways, they mean that involving patients and the public in the healthcare system is not generally characterized as an area underpinned by evidence-based practice or even by the recognition that ideally it requires evidence to inform best practice.

With these difficulties in mind, we recognize this is a critical time to move forward in developing a coherent evidence base which is conceptually clear and methodologically robust and can inform future instrument development. While some may view involving patients and the public as an altruistic activity which aims to democratize healthcare and so may not require an evidence base in the same way as other areas, this approach has a number of implications. While evidence has become an important concept in health, particularly in relation to clinical and economic aspects of care, the relative lack of an evidence base can mean it is seen as relatively low status and labelled as an 'add-on'. This jeopardizes the important contribution that involving patients and the public can make to the quality of healthcare internationally as it can be easily dismissed. The existence of a strong evidence base would not only help develop evidence-based practice in this area, but could significantly contribute to the 'business case' for involvement. In this way, it would help protect its future role as a key facilitator of cultural change that can enhance the development of patient-focused healthcare. Importantly an evidence base could also help to protect continued funding and encourage more general recognition. All these reasons make the need for an evidence base imperative.

An example of research that will contribute towards closing this gap in the literature is a systematic review being undertaken by our team, which is focusing on the conceptualization, definition, measurement, impact and outcomes of patient and public in health service organization, evaluation and development. This study will help to develop clearer concepts and definitions of what is meant by patient and public involvement. It will also review the measurement approaches that have been used and consider how these can be improved in the future to measure impact. This study will

also contribute to the development of a quality checklist for patient and public involvement. In addition, it will develop an equivalent of the CONSORT statement for clinical trials [10] which will advise researchers on what they need to report in papers in this area, in order to create more coherent and structured reporting, which means appraisal and future synthesis of studies will be more straightforward. It will also mean we have an appropriate evidence base from which to develop more robust forms of measurement and ensure we have the right 'metrics' to capture the impact of patient and public involvement. These metrics can draw on important principles already applied in areas such as quality of life measurement where instruments strive to be conceptually clear, reliable, valid and responsive, among other psychometric qualities [11].

Patient and public involvement has a vital role to play in democratizing healthcare, and also in developing systems and ways of working that are truly focused on the individual, to ensure we deliver the best quality of care. Developing an appropriate evidence base that both supports and enhances this endeavour is essential for the future success of this initiative.

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