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Partners in projects: Preparing for public involvement in health and social care research



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ABSTRACT

In recent years, several UK and, international funders of health and social care related research have adopted the policy of requiring explicit evidence of the ‘public’ voice in all aspects of project design. For many academic researchers engaged within research, evaluations or audit projects, this formal requirement to actively engage members of the public will present them with both benefits and challenges to securing knowledgeable, skilled, and confident lay representation onto project teams. This could potentially lead to the exploitation of those individuals who are available, appropriately informed, and adequately prepared for such activities. Currently, much of the preparation of patients or members of the public for research involvement tends to be aligned to specific projects; however, with the call for greater active and meaningful involvement of lay representatives in future national and international funding applications, there is clearly a growing need to ‘train’ sufficient numbers of confident and competent representatives to meet this growing demand. This paper describes the development of a specifically designed research awareness training programme and underpinning theoretical model, which has been specifically designed to support active and meaningful lay involvement in research, evaluations and audit projects. Developed over a four year period, the course is a culmination of learning extracted from a series of four completed research projects, which have incorporated an element of public and patient involvement (PPI) training in their overall design.

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1. Introduction

Over the past decade, the active and meaningful inclusion of the ‘public voice’ in the development of the health and social care policy and research agenda both

in the United Kingdom (UK) and internationally has been gathering momentum [1–5]. Increasingly, there is global recognition of the value that lay representation can bring to both biomedical and health services research [6,7]; with many developing and western countries demonstrating their commitment to public and patient involvement (PPI) through the creation of national consumer organisations and advisory groups [5,8].

In the UK, since the launch of the Commission for Patient and Public Involvement in Health in 2003, health and social care policy has gradually called for greater inclusion of the consumer ‘voice’ in all aspects of health care commissioning, evaluation and service improvement

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[4,9,10]. Enshrined in the Health and Social Care Act (2012), the arrival of the new ‘consumer champion’, Healthwatch, in April 2013, has clearly re-affirmed the Government’s commitment to strengthen the influence of the citizen and collective community voice in the design, development, and delivery of both local and national health and social care provision. Indeed, the centrality of consumer opinion is a key principle of the NHS Constitution [11]; a position which has recently been clearly re-emphasised in ‘Patients First and Foremost’ [12], the Government’s initial response to the recommendations of the ‘Francis Report’ [13]. Set against this contextual backdrop of re-focusing on person-orientated approaches to healthcare provision which provides value for money and cost effectiveness, it is perhaps unsurprising that a number of significant UK health related research funding bodies [8,14] have adopted the policy of requiring explicit evidence of the ‘public’ voice in all aspects of the design of submitted project proposals, from the identification of the research priority and participating in systematic reviews [15], through to the dissemination of findings, outcomes, and recommendations [16–20].

Despite the strong moral arguments, clear historical precedence, and growing evidence-base for public and patient involvement in research; for many academic researchers, the requirement to demonstrate the active and meaningful involvement of lay representation on research project teams is not without its challenges [21,22]. While it is recognised that many lay representatives may already have some knowledge and experience of research processes prior to becoming involved in projects; there are those with expert patient knowledge who wish to contribute to project teams, who do not have any previous experience of research activities to undertake the role effectively [23]. Therefore, there is evidence to suggest that some lay representatives are being recruited onto several or consecutive project teams to undertake specifically assigned roles and tasks commensurate with their growing research expertise [24]. As a consequence, relatively small numbers of experienced lay representatives are being developed to become involved in healthcare research [25]. In the context of recent policy developments and funding requirements, it could be argued that sufficient numbers of well prepared lay representatives cannot be expected to support this projected explosion, if they do not have access to formal training in generic research processes [23]. Arguably, a more systematic approach to training is necessary in order to build more lay capacity for the future [25].

In response to the growing need to actively and meaningfully incorporate the ‘public voice’ in research, evaluations, and audits, the Public Engagement in Research Programme at the University of Northampton has been specifically designed to support lay representatives, who wish to become more actively involved in health and social care research. Developed over a 4 year period, the course is a culmination of learning extracted from a series of four completed research projects, which have incorporated an element of public and patient involvement (PPI) training in the overall design.

2. Background

The language of public and patient involvement in health and social care policy and research is not new. There has long been a commitment to the meaningful inclusion of the public ‘voice’ in social policy and practice since the 1960s [26]. The emergence of the social model of disability, developed by the Disabled People’s Movement during the 1980s, has provided people with disabilities with a dynamic platform from which to influence the direction of public policy in relation to their specific health and social care needs. Rabiee et al. [27] and Tuffrey-Wijne and Butler [28] argue that since the early 1990s, social researchers, such as Zarb [29] and Oliver [30] have provided tremendous impetus to the growing field of inclusive research, by striving to both access and represent the voices of people with a disability and young people so that their views can both inform and contribute to the evaluations and outcomes of social care and support service reviews for those patient groups.

Equally, the emergence of the survivor research movement in mental health care has also long since incorporated both user-led or user-controlled research, as well as participatory research, within its expanding portfolio [18,31]; as service users and carers have been actively encouraged and empowered to be involved in the delivery and evaluation of mental health services. Simpson and House [32] identified 12 randomised controlled trials (5) and other comparative (7) studies conducted between 1966 and 2001, which described the active involvement of service users as employees, trainers, and researchers in the delivery and evaluation of mental health care, clearly demonstrating a long-standing commitment to actively including the user ‘voice’ in mental health research.

While still controversial within some academic and health circles [20,33]; several explanations have been offered as to the benefits of including the public and patient perspective in health and social care research. Many early studies are keen to point out the benefits accrued from lay representation on project teams. It can be argued that such perspectives ensure that the research process is both transparent and accessible to lay scrutiny, and researchers are more accountable for the ethical and economic decisions made concerning project design [17]. Simpson and House [32] argue that the inclusion of the patient ‘voice’ on the team provides a unique perspective ‘from the inside’ that enhances the validity of the research. Boote et al. [34] and Beresford [35] suggest patients can offer a more holistic real-world interpretation of findings that complements the view of the traditional academic researcher, as the distance between direct experience and its interpretation is more likely to be reflective of their expert knowledge and insight into the disease process or care experience under investigation. Coupland et al. demonstrate that public involvement can facilitate a greater willingness by potential participants to be recruited onto projects. Gillard et al. [19] illustrate that the involvement of service users in project design can both inform the development of the research idea or question, and ensure the user-friendly nature of the interventions and outcome measures incorporated into the overall design; while Simpson and House [9] suggest

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