



# Beyond tokenistic participation: Using representational artefacts to enable meaningful public participation in health service design



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## ARTICLE INFO

### Article history:

Received 22 November 2012

Received in revised form 8 May 2013

Accepted 17 May 2013

### Keywords:

Public participation (PPI)  
Participatory design  
Representational artefacts  
Older people  
Health services

## ABSTRACT

A number of recent policies promote public participation in health service design. Yet, a growing literature has articulated a gap between policy aims and actual practice resulting in public participation becoming tokenistic. Drawing on theory from participatory design, we argue that choosing appropriate artefacts to act as representations can structure discussions between public participants and health professionals in ways that both groups find meaningful and valid. Through a case study of a service improvement project in outpatient services for older people, we describe three representational artefacts: emotion maps, stories, and tracing paper, and explain how they helped to mediate interactions between public participants and health professionals. We suggest that using such representational artefacts can provide an alternative approach to participation that stands in contrast to the current focus on the professionalisation of public participants. We conclude that including participatory designers in projects, to choose or design appropriate representational artefacts, can help to address the policy–practice gap of including public participants in health service design.

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## 1. Introduction

There is a strong policy drive to involve patients and the public in the design of health services for both pragmatic and ethical reasons [1]. In the UK, for example, the Department of Health's report, *Creating a Patient-Led NHS* [2], highlights the contribution of public participation in creating responsive, patient-centred services, while the *National Health Service Act 2006* [3] requires that services are made

accountable to the public through consultation, providing the public with a mechanism to influence decision-making. Policies to encourage participation in health service design can be seen across a wide range of high income countries [4].

Despite efforts to engender participation, there is a growing literature that suggests there is a gap between these policy aims and actual practice [5]. Current participation activities provide little opportunity for impact [6], and when they do, other barriers arise. Public participants can find it difficult to add their experiential knowledge to the conversation and have their contributions considered legitimate within a discourse that is often focused on specialised scientific knowledge [7,8]. The result is that although public participation is now embedded in the structures that support healthcare, its role is frequently tokenistic and the public are often unable to affect outcomes.

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Enabling meaningful, as opposed to tokenistic, participation then requires finding a way for public participants to express themselves and their contributions that is both understandable and deemed valid by health professionals when designing health services. We draw upon theoretical constructs and practical tools from the field of participatory design to do this. In particular, we focus on the use of representational artefacts to structure discussions by providing depictions of current situations or future design proposals in an appropriate language for all. In this paper, we use a case study to show how representational artefacts can help to move beyond tokenistic participation in health service design, and illustrate how the approach could be used to close an important policy–practice gap.

## 2. Background

Public participation is a term that has been applied to a breadth of activities and philosophical stances, leading to much debate about its nature and purpose [9–11] and numerous attempts to characterise its diversity [12,13]. Despite differences in theoretical or philosophical approach, on the practical level, public participation remains tokenistic [12]. Healthcare institutions go through the motions of public participation, but the scope for public participants to affect change is often minimal [6,14,15]. As the opposite of tokenistic, we define meaningful participation as the ability to impact decision-making in health service design settings. Below we consider the practical challenges that must be addressed to enable meaningful participation.

### 2.1. Meaningful participation

The level of public involvement has been commonly characterised by a ladder of participation, each rung signifying the amount of weight given to the public voice [16]. Further theory development broadens this characterisation to encapsulate the mutual exchange of knowledge rather than that of a finite amount of power, and draws attention to the methods used to support participation [17]. The literature suggests that consultation is still the dominant way that the public voice is heard, a method both low on the ladders of participation and one that does not encourage a relationship of mutual knowledge exchange. Meaningful participation then must support the establishment of relationships through involving, collaborating with, or empowering public participants in such a way that they can contribute their knowledge.

One systematic review found 300 case studies that did provide opportunity for meaningful participation; however, many barriers to impacting services were discussed [15]. Public participants are often asked to partake in activities with highly structured, often opaque, protocols for communication, such as sitting on executive boards [18]. Consequently, they need to carefully direct their communication, such as target the chief executive, or as one paper describes it, ‘work the system,’ to get their voice heard, [19]. Yet, many public governors still feel that they do not have the skills to challenge professionals on the board [20]. Public participants cannot take advantage of participation

opportunities if they do not have the skills to interact in the settings in which they are placed.

Lack of receptiveness to the contribution of public participants is another barrier that has been identified. Some studies described situations in which public participation was used to legitimate decisions that organisations would have made anyway [15]. Others highlight ingrained power differences in medical culture between evidence-based medicine and personal (and thus anecdotal) experience [6]. Although anecdotes were appreciated, when resources were allocated, arguments framed in terms of evidence-based medicine had more sway. As a result, the contribution of public participants was often deemed invalid by the health professionals with whom they were interacting.

The published accounts of public participation indicate that the ability of the public to participate can be compromised by the very contexts which are meant to empower, such as being a decision-maker on a board. Accounts also suggest that when a contribution is made by public participants, it is not always deemed credible due to the relative value placed by health professionals on scientific knowledge as opposed to personal experiential knowledge. We would propose that achieving meaningful participation then requires not only providing opportunity to participate, but also facilitating participants’ ability to do so by addressing the mismatch of knowledge bases.

Thompson et al. [21] report that the ability to participate is often achieved through professionalisation of public participants. They describe how experienced public participants put significant energy into learning about the relevant science, either surrounding their condition or the research methods, in order to enhance their communication with health professionals. Participants also highlight previous qualifications (e.g. a medical degree), or recently acquired ones (e.g. training courses), to legitimate the knowledge that they do have. These tendencies are being supported through a greater emphasis on training and support for public participants in order to close what is perceived as a knowledge gap [22].

While the professionalisation of public participants may provide the ability to participate, it raises numerous issues [12]. First, it restricts public participation to those who are willing and able to gain these particular new skills. Second, the nature of the experiential knowledge that public participation is thought to offer becomes questionable, particularly if the diversity of participants is limited. Third, scientific knowledge is maintained as the dominant paradigm against which the experiential knowledge of public participants must be normalised [21]. We would suggest therefore that this approach does not enable meaningful participation.

We propose that meaningful participation requires attention to the specific methods of engagement so that they do not demand that public participants express themselves in unfamiliar ways in order to be understood or considered valid by health professionals. In the next section, we discuss how the field of participatory design has addressed these issues both theoretically and practically with representational artefacts.

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