Towards effective and efficient participatory systems approaches to healthcare work system design

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Towards effective and efficient participatory systems approaches to healthcare work system design
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Abstract

Context: The study is focused on patient and public involvement in the regional service development process in one county in the UK, with a wider scope provided through review of literature.

Objectives: The research has two main objectives: firstly to investigate the current state of service user and staff participation in the regional health service development process in the UK; and secondly to critically analyse the level of participation and systems awareness in the participatory methods used.

Methodology: A single case descriptive case study is used alongside a scoping review of relevant literature that follows a systematic approach.

Main results: The case study explored a complex service development process with the main findings being: i) varied levels of collaboration between multiple organisations of commissioners, providers and user representatives; ii) incomplete information loops with an unclear structure of information flow from service user/staff into the development process and a lack of feedback on changes made to service users; iii) difficulties in representing the views of a diverse population of service users, compounded by some single issue focus amongst service development participants; iv) an engagement gap with staff for service development events. The literature review uncovered practical issues in the application of participatory approaches and a lack of application of systems methods and models in the most widely used participatory approaches.

Conclusion: The review of literature and description of practice found a gap between the practical application of participatory approaches in healthcare system design and theory on systems approaches to healthcare. We propose it would be beneficial to bridge the gap between structured systems approaches to healthcare system design and the current efforts of participatory design occurring in practice.

Keywords: healthcare ergonomics, systems approach, co-design, participation

1. Introduction

It is understood that it is necessary to take a systems approach to healthcare quality improvement to provide sustainable and significant quality and safety improvements to healthcare systems (Carayon et al., 2014). Systems approaches require the involvement of relevant stakeholders to be at their most effective (Hetlinger et al., 2015), in healthcare, staff and patients bring a wealth of knowledge that is needed to understand and improve healthcare systems. Furthermore, involving stakeholders and end users in design is prevalent in contemporary Human Factors and Ergonomics (HFE) theory and practice, with collaboration...
between healthcare and HFE professionals necessary for the discipline to reach its full potential in benefitting healthcare (Waterson & Catchpole, 2015).

Patients possibly have the most complete view of the care they receive and with their families could be useful problem detectors within the healthcare system (Amalberti & Vincent, 2016). However, motivations for patient involvement in healthcare go beyond quality improvement and safety, with service user involvement in the planning and development of healthcare services recognised as a democratic right in nations such as the UK (NHS, 2013). Accounts on the history of patient and public involvement in the UK health service shows involvement spanning both democratic and consumerist approaches (Butler & Greenhalgh, 2011; Coulter, 2013). The democratic and consumerist approaches to involvement are discussed by Beresford (2002) who, while recognising the approach models may blur together at times, describes significant differences between the two. The consumerist approach is said to be framed mainly in market research terms of improvement of products and services through data collection of market testing and feedback, with the initiating agency (e.g. care provider) then deciding what to do with that data and what changes to make (Beresford, 2002). Whereas the democratic approach views inclusion as the achievement of people’s human and civil rights, and is concerned with enabling participants to have direct capacity and opportunity to make change (Beresford, 2002). In HFE and design these involvement models can be related to those of user centred design (consumerist approach) and participatory or co-design (democratic approach). Participatory ergonomics and design describe benefits of stakeholder involvement beyond problem identification, with increased relevance of devised solutions and in the implementation of change; with the proposition that stakeholders are more likely to accept and drive towards changes they have ownership of (Gyi et al., 2015).

This study seeks to explore the current state of involvement and participation in health service design and whether this involvement is done with awareness of the systems approach.

2. State of the art

User involvement and in particular co-design has become increasingly popular in its application to public services, with examples in health (Nesta, 2013), transport and education (Bradwell & Marr, 2008). A type of participatory design has been developed for application to healthcare services in the form of Experience Based Co-design (EBCD) (Bate & Robert, 2007; Robert et al., 2015) with the use of EBCD growing since its 2005 pilot (Donetto et al., 2015). EBCD is a six stage process that can take 9 to 12 months to complete. It involves gathering staff, patient and carer experiences, and using small co-design groups to work on identified priorities and culminates in celebrating and reviewing the project (Robert et al., 2015). A toolkit for EBCD can be found on the King’s Fund website (King’s Fund, 2013).

3. Objectives

This study set out to investigate the current state of service user and staff participation in the regional health service development process. The specific objective was to critically analyse the level of participation and the systems awareness in the methods used. The study aims to identify current implementation gaps to be addressed and the need for further research in order to achieve the effective and efficient application of participatory systems approaches to the design of healthcare services.

4. Methods

The study includes both a case study and literature review.
4.1 Case Study
A descriptive case study approach (Yin, 2013) was adopted to gain a detailed understanding of how participatory approaches were applied for health service development at a regional level in one county in the UK. The case study was centred on one Clinical Commissioning Group (CCG) which plans and purchases health services for a population of 366,000. Data were collected through six semi-structured interviews, documentary analysis and observations at meetings and events.

The six interviewees consisted of members of patient representative groups (n = 4), commissioning group patient experience officers (n = 1), and a member of the voluntary and community sector (n = 1). The documentation used for analysis consisted of reports and meeting minutes from staff and service user engagement events, collected for the period of January to September 2015, 35 documents were included in the analysis. Topics covered in the interviews included: descriptions of service design approaches, information flow between stakeholders, level of stakeholder engagement, barriers to collaboration and use of IT support. Observations were made at service development board meetings, engagement events and market research events. The data from observations, documents and interviews was converged and analysed thematically. Ethical approval was granted from the Loughborough University ethics committee and the research was deemed as non-portfolio work thus not requiring NHS ethical approval. All participants gave informed consent.

4.2 Literature Review
The review aimed to answer the following research questions:
- What methods of participation have been used in healthcare service and system design?
- What challenges were found in applying participatory approaches to healthcare?
- What opportunities exist for future research?

The electronic databases of Google scholar, Scopus, Science Direct and PubMed were searched using combinations of the search terms healthcare/health service and participatory design/co-design/participatory ergonomics and co-creation. To prioritise articles the review includes articles on projects where patients, public and healthcare staff had been actively involved in analysing and designing a healthcare service, process, organisation or work system.

5. Results

5.1 Case Study Findings
The case study explored a complex service development process with the main findings being:

i) varied levels of collaboration between multiple organisations of commissioners, providers and user representatives;

ii) incomplete information loops with an unclear structure of information flow from service user/staff into the development process and a lack of feedback on changes made to service users;

iii) difficulties in representing the views of a diverse population of service users, compounded by some single issue focus amongst service development participants;

iv) an engagement gap with staff for service development events;
The involvement process most closely resembled a consumerist model, with data collected from service users and then processed and presented to commissioners and health service providers through reports and oral presentations. The providers and commissioners then decided what to do with the data and how to use it to inform design. Data collection was undertaken through surveys, short interviews and some workshop activities involving emotional mapping and the sharing of a developed vision for community health services. The main issue raised at the data collection stage regarded difficulties with representation of service users and frontline healthcare workers. Time constraints for busy working healthcare staff and service users make involvement in lengthy service development events difficult. There is also difficulty in representing the diverse population of service users and particularly seldom heard groups, these issues were expressed in the interviews e.g.:

‘The difficulty is how to get in touch with the 12,000 people though. Which is how many we represent’ – Interview 5

‘It’s the people that you never get, we’ve not yet cracked how to engage them’ – Interview 4

‘In my view you’re not necessarily getting a broad spread of people. And often it’s driven from a personal agenda rather than a wider agenda’ – Interview 2

It was unclear how the information collected from service users was translated into service changes by healthcare providers. At the same time, there was a lack of feedback of changes to service users. This was also mentioned by three interviewees:

‘And I think the next bit of the loop is how do we then go back and go full circle to make sure that the improvements or the recommendations we’ve made: A. are being taken seriously and B are being implemented.’ – Interview 2

‘They don’t tend to give us much feedback on how we’ve influenced them. As an organization it can be quite difficult to see what impact we’ve really made.’ – Interview 1

‘A lot of people have told us that they can’t see, and we said this at consultation, where have they done it? They haven’t. So there’s that kind of disconnect.’ – Interview 1

‘We’re not always very good at feeding back. And I know when I’m out talking to people, one of the things they say is that you don’t really feed back to us do you.’ – Interview 6

On the methods used within the process, there was limited application of service design methods and no evidence of HFE system design methods. The experience gathering methods used were based on EBCD, with emotional mapping in use, and there were some co-design elements within service development, however EBCD itself was not found to be carried out in its entirety.

5.2 Literature review

After screening titles and abstracts, 46 articles were taken forward for full text review, after removal of theory based articles, duplicates and those without access to full text versions, 28 articles relating to 19 projects were included, a summary of these is provided in Table 1.
5.2.1 Types of participation

All of the included projects had recognisable elements of the democratic model of involvement. Of these 12 of the 19 projects referred to co-design as the participatory method used within the project, with 10 of those using EBCD. Simulation, action research, the Delphi technique and participatory ergonomics were the other face-to-face participatory approaches used. In 2 projects the web was used, through an open innovation platform and a wiki as a participatory tool.

Table 1. Summary of literature

<table>
<thead>
<tr>
<th>References</th>
<th>Project application</th>
<th>Participatory methods</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowen &amp; Dearden, 2010 Bowen et al., 2010 &amp; 2013 Morrison &amp; Dearden, 2013 Wolstenholme et al., 2010 &amp; 2016</td>
<td>Outpatient services for older people</td>
<td>Co-design (EBCD)</td>
<td>Patients and staff</td>
</tr>
<tr>
<td>Cooper, Gilmore &amp; Hogg, 2016</td>
<td>Adult psychological therapies service</td>
<td>Co-design (EBCD)</td>
<td>Patients and staff</td>
</tr>
<tr>
<td>Donetto et al., 2014</td>
<td>Survey of EBCD applications</td>
<td>Co-design (EBCD)</td>
<td>Patients and staff</td>
</tr>
<tr>
<td>Gustavsson, 2014</td>
<td>Neonatal care</td>
<td>Co-design (EBCD)</td>
<td>Patients and staff</td>
</tr>
<tr>
<td>Larkin et al., 2015</td>
<td>Mental health</td>
<td>Co-design (EBCD)</td>
<td>Patients and staff</td>
</tr>
<tr>
<td>Lcock et al., 2014 Lcock et al., 2014</td>
<td>Intensive care and lung cancer in England</td>
<td>Co-design (Accelerated EBCD)</td>
<td>Patients and staff</td>
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<tr>
<td>Mulvale et al., 2016</td>
<td>Child and youth mental health</td>
<td>Co-design (EBCD)</td>
<td>Patients, families and staff</td>
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<td>Pickles et al., 2008 Bate &amp; Robert, 2007b</td>
<td>District general hospital neck cancer service</td>
<td>Co-design (EBCD)</td>
<td>Patients and staff</td>
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<tr>
<td>Springham &amp; Robert, 2015</td>
<td>Mental health and community services</td>
<td>Co-design (EBCD)</td>
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<td>Tsianakas et al., 2012</td>
<td>Breast and lung cancer services</td>
<td>Co-design (EBCD)</td>
<td>Patients and staff</td>
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<tr>
<td>Bowie et al., 2015</td>
<td>Design of a safety checklist at a general practice</td>
<td>Co-design - face to face workshops - Adapted Delphi technique</td>
<td>Staff</td>
</tr>
<tr>
<td>D'Young et al., 2014</td>
<td>Services for adults with haemophilia</td>
<td>Co-design - focus groups</td>
<td>Patients and family members</td>
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<tr>
<td>Elg et al., 2012</td>
<td>Orthopaedic, rehabilitation and gastroenterology care processes</td>
<td>Action research - Patient diaries - Workshops with staff</td>
<td>Patients and staff</td>
</tr>
<tr>
<td>Farmer and Nimegeer, 2014; Farmer et al., 2015; Nimegeer et al., 2011</td>
<td>Rural primary healthcare services</td>
<td>Action research - Card sorting</td>
<td>Public</td>
</tr>
<tr>
<td>Hempe et al., 2013</td>
<td>Specialist service for adults with intellectual disabilities</td>
<td>Delphi method</td>
<td>Carers, staff, policymakers</td>
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<tr>
<td>Anderson &amp; Broburg, 2015</td>
<td>Hospital work systems</td>
<td>Simulation – full scale mock-ups and table-top models</td>
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<td>Xie et al., 2015</td>
<td>Family-centered rounds process</td>
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<td>Bullinger et al., 2012</td>
<td>Design of products and services for rare diseases</td>
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<tr>
<td>Den Breejen et al., 2012</td>
<td>Clinical guideline development</td>
<td>Wiki as a participatory tool</td>
<td>Patients</td>
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</table>
5.2.2 Effectiveness of participatory approach

Many of the articles were limited in formal evaluation of the approaches used; however most of the reflections on co-design methods were positive about the approach. One of the main criticisms of co-design and specifically the EBCD approach is in the seemingly small-scale changes when considering the time given by staff and patients to see projects to completion (Donato et al., 2014). One previous co-design project has reported on a lack of sustainability in quality improvement, with improvements that occurred during the project beginning to reverse once the co-design had ceased (Springham & Robert, 2015). There is a lack of evidence on the long-term impact of participatory approaches.

5.3 Representation

Representation is a key issue found in both the case study and literature review. Participants in the case study reported on the difficulty in representing diverse populations and a reported gap in staff engagement in participatory work. Literature reported on the difficulties in representing multiple stakeholders (Xie et al., 2015), potential bias on self-selected participants in using both the Delphi technique (Bowie et al., 2015; Hempe et al., 2013) and co-design (Tsianakas et al., 2012) and difficulties in involving vulnerable patients (Mulvale et al., 2016). There are reports of staff feeling guilty about devoting time to co-design projects causing them to drop out of the process (Bowen et al., 2010). The potential use of the web in broadening representation is considered in two studies (Bullinger et al., 2012; Den Breejen et al., 2012) this exploratory work shows early promise, however the case study element of this work found a lack of IT infrastructure in place and the use of web based collaboration may be far from everyday practice.

5.4 Systems awareness

There was a lack of systems awareness in both the case study and literature review. Within the literature the Systems Engineering Initiative for Patient Safety (SEIPS) model (Carayon et al., 2006) was used in 2 projects, beyond this there was no formal use of systems models or approaches in either the literature or case study. In the approaches used it appears there is little understanding of how potential changes that are suggested and implemented could impact on other parts of the system in question. This lack of systems understanding may impact on the ability to deliver recommendations and change beyond the small-scale changes that are the most common outcome of co-design work.

6. Discussion

The main findings relate to challenges in the application of time consuming participatory approaches with multiple stakeholder groups, the difficulties of implementing change in complex healthcare systems and issues of representation.

The case study found a predominantly consumerist approach to involvement with some elements of co-design, although the level of impact service users and staff had on decisions and change appeared to be low. The literature explored projects aligned more with the democratic approach to involvement with a growing use of co-design methodology. There is limited evaluation of the effectiveness of either approach in achieving long-term, sustainable improvement. In a survey of co-design projects one of the main criticisms of co-design and specifically the EBCD approach is in the seemingly small-scale changes when considering the time given by staff and patients to see projects to completion (Donato et al., 2014). Alongside the most often reported small-scale changes in previous co-design work, the case study participants found difficulty in seeing how the information gathered from patient and public
involvement was actioned and translated into changes by service providers. There appears to be a lack of systems awareness in the main approaches used. Two projects in the literature used a systems model (SEIPS) to guide improvement work, but no evidence of use of systems methods and models was found in the case study or the EBCD methodology.

From a patient safety perspective there can be interest in using staff, patients and public as quality detectors within healthcare systems. There was criticism in the public inquiry into the failings at Mid-Staffordshire trust (Francis, 2013) that both the patient involvement model and the staff whistleblowing model were ineffective in uncovering the issues at their hospital trust in a timely manner. The changes and reorganisations of the health service in the UK has meant the model of involvement investigated in this study is different to the model that existed during the Mid-Staffordshire incidents, however it is unclear how effective this model is at using patient feedback in detecting issues and analysing system performance. It is said that the use of STAMP (Systems Theoretic Accident Modelling and Processes) can improve system performance analysis, with the concept of safety constraints providing direction to identifying leading indicators for changes over time that could increase risk of accidents (Leveson, 2012). Research could follow by using STAMP to learn from both the Mid-Staffordshire incidents and to explore the feedback mechanisms within current safety control structures in healthcare systems with the potential of making recommendations for improvement.

7. Future direction

This exploratory study leads to planned future research involving prescriptive work applying STAMP in the participatory design of healthcare services and work systems. We see potential in finding a balance between structured systems approaches of HFE and participatory design approaches. Research will consider how using structured systems approaches will influence the analysis and design of work systems by patient safety and healthcare staff, and investigate the usability and usefulness of systems methods.

References


