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Participatory Healthcare Service Design and Innovation

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ABSTRACT

This paper describes the use of Experience Based Design (EBD), a participatory methodology for healthcare service design, to improve the outpatient service for older people at Sheffield Teaching Hospitals. The challenges in moving from stories to designing improvements, co-designing for wicked problems, and the effects of participants' limited scopes of action are discussed. It concludes by proposing that such problems are common to participatory service design in large institutions and recommends that future versions of EBD incorporate more tools to promote divergent thinking.

Author Keywords

Experience based design, Older People, Service Design.

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI); Miscellaneous.

INTRODUCTION

User-centred Healthcare Design (UCHD) is a UK team of researchers and practitioners from design and healthcare developing methodologies for healthcare service design. Our approach has a focus on people's lived experiences (McCarthy and Wright, 2004) and a commitment to participation in designing as a means of ensuring that what is designed is relevant to their practices, needs and values. Our first step within this work was to understand how patient experience and participation are already used for service design in the UK's National Health Service (NHS), which led us to the Experience Based Design (EBD) approach. We applied EBD methods to improve outpatients' services for older people at Sheffield Teaching Hospitals. Our experiences have identified some limitations in EBD and some challenges for participatory service design in large institutions generally.

EXPERIENCE BASED DESIGN

Experience Based Design (Bate and Robert 2007, NHS Institute for Innovation and Improvement 2010) was developed and is subsequently employed within the UK's NHS as an approach for the design of healthcare services and can be regarded as the 'state of the art' for participatory design of services within the NHS.

Rather than being a single prescriptive method, EBD provides a range of techniques and tools within a four-

phase structure for patients, carers and staff to work together to: *capture* and then *understand* their lived experiences of healthcare; *improve* a service based on this understanding; and *measure* the effects of change.

In capturing experience, EBD's primary focus is on participants' stories of using or working in the service, told in their own words. One-to-one interviews and video diaries can be used. In this it can be related to scenario and narrative based design approaches (Carroll, 1995; Dearden et al., 2006). Patients, carers and staff use their stories to identify where service improvements are required by creating 'emotional maps'. In groups, participants share their stories and identify 'touchpoints' (points of interaction with the service such as a letter, a phone call, or a physical interaction with a person) and their feelings at each touchpoint. Participants plot these touchpoints and emotions on a long chart with the stages of a patient's journey (or a staff member's day) placed along the top. Positive emotions are placed towards the top and negative emotions towards the bottom. Clusters of negative emotions around touchpoints on the map then suggest areas for improvement.

EBD suggests facilitating 'co-design' teams of patients, carers and staff to explore and implement service improvements, based on the understanding developed in earlier phases. Finally, evaluation of service improvements is shared with participants.

OUTPATIENT SERVICES CASE STUDY

Local Context

Sheffield Teaching Hospitals obtained funding for a one-year service improvement effort on "*Better Outpatients Services for Older People*" (BOSOP), which provided an opportunity for us to explore the EBD approach. The trust includes numerous specialised outpatient departments across two large hospitals but BOSOP focussed on general medical outpatients (MOP) at the Royal Hallamshire Hospital with the aim of sharing the generalisable findings with other departments.

Participants

12 older patients and carers were recruited from MOP clinics and via Sheffield Churches Council for Community Care (SCCCC), a voluntary organisation who provide support such as help with hospital attendance and discharge. SCCCC staff also participated as advocates for older people, to represent their organisation's service users and their own experiences as carers.

Nine outpatients staff were recruited including nurses, the ward sister, a health support worker, outpatients clerical staff, an ambulance dispatcher, a medical doctor, and a hospital volunteers coordinator. Most were 'front-line'

staff performing rather than managing the regular operations of the department. The number of participants engaging in project activities varied due to patients' availability and staff work pressures, but a core group of five patients, five SCCCC advocates and six staff were significantly involved throughout.

A project steering group was established consisting of senior managers for relevant areas, representatives from a patient forum and SCCCC, an MOP nurse (Anne), and ourselves as UCHD researchers.

Process

Capturing Experiences

EBD is geared towards healthcare staff rather than skilled researchers using its tools to affect change. Therefore nurse Anne and the SCCCC participants collected patient stories and the researchers collected staff stories following a training session on conducting informal 'story telling' interviews and using digital audio recorders as these skills were unfamiliar to them.

Notable in the patients' stories was the breadth of the 'patient journey' covered and the compelling accounts of the emotional highs and lows of using outpatient services and the hospital more generally:

"The very fact of going to hospital for something reasonably straightforward [...] can be a worry. [...] If you have got to wait for an appointment, there is that amount of time, for you to build up an emotional concern about it. Getting there is also [a] building-up of emotional tension. And then when you get there; I've had an ECG before. Even so, you know it's uncomfortable.. It's a disturbance.. It's an emotional [...] roller coaster." Q1: Jack, Patient

"We were a little bit late and we couldn't find anywhere to park [...] so [my daughter] went ahead to get my appointment and I fell, right outside the Accident & Emergency place. [...] There was an ambulance driving through. [The driver] stopped and got out and a man that was walking by, they came and lifted me up. They were fantastic. It shook me up. [...] I grazed my elbow and I grazed my hip but I didn't break anything and we got in there and saw the doctor and I was okay. [...] You see I'm frightened of being late." Q2: Ruth, Patient

"The staff are fantastic. As I walked in the staff sang happy birthday to me!" Q3: Jimmy, Patient

Understanding Experiences

Two half-day 'experience events' were held where separate groups of patients and carers, and staff shared their stories and produced emotional maps of their experiences. At a third experience event both groups shared their maps (and stories) with each other and used them to collectively agree which areas of the service needed improvement. This included: the information patients received prior to their outpatient visit; the scheduling of appointments and hospital transport; the facilities for dropping-off patients at the department; and getting help and information on arrival and during a visit.

Improving Experiences

Participants formed two 'co-design' teams who then met regularly over two months to discuss their agreed areas

and propose improvements. Participants used 'action cards' from the EBD toolset to record their intended activities and to set the agenda for following meetings. At the end of this period a plenary event was held to review and prioritise the proposed improvements and divide them into a series of implementation projects. In some cases, the actions required to implement the improvements were straightforward:

- Patients were reluctant to use one waiting area as nurses could not readily see it from where they called them in to see their doctor. So, participants requested convex security mirrors to improve visibility.
- Staff were receiving numerous queries from patients and visitors following the removal of a toilet sign along with a relocated department's sign. Participants therefore had the toilet sign re-instated.

However other proposals needed developing further and required more involved implementation:

- Patients had difficulty navigating the hospital. Participants consequently proposed to develop and test new way finding materials but needed to recruit two post-graduate graphic design students to help them devise prototypes.
- Patients were unhappy with outpatient appointments often occupying most of a day. Participants identified this as largely due to the scheduling processes and the interactions between the hospital and ambulance service. Much of the detail of these processes was inaccessible to participants so the researchers modelled the existing systems and devised an alternative, titled *Flexi-list*. Even so, this proposal was halted at an outline stage due to difficulties engaging with process managers and considering all the scheduling process' dependencies.

Other co-design and implementation activities presented different challenges. Two detailed examples follow.

Improving Appointment Letters

Patients, carers and staff agreed that the information patients received prior to a visit should be clearer and more comprehensive to reduce the anxiety that patients experienced in their initial contact with the service. A co-design team evaluated existing appointment letters and designed a new letter addressing their concerns. The new letter had a photograph of the correct entrance (rather than an abstract number), a list of items to bring (e.g. a urine sample) and a description of the likely format of a visit (e.g. that it may take a full morning or afternoon).

The plenary event agreed that the new appointment letter should be tested with older patients. Although participants volunteered to assist with this implementation project, it was mainly undertaken by the researchers as it required liaison with stakeholders that patients and staff did not have the time or resources for. E.g. gaining approval from the hospital's patient liaison service, and resolving the technical implementation of the letter through the hospital's existing IT systems.

The new letter was subsequently piloted with the MOP clinic's new older patients and is now used as standard for MOP clinic appointments. It has also become a template for good practice across the organisation.

Improving A Road

Several patients described the difficulties of visiting outpatients by car, such as Ruth's story (Q2, above). Ruth was shaken by her fall but the situation was exacerbated by her fear of being late for her appointment. Consequently facilities for dropping off patients (and parking) were agreed as areas for improvement.

The Hallamshire Hospital consists of several buildings in a concentrated area on the edge of the city centre with a mixture of public and hospital-owned roads between them. These roads become very congested and the area outside the outpatient building ('A' Road) has to cope with waiting ambulances, taxis and cars dropping off and waiting for patients, space for disabled parking, and cars entering and leaving a small multi-storey car park (fig. 1).



Figure 1: Main Outpatients building entrance, A Road

The majority of the co-design team's work on this area was fact-finding: why some disabled parking spaces had been removed, where and how long taxis could wait, and how long visitors could park for free. Dorothy (advocate) and Ruth (patient), undertook a 'mystery patient' visit to record the experience of a first time visit (Dorothy had not visited before), after which they noted that crossing A Road made them feel uneasy and vulnerable.

Two other team members, Jack (patient) and Joe (advocate), proposed some changes to A Road to improve facilities for 'dropping-off' and pedestrian access, but felt that they did not have the expertise to produce practical suggestions. The team agreed to seek external help. The team discovered that Kevin, a hospital estates manager, had commissioned a safety study from the Transport and Highways division of the City Council. Richard, the report's author, agreed to assist the team.

Jack (patient) and Anne (nurse) worked with the researchers to review the study and write an appendix detailing patient and staff experiences not previously considered in the engineering deliberations. In a session with Richard and the researchers, Jack & Anne developed a new road layout using large-scale maps, models and drawing materials. Richard refined the proposal into a detailed technical drawing, which was presented to Kevin in the hospital's estates department.

Kevin was enthusiastic about the proposal as being "achievable", tying-in to previous proposals (by the hospital and Sheffield City Council), and having the potential to improve the situation. However he was unable to progress the proposal directly and promised to discuss it with the hospital's estates director.

Measuring Improvements

EBD recommends evaluating improvements using both subjective measures (e.g. patients' experiences) and objective outcomes (e.g. attendance rates) but does not provide an explicit process. Although some evaluations took place during the project (such as patient surveys on the new letter), shared evaluation of outcomes was challenging. This is because isolating the effects of individual changes in a complex institution such as a hospital is difficult (e.g. attendance rates are affected by several factors besides appointment letters). The researchers are therefore developing a mixed methods evaluation framework to assimilate the multiple inputs, processes, data and outputs of the project, informed by Realistic Evaluation (Pawson and Tilley, 1997).

REFLECTIONS

Reflecting on our use of EBD we identified some limitations.

Beyond Experience Based Fixing

We found that EBD provides effective techniques for drawing out participants' experiences of healthcare services and identifying areas for improvement. However it provides less guidance on how to move from stories to designing improved services. The *Guide and Tools* booklet supporting EBD includes 24 and 22 pages on the *capture* and *understand* phases with only 12 and 8 on *improve* and *measure*. The main improvement tools the booklet provides are a simple form that maps an identified problem to a proposed action, and cards for recording these actions, with no specific tools to encourage divergent thinking, although web resources are suggested (www.institute.nhs.uk/thinkingdifferently).

Generating ideas in general discussion meetings, as EBD suggests, is well suited to identifying and implementing changes that are easy to accomplish, often in the form of 'fixing' what is 'broken' rather than searching widely for radical solutions. In BOSOP, the needs for the toilet sign and waiting area mirrors were quickly identified and straightforward to solve. However where the means for improvement were not immediately obvious, such as with A Road, the toolkit offered little assistance. Our strategy was to set up discussions with external specialists around the identified problems.

EBD's co-design methods tend to delineate problems and converge toward solutions early in the process, when exploring alternative framings could reveal different issues and identify radical opportunities. Design involves problem setting as well as problem solving, often challenging and reframing the given design brief (Schön 1995). This is particularly important with complex problems.

Co-designing for Wicked Problems

In BOSOP, some areas displayed the features of "wicked problems" (Rittel and Webber, 1973). For example, there were numerous ways that patients' experiences of using A Road could be improved (physical layout, parking restrictions, taxi waiting times, traffic flow in surrounding roads etc.) with each tactic altering the nature of the problem, and no clear single solution to all aspects. Some BOSOP problems were "tame" (ibid.) – all the

information necessary to solve them could be gathered in advance (e.g. the toilet sign). Wicked problems resist analysis-synthesis approaches as some of the information required to tackle them only becomes apparent when attempting their solution.

Designers deal with wicked problems by devising and envisaging (through sketching and prototyping) potential solutions rather than attempting to break down and detail every influencing factor first (Buchanan, 1995).

A Road could not be tackled by working in the problem space alone (via fact-finding). By creating and imagining alternative road layouts, participants began working in the solution space, which revealed new aspects of the (wicked) situation and enabled them to better understand how it might be improved. Participants' discussions then became less about "what causes this problem?" and more about "is this an improvement?"

Designing was straightforward when the skills and tools were accessible (e.g. a word processor to draft letters) but required specialist expertise when working in technical domains (e.g. a new A Road layout).

EBD considers patients, carers and staff as partners throughout the process. Including additional experts then means facilitating participatory engagement with them without moving down the "ladder of participation" (Arnstein, 1969), e.g. for A Road, producing the report appendix was "informing" participants of the hospital's mechanisms for change whereas the road layout proposal was "consultation" of participants' ideas for change.

Service Design and Scope of Action

Another obstacle to improving the service in BOSOP was participants' limited scope of action. Many elements that contribute to patients' experiences of the MOP service are not under the direct control of its staff and managers, e.g. arrival at the hospital is mediated by other agents such as the city's traffic planning department, taxi and bus services, the operators of the multi-storey car park, and the ambulance service. All of these agents can affect patients' experience of arrival and waiting and individual participant's responsibilities within a large and managerially complex institution do not enable them to implement changes of such a wide scope.

Although the new appointment letter was straightforward to design, its implementation required integration with existing IT systems and clerical processes and approval from other stakeholders across the Trust. Thus, implementation required effort by staff participants to persuade external agents to make changes. The suggested changes to improve way finding had to take into account NHS signage and branding regulations, and changes could only be made by presenting recommendations to a Trust-wide committee for their consideration. Similarly, the new A Road layout could only be offered as a design proposal to the Trust's Estates department.

In some instances change would have been easier with more middle-management participation, such as exploring the *Flexi-list* for appointment scheduling. However we believe these difficulties are symptomatic of

re-designing services in large institutions in general, particularly, as with BOSOP, where services must continue operating throughout the change process.

CONCLUSION

Improving the outpatients service in BOSOP highlighted some challenges that we believe are common to the participatory design and innovation of services in large institutions. Co-design activities should resist converging to solutions too early, instead creating space for participants to step back and explore common factors and more radical solutions. Although participants' limited scope of action in large institutions can hamper implementation, designing offers a way of tackling the wicked problems often encountered in service design. Consequently, future versions of EBD should include more techniques and tools to help in envisaging and exploring alternative possibilities.

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