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ORGANISATIONAL MATTERS

Experience-based design: from redesigning the system around the patient to co-designing services with the patient

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Involving patients in service improvement and listening and responding to what they say has played a key part in the redesign of healthcare processes over the past five years and more. Patients and users have attended stakeholder events, participated in discovery interviews, completed surveys, mapped healthcare processes and even designed new hospitals with healthcare staff. However, to date efforts have not necessarily focused on the patient's experience, beyond asking what was good and what was not. Questions were not asked to find out details of what the experience was or should be like ("experience" being different from "attitudes") and the information then systematically used to co-design services with patients. Knowledge of the experience, held only by the patient, is unique and precious. In this paper, attention is drawn to the burgeoning discipline of the design sciences and experience-based design, in which the traditional view of the user as a passive recipient of a product or service has begun to give way to the new view of users as integral to the improvement and innovation process.

The government has set itself the aim of a "patient-led NHS". But our health services still have a long way to go before we can say that they are really putting patients first. Being an NHS patient is too often a frustrating experience.

In the wider context of healthcare reform, there is growing recognition that although the process and current pace of change will continue, the way in which that change happens (including the move towards more patient-centric services) will need to be different. Existing perspectives, methods and approaches (and the underlying theories that drive them) cannot be relied on to deliver the required change in the time and on the scale required.³ It is necessary to widen and intensify the search for "better" and more effective theories and approaches to large-scale change and whole systems transformation, particularly those at the participative end of the spectrum. However, although the need for new and innovative approaches is broadly accepted, most sources currently do not specify what these approaches are, or where they will come from.

DESIGN SCIENCES

One rich, and as yet largely untapped, corpus of knowledge and ideas is the wider discipline of design sciences and the design professions, such as architecture, and computer, product and graphic design. Healthcare may sound a far cry from the worlds of product design and architecture, but one thing unites this extremely diverse group of professionals and gives them good reason for moving closer to each other: the common aim of making it "better" for the user. And, more specifically, doing this by making the users integral to the design process itself and focusing on the experience "inside out" of their moving through the service and interacting with its various parts.

A further reason for strengthening the link between healthcare design and the discipline of design more generally is that "good design" of healthcare services—and the resulting "good experience"—is essentially no different from good design in any sphere (fig 1), this being a function set by Berkun⁴ (adapted by Bate *et al*³).

Healthcare has always been associated with the first two aspects of design (performance in terms of the use of evidence-based practice, pathways and process design; and engineering in terms of clinical governance and standards and safeguards for patients), but arguably it has

Designing—or redesigning—healthcare processes from the patient's perspective has been a key concept in contemporary improvement efforts. All developed countries around the world have seen a rapid growth in practical redesign initiatives, which have in common the aim of thinking through the best process to achieve speedy and effective care for patients and users.¹ However, although "patient/user involvement" has been around healthcare for a long time now, unfortunately what it gains in longevity, it seems to lack in vitality and urgency. The ground, and the language itself, often appear tired and the phrase "patient centred" grossly overworked. Although these may be providing a particular set of insights and approaches, they may also be suppressing or shielding out others.

There is also the issue of the gap between the rhetoric or ideology and the practice. In most countries, despite the longevity of the "patient involvement" concept, healthcare systems are still not putting patients first. A recent influential report² suggests that the health service in England could often seem to be designed around the needs of healthcare staff rather than patients. Although there was much for the health service to celebrate, the authors added that

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Abbreviation: EBD, experience-based design

never been engaged in anything to the same extent as with the third (designing human experiences, as distinct from designing processes). The three are very different. For example, one can have the perfect process (fast, efficient, no bottlenecks) or pathway (evidence-based) but an incredibly poor experience, or even a poor quality process and pathway, and a reasonable or good experience. One wonders what is the point of a great process and a terrible experience, which is why we believe the balance needs to be restored to take account of the latter. Rather, the traditional mindset continues to focus on preference and choice; listening, understanding and responding; and support, consultation and complaints, where influence rather than experience is the focus.

We suggest that designing services, environments, interactions and processes for the human experience—literally targeting experience—poses a formidable, but highly worthwhile, challenge for healthcare improvement professionals. This is not just about being more patient-centred or promoting greater patient participation. It goes much further than this, placing the experience goals of patients and users at the centre of the design process and on the same footing as process and clinical goals.

Examples from the US include ongoing work led by the Institute for Family-Centred Care, which focuses on the experience of care and shows that the active participation of patients and carers in clinical care and quality improvement enhances outcomes.⁵ Similarly, at the Cincinnati Children's Hospital, as part of the Pursuing Perfection initiative, parents of children with cystic fibrosis are teaching hospital staff how to improve care and services on the basis of their own experiences in the hospital.⁶ The health literacy programme at the Iowa Health System includes patients and families in redesigning the consenting process for surgery and other procedures, and includes patients "teaching back" to clinicians what they understand from the consent discussion and documents.⁷ In England, staff at the new Evelina Children's Hospital in London are experimenting with new ways of working, taking their cue directly from patients and their families to establish what makes their visit good and what could make it better. The project has been called "Improving the Patient Experience", and the hospital is full of ideas suggested by the youngest customers and their families who wanted colour, light and fun. Staff training, which uses scenes from children's real life experiences played by actors, enables staff to reflect on what makes the experiences of children and their families the best they can be.⁸

The nature of the challenge in these initiatives is to understand the experience of care at a deep level, always bearing in mind that it includes all aspects of subjectively experiencing a product or service—physical, sensual, cognitive, emotional, kinetic and aesthetic—and to use this understanding to design a healthcare experience that will be more successful and fulfilling than it has been before.

EXPERIENCE-BASED DESIGN

Although not used in healthcare, experience-based design (EBD) can be regarded as an extension of the current trajectory of improvement methods that will not entail starting anything from scratch. EBD is a user-focused design process with the goal of making user experience accessible to the designers, to allow them to conceive of designing experiences rather than designing services. Experience is designated as "how well people understand it, how they feel about it while they are using it, how well it serves its purpose, and how well it fits into the context in which they are using it". By identifying the key moments and places (moments of truth or touch points⁹) where people come into contact with the service and where their subjective experience is shaped, and therefore where the desired emotional and sensory connection needs to be established—and working with the front-line people who bring alive those various touch points in the journey—it is possible to begin designing experiences rather than processes.

On the present "continuum of patient influence" (fig 2), starting from complaining and information giving, to listening and responding, through consulting or advising, to full participation and involvement—all of which are currently found within the lexicon of healthcare improvement—EBD is one step on, being about co-designing services. In this, the traditional view of the user as a passive recipient of a product or service gives way to the new view of users as the co-designers of that product or service, and integral to the improvement and innovation process.

The core problem in studying experience is that, as an inner subjective, immaterial phenomenon, it can never be accessed or observed directly, but only indirectly through the words and language people use to describe it when they look back at it. In this sense it is not "real" at all (as it actually was or is at the time), but a reconstruction or reconstitution of something lived through—an elapsed, recalled experience. Words put meaning on that experience reflectively and retrospectively, and represent "what I make of what I have lived through". As radical activist Alinsky¹⁰ once so nicely put it:

Happenings become experiences when they are digested, when they are reflected on, related to general patterns and synthesised.

Words translate those happenings into experience, which is why narrative and storytelling play such an important part in our armoury of improvement methods.

CO-DESIGNING SERVICES WITH THE PATIENT

There are obvious resonances with the current concept of patient-led services, but the "co" suggests more of a partnership and shared leadership, with healthcare staff continuing to play a key part in leading service design alongside patients and users (collective leadership), and being able to input their perspectives and experiences on level

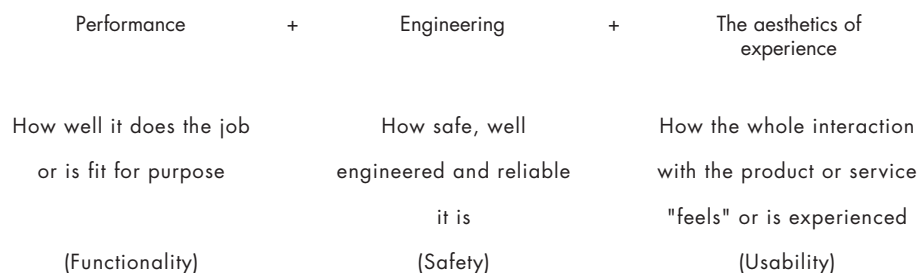


Figure 1 The components of good design.

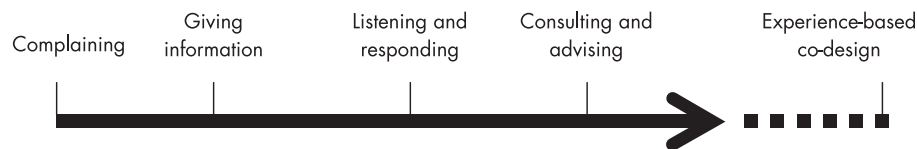


Figure 2 Continuum of patient influence.

terms. At the same time, it does not mean trying to make patients and users healthcare or design “experts”, but having them there because they are patients—“lead users” rather than leaders—with that precious and very special kind of first-hand knowledge we call experience. They are there primarily for their experience, not necessarily for any prior expertise they may be able to offer (although such expertise may be useful and, over time, patients may well develop new forms of expertise if they are sensitised to what a good care experience could be and how their own experiences might be improved).

Stories and storytelling are the basis of experience design. As the repository of experience, they contain almost everything that is required for a deep appreciative understanding of the strengths and weaknesses of a present service and of what needs to be redesigned for the future.^{11 12} Charon¹³ has perfectly summed up the potential of narrative and story-based medicine to “fix things that do not yet work”:

Sickness unfolds in stories. Whether in a patient’s chief complaint, a family member’s saga of surgery, an intern’s presentation at attending rounds, or a death note in a chart, the events of illness unfurl and accrue meaning by being told. Equipping health professionals with the wherewithal to recognise, absorb and be moved by the stories patients tell—might go a long way toward fixing what doesn’t yet work in medicine.

The desired end result is a positive connection and interaction between the person and the service.

This means that design systems, pathways and processes, concepts that have dominated health service design work for nearly a decade, need to move over and make room for it, science and the objective sitting alongside the aesthetic and the subjective. It is not a question of replacing them—there will be as great a need as ever for process mapping, care pathways and other well-established methods and tools as before—but of expanding and enriching the concept of service improvement, and with it our storehouse of methods and techniques.

THE NEXT GENERATION OF IMPROVEMENT METHODS AND PROCESSES

It is important to be clear about what experience means in the healthcare context, as it can so easily become confused with neighbouring but very different concepts such as perception or attitude, or getting the views of patients about the service they receive (eg, surveys get attitudes, but they do not get experiences). Experience is this and more. It is a particular and very special kind of knowledge acquired from close and direct personal observation or contact. The task for experience design is to gain access to that knowledge and use it in the service of a better design and a better experience for the user. That knowledge is expressed in what a person thinks, feels and says about the experience of a service, process or product he or she has encountered. To explain why the experience of attending a diabetes clinic looks and feels good (or not) requires an understanding of the interaction and relationship between the user and that service. If that

relationship can be disentangled and understood, then it can begin to be shaped to look or feel better. Various methods, individually or in combination, may be called in to service, to gain access to, and design, user experiences. We have briefly reviewed these methods elsewhere.¹⁴

You may wonder what is new or different in any of what has been said so far from, say, a focus group, patient forum, attitude survey or discovery interview. We would suggest five differences between where things are now and where they could be if concepts of user participation and EBD were incorporated into future healthcare designs.

- Rather than using user groups to feed back suggested changes in healthcare processes and services, EBD is a joint venture that involves users and professionals working together over a period and throughout the change process as the co-designers of a service.
- The focus of experience design is not so much on user views, attitudes, needs and perceptions (although all come into it) as user experiences—creating not just a service but a whole experience that appeals and works on a cognitive and emotional level.
- The focus is on designing experiences, not processes or systems or just the built environment. In contrast with traditional process mapping techniques, the focus here is on the subjective pathway (the touch points) rather than the objective pathway, the internal rather than the external environment.
- Getting at experiences is a specialised activity that needs to be learnt and practised. What often poses as experience research is actually little more than a conversation that anyone may have had, and words and stories without analytical frameworks do not speak for themselves. It is how they are to be used in the discovery and change process that is important.
- In interpreting experiences, the main challenge is to understand how the interface between the user and service is shaped. Most traditional service improvement methods, including those in healthcare, do not concern themselves with that relationship. It is important to appreciate that usability and interactivity are not only about how “nice” the service feels but also about the two other basic elements of design: safety and functionality (fig 1).

To briefly illustrate one way in which healthcare improvement may learn from the design sciences, we direct readers to a paper by Nielsen,¹⁵ a designer, who recently reviewed a study published in JAMA.¹⁶ This study reported on 22 ways that automated hospital systems can result in the wrong drug being dispensed to patients. Most of these flaws are classic usability problems that have been understood for decades. All of these flaws existed and remained uncorrected, says Nielsen, because of the failure of healthcare designers to be aware or reap the benefit of the last 25 years’ experience with usability research. More worrying, by relying on a questionnaire survey rather than observing actual experience, this particular study, he suggests, may have considerably underestimated the true error rate. His comments and the study itself are disturbing, and we are left to speculate on the

proportion of design efforts, even those that “listen” to users, that are failing to uncover potentially fatal processes.

The participation of users in co-designing services has been less prevalent in healthcare than it has been in the design professions in general, where we have seen a variety of approaches, models, tools and techniques being developed to incorporate users’ knowledge from past experiences of a product or service into design processes for future products and services. To counter these criticisms of healthcare improvement work, a wealth of new material is available in the design sciences—which has been noticed and is now beginning to be incorporated into plans for the next 5 years of modernisation¹⁷—and, wider still, in the philosophy and ethnography of experience that has the potential to take healthcare service improvement in some new and exciting directions.

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