



Radical innovation in the health service – the Bolton diabetes care prototype

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RED

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Public services represent an important innovation challenge – that of dealing with multiple stakeholders and the ‘contested’ nature of innovation (Hartley 2005). Whilst it may appear that the driver of competitiveness is lacking and people have little choice in public services, the reality is that there is increasing pressure for change but coming from multiple and often conflicting directions. Demands for cost cutting on the funding side push providers towards more efficient solutions but at the same time advocates and lobby groups on behalf of users are driving towards non-price aspects such as service quality, flexibility and customization. The result is increasingly a search for complex solutions to complex problems – and suggests that some of the most radical innovation is actually taking place in and around the public sector (Albury 2004).

These arguments take on particular significance in the context of public services like healthcare where the demand side is increasingly pushing for customization and tailoring of high quality services whilst the supply side is trying to deal with the economics of efficient delivery to meet the needs of these increasingly vocal stakeholders. Arguably the stage is set for radical innovation and the requirement is for new tools, such as those offered by design, to be deployed.

The innovation challenge in the UK healthcare sector

The UK, as many other countries, faces significant challenges to its healthcare system. A combination of complex drivers are coming together to create the conditions where the current systems will fail. Increasing life expectancy means more people will be requiring support for longer – and many of them will suffer from chronic diseases which are age-related such as diabetes and stroke which are particularly expensive to treat. Other lifestyle –linked problems such as growing obesity levels put further pressure on a system which already consumes around 10% of GDP – yet this burden will have to be borne by a shrinking taxpayer base as the population distribution ages. Expectations have risen since the inception of the National Health Service (NHS) in 1947 but continuing to deliver a broad-based package of care free at the point of delivery without incurring crippling financial costs is likely to become impossible in the years to come. The problem is not amenable to simple single point solutions like a new drug or therapy – instead it requires system-level intervention involving patients, carers, drugs and other treatment regimes across a broad therapeutic range, healthcare funding, etc. Radical innovation will be forced upon the sector.

The NHS is already a huge and complex organization – the largest employer in Europe with the biggest purchasing budget. There is a complicated web of actors within the system – clinicians, managers, associated service providers, etc. – and it interacts with a very wide range of stakeholders – patients, carers, relatives, medical suppliers, funding agencies, local and national government, etc. Innovation in this system involves both diffusion of improvement innovations and radical new treatments and approaches such as new equipment or surgical techniques. But it is likely that the fundamental shifts and rising complexity facing the NHS will mean that there is increasing pressure towards completely different models which require reframing and the emergence/co-evolution of radically different alternatives.

The need to manage such change is widely recognised – the NHS itself is in the middle of a 10 year reform programme – and there is growing recognition that existing perspectives, methods and approaches (and the underlying theories that drive them) cannot be relied upon to deliver the required change in the time and on the scale required. A key theme in the exploration of such radical alternatives is the need to incorporate new elements and perspectives in the frame and in particular to find ways to engage users much more actively.

As a recent report put it, 'current approaches to public service reform are reaching their limits a wide range of prominent issues, including the environment, crime, and public health concerns such as smoking and obesity, cannot be adequately addressed by traditional services. Effective responses must encourage new norms of behaviour within society, developing approaches in which those who use services become involved in their design and delivery...we need a radical transformation and a new approach: co-created services'.

(Leadbeater 2004)

Co-created services of this kind require mobilisation of knowledge and resources which are distributed across communities and an active engagement of members of those communities – rather than central and unilateral supply driven solutions. This raises again the issue of user-led innovation. Co-design also helps deal with the customization argument – rather than trying to design one size fits all, work with diverse users allows configurations which bring their particular set of needs and wishes into the equation.

This mirrors the wider moves towards what Von Hippel calls 'the democratization of innovation' and implies much higher levels of user-engagement in design and development of customized solutions matched to local and specific needs rather than a generic 'one size fits all' approach (Von Hippel 2005). At the same time such alternatives need to reflect the economic challenges of delivering high quality care in such specific configurations – there is a risk that innovations will revert to the traditional cost/quality trade-offs common to manufacturing operations management during the last century.

Searching for such radical solutions which engage users and which also deliver workable options requires the use of new tools and techniques and a number of experiments are underway which draw on design approaches. The following example illustrates the range of such work and the role which design approaches play within them.

The RED project

One of the major health issues identified by the UK Wanless report in 2002 is the rising challenge of chronic disease. Around 12 million (approximately one in five Britons) suffers from a chronic disease. These numbers are likely to rise if factors influencing chronic conditions, such as diet, lifestyles, and smoking, are not addressed as the population ages. The incidence of diabetes for example, closely related to obesity, has risen to 1.8 million people in just eight years, costing the NHS £10 million a day.

It represents a complex problem but also one in which a user-led approach might offer significant new opportunities. For example, the average person with diabetes spends about three hours a year with doctors, checking prescriptions and general health – but they spend thousands of hours a year self-managing their condition. Traditional approaches to public service reform target innovations which give a diabetic more choice over their GP, a booked appointment or a patient's charter. But there is clearly considerable scope in focusing on the thousands of hours the diabetic self-manages, through offering peer-to-peer support, better training and tools to cope with diabetes. And further traction could be gained by emphasising prevention rather than treatment and increasing educational and other activities in this direction.

There is good evidence to support this holistic view of chronic disease management. Between 1997 and 2002 there was a 23 per cent fall in deaths from diseases of the heart and circulatory system in the UK. Much of this reduction was due to reforms to NHS cardiac services, particularly improved treatment of people who had suffered a heart attack. But a significant part was also due to lifestyle changes that swept the country 20 to 30 years earlier, when middle-class men in particular, gave up smoking in their millions. In the first approach, users were patients in need of effective NHS services while in the second, the users were active participants.

As the Wanless report argues the future of health care in an era of chronic disease, would turn on the 'full engagement' of people in their own health care. Whilst hospitals play a key role there is scope for much higher levels of engagement across the user community. But the emergence of a more integrated system will involve bringing in a wide range of stakeholders and working in the 'contested' innovation space out of which radical alternatives may emerge.

One experiment in this direction has been work towards co-creation/co-evolution of new diabetes services within the Bolton area of north-west England. At present an estimated 10,000 residents suffer from diabetes (almost one individual in every ten households) in the area. This absorbs 5 percent of NHS resources locally, and 10 per cent of hospital patient resources, a pattern that is similar to that nationally, exemplifying the challenges of chronic disease management. In response, Bolton has already developed an impressive track record of 'traditional' innovation solutions to the problem but progress has been largely inspired by the professional managers and clinicians rather than diabetics themselves. This 'medical' model of engaging with diabetics and residents more generally has some limitations and the interface between patients, professionals and workers in the diabetic centre has proven to be a particularly intractable problem. In the words of one clinician, improving this interface 'would make a good service fabulous', but professionals from various institutions involved in the system recognised that this would require radical re-organisation of a service around the patient.

The RED project was a prototype which looked at the ways in which the interface between people with diabetes and a range of required services could be improved and at how diabetics might support each other. Arguably such a co-created service would entail both participation and change on the part of the diabetics themselves and the professionals currently engaged in delivering services. There was also a focus on prevention since avoiding secondary complications depends critically on the person with diabetes, their lifestyle and their monitoring and self medication. Dealing with this issue highlights problems with the organisation of the diabetes care service itself and for bottlenecks within it. In Bolton for example there is a two year waiting list for orthopaedic shoe fittings (cost £100) which can save the need for amputations (cost between £30,000 and £40,000). Such bottlenecks are far from unique to Bolton or to diabetes management and reinforce the need to maintain prevention as a founding principle in the approach to co-creating services.

Having advertised the project in GP surgeries in the area, the team found a group of 20 willing participants, all diabetes sufferers ready to share their experiences of living with the condition. The first stage of the project involved the team spending time with the diabetes group – in their homes, at the shops and at work – conducting interviews and informal discussions to find out as much as possible about living with the condition. By focusing on the group's individual lives, not just their disease, the team built up an in-depth understanding of the real issues that affect sufferers' ability (or inability) to manage their diabetes effectively day to day. (Once again the design methods deployed here are essentially ethnographic in nature, using storytelling and related approaches).

'We developed a number of exercises to draw out what having diabetes meant for each participant and how they saw their current treatment routines. We built up detailed portraits of each group member, and used these in a series of workshops with healthcare professionals, other patients and designers.'
(Jennie Winhall, part of the Design Council team)

Over time, common patterns began to emerge within the group, and it became possible to identify three profile categories based on how individuals approach and manage their condition; 'knowing struggler', 'determinedly naïve' and 'able knower'. These categories were not designed to pigeonhole or stereotype sufferers, but to help identify the key areas where innovative intervention could make a real difference.

'From the portraits, it is easy to see that the immediate context for our work was diabetes management,'... 'Diabetes is difficult to deal with, and the results of poor management may only become visible after many years. With this in mind, it can be difficult for sufferers to motivate themselves to sustain healthy living and medical regimes day after day.'

In addition to work within the formal NHS system involving a more patient-centric approach to diabetes education the RED project focused on the everyday lives of sufferers struggling to apply such lessons effectively. The argument was that what was required was a service to provide not just knowledge about diabetes but also the ability to help people internalise it, act on it and then embed it in the pattern of their life.'

Such an approach would try and address several key points, including:

- Bridging the gap between education and action
- Offering the opportunity for more effective communication between patient and carer
- Encouraging the inclusion of family and friends to provide vital support
- Delivering more bespoke education
- Offering the NHS the freedom to experiment if standard services or approaches are not working

These principles became the focus of prototype work within the Bolton area. Using such prototypes as boundary objects around which learning and co-evolution of new services could take is an interesting application of design methods. As one team member explained,

'rather than concentrate on trying to create the ideal scenarios presented by the healthcare experts, we instead developed a series of stepping stones to take the ground-breaking work already happening in Bolton in the direction of that ideal future.'

Ideas for the tools and services that could facilitate these positive changes included:

- a service in which more 'able' diabetes patients are matched with those struggling with the condition to act as mentors
- the introduction of 'Just in Time' techniques, inspired by manufacturing industry, to eliminate doctors' waiting rooms

- the opportunity for patients to choose a life coach to inspire and motivate at potentially difficult times
- the development of a ‘future magic mirror’ which would show patients how the lifestyle choices they make now will affect them in the future

An example of how these prototype ideas began to crystallise into tangible and achievable products and services is in the area of doctor / patient consultations. Specifically, the team looked at how these consultations could potentially reveal the crucial – but currently hidden – enablers and barriers to effective self-care. This alternative approach was based on a series of cards with real-world descriptions of diabetes needs, for them to choose from during consultations.

The cards would help to bring out dimensions of their lives previously hidden to their caregivers, providing the flexibility for patients to define their own diabetes care agenda.’

A ‘mock-up’ set of 72 ‘needs’ cards was developed, organised into themed suits with appropriate graphics added to help illustrate the scenario each card described. These cards were essentially a ‘boundary object’ around which exploration and articulation of key themes could take place. They were presented and modified in a continuing conversation with a wide range of health care managers and professionals, as well as diabetes sufferers and their inputs built into the emergent design. Importantly there were also several blank cards in the pack, so if patients couldn’t find a card that best described how they felt, they could literally write their own healthcare agenda.

After three rounds of exploration the ‘deck’ of cards was reduced to 40 plus blank cards and became a useful tool to explore and articulate potential new services. One issue which emerged was that, despite excellent medical and educational support, many diabetes sufferers failed to manage their condition effectively because of a lack of ongoing emotional and motivational support. The interaction catalysed by the card development process identified this as a priority area for service innovation. Jennie Winhall commented,

‘... having created the deck of agenda cards, we had found a way of opening up dialogue between diabetes patients and their healthcare providers But our research had also led us to the conclusion that much of the support needed by diabetes patients might be better off coming from someone outside the medical profession – a third party change agent, more like a life coach...The concept emerged (of) a personal trainer for people with diabetes, or indeed any chronic condition that requires an ongoing commitment to lifestyle and behavioural changes.’

Several factors pointed the team towards the idea of a life coach-style helper:

- consultant diabetologists gave feedback that called for a new kind of care worker to connect with patients on a one-to-one basis
- behavioural psychologists showed evidence that care professionals armed with even rudimentary motivational interviewing skills can have a positive impact on people trying to change their behavior
- a pilot scheme assessing the benefits of regular motivational phone calls for diabetes patients gave positive results
- another Design Council project in Kent involved a scheme where personal trainers helped community groups initiate and maintain healthy activities

Solutions such as the agenda cards and the personal trainers complement existing educational and medical resources by tackling the issue of chronic disease management from the perspective of the individual, providing a means by which those with diabetes can gain greater control of their disease and its effect on their lives. Testing the ideas in practice across a range of sites has provided positive feedback about this potential new direction in service design. As one diabetes consultant nurse explained,

'I was really interested in this new scheme because so much of what we do doesn't achieve what we want it to. The project has provided a fresh eye on long-term condition management – and that's got to be a good thing. If this succeeds it's going to improve our consultations, patients will be happier, they'll have a better quality of life and we'll be giving a better service. It could also be used to help manage other long-term conditions.'

For more detail – and a short video of the case – visit the Design Council website at www.design-council.org

References

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