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Service Innovation for Living Well with Type 1 Diabetes

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ABSTRACT

The UK's NHS must evolve to embrace the co-production of health outcomes and patient-centred care to shift from the reductive treatment of illness to a holistic promotion of wellness. We are developing a methodology for service innovation building on this. Designing innovative services for young people with type 1 diabetes surfaced different views of wellness from health professionals, young people and their parents. Our challenge has been to value each perspective in what we have designed. Deploying artefacts enabled constructive dialogue with our participants, so how might interactive artefacts challenge views of wellness?

Author Keywords

Service design, innovation, participatory design, Diabetes

ACM Classification Keywords

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

INTRODUCTION

The UK's National Health Service (NHS) must evolve to cope with changed social and economic circumstances. Its 60-year old care model reflects the then primary demand from acute diseases and casts people as compliant patients whose role is to report their symptoms for clinicians' diagnosis and treatment. Re-evaluation is being driven by an ageing population, the rising incidence of long-term conditions with a consequent need for self-care, and greater expectations from those accustomed to customer-centered private sector services. Two key principles within this are: The *co-production of health outcomes*, where clinicians work together with individuals (and their relatives, carers and community organisations) to promote their health, (e.g. Open Health [4]); and *Patient-centred care*, as recognized by the UK government who suggest that NHS "services are designed around individual needs, lifestyles and aspirations" [7]. This parallels developments in human-centred design, such as a shift from usability to fundamental support of human values like dignity and independence [3].

Designing Services for Wellbeing

Co-production of health outcomes and patient-centredness also characterise a shift from the reductive treatment of

illness to a holistic, inclusive and participatory promotion of wellness or wellbeing. Building on these foundations, User-centred Healthcare Design (UCHD) is developing a methodology for health service design, using:

- A holistic understanding of people's lived experiences rather than limiting enquiry to clinical encounters [8];
- User and provider participation so that services reflect disparate sources of expertise [2] and consequently afford the co-production of health outcomes; and
- Activities centring on artefacts to enable collaboration and dialogue between participants [6].

These elements have a part to play in designing interactive systems that promote wellbeing, but our primary interest in this workshop connects with the last item. We have used narratives and illustrative artefacts to afford disparate stakeholders' participation in health service innovation. However, we would like to explore the use of interactive artefacts to facilitate a design conversation with this group.

CASE STUDY: LIVING WITH TYPE 1 DIABETES

Type 1 diabetes is a long-term condition that requires significant self-care, including regular monitoring of blood glucose levels and adjustment of insulin dosage according to diet and activity. Many young people struggle with self-care leading to adverse health complications such as retinopathy, nephropathy and neuropathy [1].

In South Yorkshire, care for young people with diabetes is currently focused on regular clinic visits, where their metabolic control is checked and self-care advice provided by specialist nurses, dieticians and doctors. However many young people fail to attend and young people have told us that they find them lengthy, dull and patronising.

In 2011 we began a project to develop innovative new services for young people with type 1 diabetes based upon an understanding of their lifestyles rather than an evaluation of an existing service. We have run a series of workshops with two support groups for young people with type 1 diabetes and their families, and a Diabetes Specialist Nurse in South Yorkshire. In these events we have understood the experience of living with type 1 diabetes (and of being a young person), devised a broad range of service ideas, and converged to build and test practical new ways of accessing diabetes support and information.

The making, adaptation and appropriation of artefacts played a key role throughout these activities in stimulating and opening-up dialogue with participants. For example:

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- Writing and drawing concerns on ‘body-maps’ (large outlines of human figures) drew out participants’ lived experiences of diabetes in an accessible manner;
- Finishing storyboards from initial scenarios using ‘joker-cards’ of fantastical items to inspire ideation (e.g. ‘how could you use Doctor Who’s sonic screwdriver here?’) enabled consideration of broader possibilities through developing ‘blue-sky’ ideas in a fun way; and
- Devising props for a ‘Dragon’s Den’ presentation to four invited experts enabled participants to refine and claim ownership of their ideas.



Figure 1. Dragon’s Den presentation of Tear-Free Testing

Findings: Living Well with Diabetes

Our work showed that type 1 diabetes impacts young people in three main contexts: at school, at home and in public. Within these areas, they had several concerns:

- Not being seen as different. Diabetes self-care can draw unwanted attention;
- Tackling ignorance and helping others to help you;
- Taking away some of the burden of self-care;
- Being more independent and (for the parents) knowing that a ‘safety net’ was there if young people needed help.

For example, our participants developed the *Tear-Free Testing* idea (Figure 1) where a contact lens with embedded electronics tests the glucose levels in the wearer’s tears and changes colour to alert friends to problematic levels.

Over-arching these concerns was the theme of ownership. Clinical encounters and the active role taken on by parents left many young people feeling “who’s diabetes is it?” and that they self-cared mainly to keep clinicians and parents happy. Also, views of what living well with diabetes means differ: wellness means good metabolic control according to recognized clinical measures on one extreme, on the other it means no lifestyle impacts (even if this translates to stopping self-care and negative health consequences). Our design challenge then was to value both definitions – to reduce the lifestyle impacts of self-care by making support and information easier to access.

The basic principle of diabetes self-care is straightforward (insulin adjustment according to diet and activity). However fitting the associated tasks into everyday life is difficult.

Expertise exists both from NHS clinicians and others living with diabetes. Our proposed solution is to join up this support and make it accessible via means that fit young people’s lifestyles so that they can claim ownership of their diabetes (e.g. text message consultations with a nurse).

DISCUSSION

Our use of artefacts in the diabetes project has enabled us to develop service ideas that would enable young people to live well with this condition. These artefacts served the design process by stimulating dialogue, prompting divergent thinking, and facilitating convergence to implementable services. Artefacts prompted participants to reflect on experiences and possibilities through activities in workshops. Could interactive artefacts be deployed in the field to prompt reflection through everyday practices [5]?

Design methods using reflection via artefacts could then challenge disparate views of wellness and create services and systems that promote wider conceptions of wellbeing.

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