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Engaging teenagers productively in service design

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\textbf{A B S T R A C T}

Engaging young people in participatory design can be challenging, particularly in health-related projects. In a study co-designing diabetes support and information services with teenagers, we found framing activities using popular culture was a useful strategy. Various cultural references helped us stage activities that were productive for the design process, and were engaging for our young participants (e.g. exploring practical implications through discussions in a ‘Dragons’ Den’). Some activities were more effective than others and the idea of language-games, which has been widely explored in participatory design, explains why our strategy was successful when there was a clear ‘family resemblance’ between the popular cultural references and certain essential stages of designing. However, attention is required in selecting appropriate cultural references if this strategy is adopted elsewhere, and design facilitators should focus first on devising accessible language-games, rather than expecting popular cultural references to provide complete solutions to the challenge of staging participatory design.

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\section{1. Introduction: The challenge of designing with teenagers}

Pedersen and Buur [1] highlight the need to make participatory design workshops both \textit{engaging}, to encourage participants’ involvement, and \textit{productive} to ensure that new design proposals are generated that are relevant to participants’ lives. This can be particularly difficult when working with young people.

Being a teenager is a challenging period in a young person’s development. According to the UK National Children’s Bureau (2012) 60% of young people in the UK feel stress about school work and exams, 35% about their physical appearance, and 32% about friends. Further, parents are relaxing their control whilst remaining engaged with decision-making [2]. The challenges are even greater for teenagers who have long-term health conditions. For example, Type 1 Diabetes Mellitus\textsuperscript{1} (henceforth diabetes) is a lifelong condition requiring indefinite self-care via regular insulin injections adjusted according to activity, diet and illness to maintain appropriate blood glucose levels. Poor control of blood glucose has short-term health impacts (e.g. the sickness, lethargy and disorientation associated with ‘hypos’) but crucially has potential long-term adverse health complications such as retinopathy, nephropathy and neuropathy [3].

In addition to dealing with school work, growing up, and boyfriend or girlfriend relationships, teenagers with diabetes also need to manage disciplines of blood glucose monitoring (both current and trends over time) and balancing their food and alcohol intake, physical activity, and insulin dosage accordingly. These factors affect the blood glucose levels of someone with diabetes along with stress, growth, and emotional excitement — all prominent features of being a teenager [4]. Even if a teenager undertakes all the correct diabetes management steps he or she may still feel frustrated, ashamed, afraid, or angry (ibid.). Teenagers need the support of their parents and medical workers, as self-management is challenging to maintain [5], but are also gradually taking greater responsibilities on themselves. Children with diabetes may not want to talk about their condition and this attitude becomes even stronger during adolescence when acceptance by peers becomes a central focus [2].

The early development of participatory design methods, exemplified by Bjerknes et al. [6], Greenbaum and Kyng [7], positioned participatory design within the workplace where adult

\textsuperscript{1} Type 1 diabetes is typically diagnosed in childhood or adolescence and unrelated to lifestyle factors. Type 2 diabetes is a different condition that usually appears in adulthood, often linked to poor diet and obesity.
participants had clear external motivations for engaging (e.g. protecting their jobs, designing better working environments). As participatory design has moved out of the workplace, the question of how to motivate engagement has become more pressing particularly when participants feel little enthusiasm for or ownership of the design domain. For example, [8] experienced difficulties developing an emotional intelligence educational tool with teenagers with behavioural problems and recommend that designers pay attention to the design methods and communication tools that they apply: working in small groups, defining simple tasks and objectives, giving clear instructions, and using many short activities with immediate outcomes. Mazzone et al.’s work was conducted in the context of schools (and pupil referral units), as were many other examples of participatory design with teenagers (e.g. [9–11]). Outside of the school setting, [12], reflecting on their experiences working with teenagers to redesign exhibitions in a museum, report problems that arose when designers deconstructed young people’s design ideas and prototypes to incorporate them into new design concepts. Tensions emerged between the young people and the design team, when some of the teenagers reported feelings of frustration that their ideas were not being implemented as they expected and considered withdrawing from the project. Developing a shared understanding of the design process is critical to maintaining trust, and Iversen and Smith (ibid.) recommend that designers should create design space for each concept as a way of showing due respect for the efforts of the young people involved.

This paper reflects on a ten-month project working with a group of young people with diabetes (all teenagers with the exception of one 8 year old participant), together with family members, to design innovations in the healthcare services that are provided to support self-management of their condition. Many of the activities that we conducted within the project drew upon elements of popular culture (TV shows, films, everyday activities, on-line social networks). In this paper, we examine how those elements helped to make co-design activities engaging and productive, but also on the limitations of this strategy.

2. Designing with teenagers

2.1. Teenagers as design partners

Our review of the existing literature identified a range of ways in which teenagers have previously been involved in design projects. Many projects have involved teenagers as a source of information for design via e.g. observation [13], focus groups [14], interviews [15,16], questionnaires [15]. Later in development, when designs have been developed to early stage prototypes, teenagers may be involved as design informants by involvement in user testing, e.g. [17]. Recent trends in design have emphasised the potential of ambiguous inputs as a way to provide creative inspiration for designers [18,19]. Drawing on this tradition various researchers have involved teenage participants in making activities to provide inspiration to designers, for example using workshops [15,12,14], visual materials and technology probes [15], role-playing activities [14], Lego Serious Play [20], and comic-strip creation, scenario visualisation, and drawing and labelling facial expressions [8]. Some projects have involved teenage participants in various kinds of rating activities to help designers understand their preferences and priorities, for example using ‘cool wall’ [21] or by card sorting and dot voting [14]. Finally, some projects have worked with teenagers directly developing ideas for digital systems using e.g. focus groups, workshops, role-playing and paper prototyping [14], or collaborative prototyping with mock-ups [12]. Our case study is of this last form in that our goal was (as much as possible) to engage teenagers directly in developing new proposals for the health services that are provided for them.

2.2. Teenagers with diabetes

A few studies have engaged teenagers with diabetes in participatory research and design. Webster [22] engaged young people in workshops to develop personal strategies to gain confidence in self-managing their condition. Van Staa et al. [23] asked trained young people and chronically ill adolescents to conduct interviews at a disco to evaluate existing hospital services (however the young people were not actively involved in redesign of those services). Franklin et al. [24] developed the “Sweet Talk” text messaging system to support insulin therapy, adopting a traditional software development lifecycle involving requirements gathering, prototyping, implementation, evaluation and reporting. Their approach involved young people primarily as design informants rather than co-designers.

The closest body of work to our own is that of Glasemann and Kanstrup [4] who co-designed services to support self-management with young people with diabetes using visual materials (e.g. tool box, creativity pack) to envision mobile diabetes support. In a later work, [25] conducted interviews, observations, food quizzes and paper prototyping at a diabetes summer camp to support design of a carbohydrate counting mobile game. Glasemann and colleagues also reflect on the challenges working with young people with diabetes: recognising the difficulty of bridging the gap between their visionary ideas and possible implementation [4]; the difficulty in establishing discussions about diabetes [25]; and the importance of designing with a focus on a person’s youth rather than their condition [26].

2.3. Motivating participation

Glasemann and Kanstrup [4] note the importance of motivating young people’s participation and empowering them to consider themselves as innovators. Edwards et al. [15] provided cash rewards and noted the value of youth leaders and parents/carers as ‘authority figures’ in keeping teenagers engaged. Such approaches rely upon external motivation but engagement can also be motivated through attention to the participatory activities themselves. In contrast to Edwards et al., [27] found that open activities emphasising free discussion and collective decision-making were more engaging for participants accustomed to a youth centre’s ‘correctional culture’. When working with young people with low motivation, [8] note the importance of relating tasks to concrete examples and familiar situations, having short activities with clear outputs, and demonstrating the value and intended usage of participants’ contributions. A common tactic in Mazzone et al.’s approach was also to ensure that activities were enjoyable for participants, e.g. icing emotions onto biscuit ‘faces’. Danielsson and Wiberg [9] suggest avoiding activities that closely resemble how children create (e.g. manipulating low-fidelity prototypes) in favour of activities that emphasise teenagers’ adult capabilities (e.g. focus group discussions).

This work emphasises the need to actively engage young people in design activities and enable their contribution, but highlights the complexity of this challenge particularly when certain tactics somewhat contradict each other (e.g. making activities fun but not overly childish). When co-designing health services with young people where personal benefits are initially unclear to them (as in our work), the potential for external motivation is limited and ensuring the design activities themselves sustain engagement is of crucial importance. Our aim was then to conduct a design process that provided intrinsic motivation for participation. In doing so, the key learning we took from the above examples was to adapt activities around young people [8] following the interests, themes and ideas that emerge [27].
3. Research context

3.1. Health service design

The work presented in this paper forms part of a wider five-year research programme bringing together researchers from design, HCI and healthcare, titled User-centred Healthcare Design (UCHD), which aims to develop methods for effective service improvement and innovation that can be adopted within the UK’s National Health Service (NHS). In recent years service design has been recognised as a distinct field that includes a professional network with associated conferences and ‘Touchpoint’ journal [28], international academic conferences (e.g. ServDes, ISIDC) and websites offering tools for practitioners [29]. Research into service design has followed [30] and the application of service design to healthcare is being explored [31].

Mager and Sung [30] observe a shift in the focus of design from the tangible world, to interactions, to experience, to services. Services include digital and computer-mediated communications, physical artefacts (e.g. printed information and letters) and interactions with service-providers. Although such ‘touchpoints’ may be familiar, the service, as an interconnected whole, is an abstract entity. Hence, key to service design is the use of visualisations (e.g. stakeholder and process maps) to make systems understandable and available for manipulation. Service design has experience as a central focus and considers the entire user journey including experiences before and after service encounters (ibid.) and in settings not governed by the service-provider. Further, service design is oriented towards future as well as existing service-users (particularly the case for health services responding to newly diagnosed patients). Therefore participatory design methods focused on the workplace are insufficient for the holistic, experience-based approach that service design requires.

To contribute to this area, UCHD is developing a methodology for health service design and exploring how such an approach can be effectively translated for use by relevant health professionals. Our principal means of doing so is via design projects as case studies.

3.2. Design methodology

Our first case study explored the ‘state of the art’ co-design approach used in the NHS – Experience-based Design (EBD) [32] – that we used to improve an existing service [33]. We found that EBD provided limited guidance on the ideation phase of design, when new service ideas are designed and developed, and in that earlier project, participants tended to converge early to simple ‘quick fix’ solutions without sufficient divergent thinking [34]. Hence, our principal intention in this second case study was to prompt significant innovation by: beginning with the day to day life experiences of a particular group (rather than experiences related to a specific service); exploring potential services beyond current clinical settings (rather than restricting the design work to a specific service or location); and using ‘designerly strategies’ to promote creative thinking in participatory activities (beyond the limited methods offered by EBD). We use the term designerly strategies to describe ways of working typically used by designers when dealing with complex or ill-defined problems such as sketching, prototyping and making as means of enquiry. Such strategies are often collectively referred to as design thinking or designerly thinking [35].

Subsequent evaluation of our first case study also suggested that design ideas developed in projects in large, complex healthcare institutions may take months or years before they have visible impacts [36]. However, it was important to the project and to the broader research programme that the project should lead to ideas that would be practically feasible for implementation by those responsible for the existing health services. Thus, our diabetes design project set up a tension between devising genuinely innovative services whilst also ensuring that these service ideas were implementable. Our second concern was finding effective ways to motivate participants’ involvement, but at the same time to ensure the project moved through stages of design to generate practical outputs.

Many projects with teenagers take place in educational settings that provide external motivations for participation, for example teachers are present to maintain discipline, and design sessions qualify as part of the educational programme [8]. In contrast our project took place outside of work and school settings and participants took part on a purely voluntary basis. Hence it was important that we developed activities that were intrinsically rewarding as well as ultimately productive. To devise activities that participants would experience as enjoyable, relevant, and creatively stimulating, we drew from participants’ casual conversations with each other and ourselves throughout the project. Here, it was clear that ‘popular culture’ such as TV shows, on-line social networks, films etc. was an engaging topic for discussion and represented common interests across the group. As a result, during the project we devised and adapted activities based on popular cultural references in order to tap into the enjoyment participants already associated with these references.

3.3. Research methodology

Our design projects function as a form of research through (design) practice [37,38] where generalisable insights about how to design are developed through designing as a form of action research [37]. Like action research, our aim has been to both understand and develop practice through practice, in a participatory manner — here the practice of health service design with the participation of design and health practitioners and health service users. To capture our experience of the evolving design process and the effectiveness of the various design methods we employed, a researcher who was not involved in the design activities interviewed individual designers prior to and following each workshop. These semi-structured interviews helped us to articulate the thinking behind our activities and reflect on their effectiveness at the time. Following the project, the researcher also interviewed two young people, two parents and the participating Diabetes Specialist Nurse about their experiences of participation. We draw from these sources in exploring the engagement and the productivity of different activities, and in assessing the value of the techniques we adopted.

As designers we wanted to understand why some of our techniques were successful, and some less so. Based on our initial reflections we developed a hypothesis that the popular cultural references were most successful when they related to playable language-games [39]. We then analysed our transcripts with this specific hypothesis in mind. In a separate exercise, we are conducting a more thorough, bottom up thematic analysis of the material, but this is beyond the scope of this paper.

4. The case study

4.1. Background studies

Prior to commencing the project, we spoke to a small number of young people with diabetes, and to a range of health professionals
working with young people with diabetes. From these interviews, we recognised that most young people experienced periods where they felt disengaged from their condition and consequently paid little attention to self-care. Through these conversations we developed an impressionistic visualisation of young people’s engagement with their diabetes over time (Fig. 1).

We also reviewed previous diabetes-related design projects and discovered that the majority focused on the artefacts associated with self-care (e.g. blood glucose monitors, insulin pumps, and smartphone apps to assist blood glucose management). We concluded that, whilst improving such tools may benefit those engaged with their diabetes, those feeling disengaged were unlikely to be using them in the first place. Instead, information and advice on the principles and idiosyncrasies of diabetes self-care to support re-engagement are required. Such support is typically provided through hospital- and clinic-centred services, which young people told us they often felt uncomfortable using and were less likely to access when they were feeling most disengaged. During such periods they were also unlikely to contact advice services that are provided at existing clinics. The green line in Fig. 1 represents a threshold degree of engagement that a young person needs before they contact the clinic. Our aim was to design something that, through greater compatibility with young people’s lives, would present lower barriers for access. Such new services would demand a lower threshold of engagement (represented by the orange line in Fig. 1), thus encouraging more frequent use.

4.2. The design process

From July 2011 to May 2012 we worked with young people with type 1 diabetes and their families to develop designs for new support services that could be provided by the local healthcare providers. Ten young people with diabetes (2 boys, 8 girls) between 11 and 16 years old (excepting one 8-year-old boy) and twelve of their parents, members of two family support groups in Rotherham and Barnsley, South Yorkshire, UK participated in the project. These support groups held occasional meetings together, and the research team agreed with them to facilitate a series of workshops that address the design challenge.

In all there were eight workshops involving a Diabetes Specialist Nurse (DSN), a project manager (with a nursing background), and three designers who acted as facilitators. Some workshops benefited from the additional input of other relevant specialists (as described below). The workshops took place every two or three weeks during school term times (activities were suspended during school holidays) with the main design work occurring over 6.5 months between workshops 2 and 8.

Workshops were held in seminar rooms at a conference facility close to a well-known shopping centre and lasted from 1.5 to 2 h in the evenings. Families gave up personal time to participate with no tangible or financial reward beyond a light meal and refreshments at each workshop. Further, teenagers often attended at the bequest of their parents who (initially) had expressed greatest interest in the project. Hence our principal incentive to motivate participation was the possibility of devising new diabetes support services that would directly improve young people’s lives. Consequently it was essential that we made the project’s potential to affect change clear and the activities that would produce this both engaging and fun, and also reinforced our commitment to produce implementable services.

The overarching design process had five broad stages of: (i) understanding and sharing experiences; (ii) exploring blue sky ideas; (iii) selecting and developing blue sky concepts; (iv) developing practical proposals; and (v) prototyping and evaluating. Each design stage involved one or two workshops depending on the gradual evolution of the design process (see Fig. 2) and participants were split into two groups of young people and one group of parents for most activities.

4.3. Workshop activities

Our principal concern in devising workshop activities was that they would engage our young participants whilst also moving the design project forward (by e.g. revealing needs, generating ideas, evaluating concepts). This meant attending to teenagers’ interests and needs, and being agile in adapting workshop activities to align with them. All workshops included a preceding half-hour refreshments session with no fixed agenda beyond informal socialising. Our aim here was to build trust and rapport between the group and ourselves, and during these sessions we became attuned to participants’ shared interests. Consequently we chose to use relevant popular cultural references as a way of creating activities that would be both familiar to and entertaining for our young people. These choices were dynamic, being developed based on our experiences and conversations with the young people, and were made in a designerly fashion – exploring alternatives and being open to change. Our discussion in this paper deals with the value of this strategy for framing design activities, so we describe the relevant elements of workshops in greater depth below.

The first workshop introduced project and participants, and began to map out areas of interest for the design work. Here, we wanted to gain a sense of participants’ preferences for consumer products and how diabetes-related equipment rated alongside them. To do this, we ran a ‘cool wall’ activity inspired by the popular BBC motoring entertainment show ‘Top Gear’.3 In the

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show presenters rate cars by placing photos of them on a wall labelled from ‘un-cool’ to ‘sub-zero’. This cultural reference was selected before we met most of our young participants, but seemed to be a good match to our goal of exploring what they found interesting, and reflected some of the playfulness that we hoped to include in our programme of design activities. At that time, we were not aware of others’ use of cool walls, which was published subsequently (e.g., [21]). In our workshop, we introduced our ‘cool wall’ activity by referring to ‘Top Gear’, and groups selected and rated everyday items from a retail catalogue alongside familiar diabetes equipment and technological innovations with the potential for diabetes care then explained their choices and ratings at the end of the session (Fig. 3). E.g. young people rated highly the recent innovation of contact lenses with embedded electronics that could sense and indicate blood glucose levels from tears, liking the possible end of the discomfort associated with glucose testing via ‘finger-pricking’ to obtain drops of blood.

Our second workshop focused on sharing young people’s experiences with diabetes. In the ‘body mapping’ activity young people explored “What is it like to be a young person with diabetes?” Initially, one of the young people lay on a large piece of paper and a silhouette was drawn around their body. Participants then wrote their thoughts on post-it-notes and placed them on the appropriate area of the outlined body, e.g. “finger-pricking hurts” was stuck on where a hand was drawn. Gradually as the group opened up to this activity, they were able to share more intimate concerns, feelings and experiences. After 20 min the group presented their thoughts to the other two groups. Following the workshop we created two personas: one for ‘Aaron’, a 13-year-old boy who had been newly diagnosed with diabetes, and one for ‘Katie’, a 16-year-old girl who had been diagnosed as a child and who had many years’ experience of diabetes. We had noticed that our young participants were very familiar with Facebook so, to make the personas meaningful for them, we presented personas in the form of Facebook profiles (see Fig. 4), using elements such as ‘wall’ discussions and likes/dislikes to replicate issues and stories shared by the young people. These personas allowed us to respect participants’ privacy whilst making their needs and concerns available as design resources in later workshops.

Fig. 2. Adopted five-stage design process and eight creative workshops.

Fig. 3. The ‘cool wall’ created by participants.
In the third workshop young people were encouraged to generate blue-sky ideas for diabetes products and services by completing four unfinished scenarios, devised by the designers from situations that participants had previously identified as challenging: living with diabetes at school (2 scenarios), in public places (e.g. shopping centres), and at home. E.g. ‘Aaron’ begins to have a ‘hypo’ whilst playing football during his school lunch break, his friend fetches a teacher whilst another pupil begins to mock him suggesting that he is drunk. To encourage participants to think divergently and not rule out ideas, we created a ‘future cinema’ including important parts of the cinema going experience (tickets and popcorn), and showed video clips and photographs of utopian visions of technologically improved lifestyles. Young people were then given written descriptions of the scenarios and worked with designers to develop ideas in response to them using large sheets of paper, pens, Lego bricks, and a variety of photos (e.g. service touchpoints, people, settings, technologies). Attendance was low at this workshop and, rather than devise distinct service ideas, young people instead discussed types of objects and devices that might be useful in such problematic situations, e.g. options for wearable monitoring technology in relation to the Aaron football scenario. Due to this limited success, we chose to run a second blue-sky ideation activity during the fourth workshop.

In devising the fourth workshop we needed an activity that would enable participants to more easily develop complete service proposals whilst retaining the ideas from the third workshop. We therefore designed four service proposals responding to the previous school and ‘out and about’ scenarios, based on the artefact ideas discussed by young people, which participants could then evaluate and develop. We also devised a new unfinished clinic scenario that, along with the previous home scenario, would be used to develop new service ideas. Service proposals and scenarios were presented as storyboards — series of framed illustrations with blank frames provided for groups to ‘finish the story’ (see Fig. 5). Again, we used various creative stimuli to encourage divergent thinking. Participants were reminded that radical innovations do become part of the everyday by watching, e.g. a clip from a 1972 episode of the BBC TV programme ‘Tomorrow’s World’ that presented an early predecessor of the contemporary mobile phone. Additionally, if idea development stalled, facilitators used one of several ‘Blue-Sky Joker Cards’ showing various fantastical objects and abilities to ask “how might (Dr Who’s sonic screwdriver/Harry Potter’s wand/a Star Wars Jedi’s light sabre/ Superman’s powers etc.) help in this situation?”

Previously, informal conversations had demonstrated participants’ enjoyment of the popular television singing competition ‘X-Factor’ so we framed the fourth workshop activities using elements from the show. We recreated the X-Factor setting using the theme music and graphics. Participants took the role of judges to select and refine one of the four service proposals (an ‘X-Factor audition’), and to develop service proposals for the two unfinished scenarios (two ‘X-Factor boot-camps’). Three groups (two of young people, one of parents) generated a total of nine service proposals from these three activities, which we then needed to narrow down to promising ideas for further development. The proposals were shared in plenary in an ‘X-Factor Final’ and each group rated the ideas with greatest ‘talent’ using scorecards. Following their deliberations, the three groups announced their ‘winning’ and ‘runner-up’ ideas using the archetypical cards in gold and silver envelopes to identify one proposal each that they would like to develop further. The designers also selected a ‘winner’, from the remaining ideas, that they would develop outside the workshops.

Hence four blue-sky service ideas were taken forward: diabetes peer support through social media; access to diabetes equipment via pharmacies; low/high blood glucose alerts using domestic media displays; and a ‘Tear-Free Testing’ system based around embedded technology contact lenses (as first seen in the ‘cool wall’ activity). The last idea was devised by one of the young people’s groups during the ‘audition’ session because they disliked all four service proposals. Instead, they imagined a system in response to the previous school classroom scenario where contact lenses monitor and display blood glucose levels and connect wirelessly to smartphone apps and insulin pumps to monitor and manage blood glucose levels. All the young people liked this system because it would enable their friends to help ‘(your eyes have changed colour’ Fig. 5) and offered glucose monitoring that would draw less unwanted attention from other pupils and teachers, which they told us was a particular problem in schools when using diabetes equipment.

The fifth workshop aimed to translate the four ‘winning’ blue-sky ideas into implementable forms. To do this we encouraged groups to present their chosen ideas in a ‘Dragons’ Den’ borrowing from another popular television show where entrepreneurs pitch their ideas to venture capitalists (‘Dragons’) to convince them to invest.

On entering the workshop room, participants were presented with the familiar ‘den’ setting including the dragons’ chairs and (fake) piles of money and the theme music and visuals from the TV programme. We then explained that groups would be presenting and defending their chosen ideas to four (as yet unseen) ‘Dragons’ who represented senior professionals with experience relevant to the contexts their ideas responded to (healthcare, education, diabetes care, and retail). The designers then worked with each group to translate their chosen ideas into investment pitches. At a set time, preparation was halted and the (previously unknown to participants) Dragons were ceremoniously invited into the room and introduced by the project manager, emphasising the depth and relevance of their experience as (i) a clinical director of health services, (ii) a secondary school teacher of design and technology, (iii) a senior diabetes consultant and research director, and (iv) a department store manager in the shopping centre frequented by

4 http://www.bbc.co.uk/archive/tomorrowsworld.<ref>
5 http://www.xfactor.itv.com.<ref>
6 http://www.bbc.co.uk/dragonsden.
participants. The Dragons then critiqued the presentations of the three groups (Fig. 6) and the designers and selected one of the four in which to ‘invest’. In the final part of the workshop, each group then worked with their Dragon sponsor to develop their idea and consider how to overcome practical obstacles.

In the sixth workshop, we aimed to evaluate and improve Rotherham’s paediatric diabetes service using what we had learned from previous workshops about what was important to young people and their parents. We developed this understanding with participants through an iterative process of sharing experiences, designing service ideas, and responding to them. E.g. ‘Tear-Free Testing’ embodied important criteria of invisibility (not drawing attention), automation (reducing the burden of self-care) and peer support (enabling friends to help).

In searching for a popular cultural reference that could be used to frame the design activities, we considered how the current service could be modelled as dynamic flows of information (e.g. clinical advice, personal goals) in and out of a system over time. This suggested a visualisation of the service as an ‘information factory’ with inputs (pipes) and outputs (conveyors) related to different stages of the patient’s interactions with the service (machines). We chose the contraptions invented by Wallace and Gromit (as seen in the popular animations in which they feature) as providing a suitable aesthetic for the factory’s machinery, which we created as sets of paper cut-outs (Fig. 7). Groups were asked to evaluate the current service by rating ‘information machines’ against criteria expressed as analogue gauges (e.g. the ‘Invisible-ometer’), and then re-design the ‘factory’ by re-arranging machines, pipes and conveyors.

We had originally planned to produce practical service proposals by this point (December) for prototyping and refinement with participants in one or two subsequent workshops. However, following the first six workshops, we only had four blue-sky service proposals. Given the lack of remaining time and a desire to produce something implementable that could directly benefit participants, we chose to consolidate what we had learned into a prototype service satisfying participants’ important criteria and needs, and addressing the shortcomings of the existing clinic-based service they had identified. We also translated the blue-sky proposals into a mobile exhibition that was later placed in public spaces to raise awareness and challenge perceptions of diabetes care.

Individual elements of the new service (titled ‘Whose Diabetes is it?’) were tested within workshops, although we primarily designed it outside of them. In the seventh workshop, new service interactions with health professionals were role-played by the research team and the Diabetes Specialist Nurse, and discussed with participants. In the eighth workshop, framed as a ‘show and tell’, participants tested tangible aspects of the service including a web resource combining professional and peer diabetes knowledge and support, text messaging as a means of getting advice from DSNs, and a coherent brand identity for a printed pack of key information and membership/important contacts cards. A final element of our proposed service was a ‘welcome event’ to introduce young people recently diagnosed with diabetes and their families to the various sources of information and support from both the NHS and through peer networks. Our participants later successfully ran a first trial of such an event with recently diagnosed families, which provided a clean ‘wrap up’ for the project. A video visualisation of the service was also produced to communicate our final project proposals to potential service users and NHS decision-makers.

The feedback we collected on the service proposal in these later sessions was generally positive, and participants agreed that service elements were relevant to the needs we had identified together. E.g. the peer support element expressed in ‘Tear-Free Testing’ also relates to the value young people placed in being able to speak to others who ‘get what it is like (living with diabetes)’ (several of our teenagers had not socialised with others with diabetes prior to working with us). So, the ‘Whose Diabetes is it?’ website included social media functionality (see Fig. 8) to enable young people to access various groups for support (friends, peer-support groups, NHS staff). This functionality also dealt with the issue of ownership frequently discussed in workshops (‘it is my parents’/DSN’s diabetes, not mine’) and is expressed in the service’s name.

5. Evaluation

Following the end of the project (and analysing our reflective interview data during the project) we examined the effectiveness, and the strengths and weaknesses of our design strategy and methods. We did not begin the project with an explicit goal of experimenting with popular cultural references, although we were aware of the use of popular cultural references within pastiche scenarios and pastiche personas [40,41], and of creative design exercises which had used the ‘Big Brother chair’ as a means of eliciting responses to design proposals. Instead, our aim was to ‘stage’ activities that were stimulating and interesting for participants. In our efforts to achieve this goal, we found that popular cultural references offered ‘ready made’ tools that could be appropriated to our purposes.

The idea that popular references were important emerged over the course of the project as a means of maintaining the young people’s engagement. Thus prior to the ‘X-Factor’ workshop, one designer observes of the X-Factor “… it is so prevalent, in popular culture but more importantly it is something that both the parents and the children have talked about and obviously are quite keyed into” and, before the ‘Wallace and Gromit’ workshop, that: “… well maybe it is a factory, its kind of inputs and outputs and machines. So we got this idea of an informational help factory and so we were still scrabbling around thinking, oh what is our popular reference, what can we use to frame this? (Project Manager) said, ‘Wallace and Gromit’ and I thought, ‘oh yeah, ding!’” (Designer 1).

Below we examine the individual popular cultural elements and discuss both our reflections as designers and the comments of the young people about these activities.

The ‘cool wall’ was useful as it provided us with insights into more or less desirable products for participants and where diabetes-related equipment rated amongst them. It also seemed to be an enjoyable activity for the teenagers, although one young person thought it “boring just sitting there cutting out of magazines … we could have done things on the computer […]. It was like being back at school” (Young Person 1).

Although we referred to the Facebook personas throughout the design project, we were disappointed that participants did not refer to them very much: “there were (Facebook personas) on the wall and people went and read them but […] other than us placing (personas) in those scenarios (they) did not feature greatly in people’s discussions. […] we spent most of last week getting those scenarios and personas fleshed out and nicely designed and
built and we might have spent the time doing something else..." (Designer 1). Young people were happy to discuss their own lives and the relevance of design ideas within them rather than needing to employ the personas during the later stages of the project. Our effort in creating the personas perhaps biased our expectations of their usefulness.

The 'X-Factor final' activity was conducted at the end of a busy ideation workshop, and yet it succeeded in energising participants to critically examine and prioritise their blue-sky ideas. It was also fun: "another good session (putting) forward your idea on what you thought was best" (Young Person 1).

'Dragons' Den' was one of our most successful activities in engaging young people in the difficult task of developing and refining a design, although young people found it "scary when you had to go up and talk in front of (the Dragons)" (Young Person 2). One designer recalled initial reluctance in his group of young people: "I remember one of them saying, 'oh, I do not think I can do this.' And one of the others said, 'ah, come on, we have got to do it, because the Dragons are here, and it is really important now.' So then they got this energy together, and all of a sudden they became really confident" (Designer 2). And participants reflected positively on the session: "It was quite good because we felt strongly about some of the ideas that we put forward and we argued our cases" (Parent). "I enjoyed being able to be an individual and put your ideas together and express how you feel in front of other people" (Young Person 1).

Although productive discussion of issues with the existing diabetes service and its improvement were held during the 'Wallace and Gromit' workshop, the information factory visualisation materials were hardly used as participants preferred to discuss their experiences and ideas directly. In reflecting on the workshop the project team commented "They were static, they were not interactive. Nobody used them, nobody touched them. They were an object" (Project Manager), "I think we got useful information out of it but from a personal level I was a bit disappointed that people did not engage with the service visualisations a bit more" (Designer 1). The participants were similarly unenthusiastic about the workshop: "I cannot remember much about that one. I remember drawing machines and linking them up and that but I cannot remember much else about it" (Parent).

Overall, young people were positive about the project "it did feel good to have your input put into something that has actually come together as a whole and a project that has been designed by us" (Young Person 1) and their contribution "it was not (the designers') opinion, it was like we all had a choice and they combined (ideas) so everyone got involved" (Young Person 2). They saw their input as valuable "because you have been there and witnessed things that have happened" (Young Person 1).

Young people were also positive about methods used "I think they were all useful because they helped generate the ideas", (Young Person 2) which they enjoyed "it is fun because you are doing something but it is not like making you work hard, it is just like getting your ideas out there" (Young Person 2).

6. Discussion

6.1. Motivating design participation

Our teenagers attended workshops in their free time, outside school and work, and initially expressed little interest in designing health services to better fit their needs (diabetes self-care being something they 'just got on with', if at all). This provided little external motivation for participation beyond their parents' involvement. Hansen and Iversen [11] plotted their means of motivating teenagers in participatory design along two axes: material versus immaterial, and extrinsic versus intrinsic. We did provide some small material, extrinsic motivators such as taking the group out bowling and providing snacks and refreshments during workshops. Like Hansen and Iversen's teenagers, our participants encountered immaterial and intrinsic motivators such as telling their own stories, being listened to and endorsed as experts in their own condition, and working in small co-operative groups. However, Hansen and Iversen's studies suggest identification and recognition by peers as important motivators, e.g. by giving the participants 'team' t-shirts that entitled them to particular privileges within their school. In our case, the negative emotions that most of our participants feel towards their diabetes means that they would not want to be marked out in such a way, and would not want to frame their identity around their condition. Hence, we had to find other means to motivate engagement, and these motivations were primarily intrinsic and immaterial. Drawing on popular culture thus emerged as an important element of our strategy.

6.2. Popular culture language-games

The varied effectiveness of our use of popular culture can be explained using [39] consideration of participatory design via Wittgenstein. Ehn notes that, in Wittgenstein's view, language is socially constructed and practices can be seen as 'language-games' where a person's speech and other actions embody their knowledge of a (skilled) practice and enable them to 'play' the game with others. Key elements that support the recognition and appropriation of new language-games are: artefacts (that provide cues and constraints around how to behave), settings (in which the language-game typically takes place), rules (which are unwritten, but are recognised by participants and govern behaviours), and roles (for different actors taking part in the language-game) (ibid., p150ff). From this perspective, practices are learned through having a family resemblance to language-games already played rather than via explicit description of the 'rules'. Ehn states implications for participatory design:

"To design new artefacts that are useful for people, designers have to understand the language-games of the use activity, or users have to understand the language-game of design, or the users must be able to give complete explicit descriptions of their demands". (ibid., p108).

Accepting, as did Ehn, the difficulty of achieving the latter, undertaking participatory design involves establishing new shared language-games that help designers understand users' activities and users understand the design activity.

Brandt [42] also cites Ehn in discussing "exploratory design games", describing four forms of which our work is closest to the fourth that aims "to design while acting out scenarios" (ibid., p63). Vaajakallio [43] sees Brandt's grouping as describing qualities rather than categories and suggests that games within co-design have three common qualities: "(1) they create a common design language, (2) they promote a creative and explorative attitude, and (3) they facilitate the players in envisioning and enacting what could be" (ibid., p100). Although the activities in our design workshops had all three qualities, in using references from popular culture, our primary focus was on the first. Here, the common language related primarily to the second application of language-games identified by Ehn, that is enabling our participants to understand and consequently participate in the design activity. The goal of understanding the existing practice was present and informed activities including the 'Wallace and Gromit' information factory, but was secondary in our work.

Ehn's discussion highlights a role for language-games in making the design process understandable — selecting popular culture references that express language-games that have family resemblance to language-games of designing. Brandt's discussion highlights the importance of making games engaging through,
in her case, family resemblance to games that are ‘fun’ to play via the provision of playing-pieces, game-boards, settings and explicit rules etc. Our tactic for engagement, instead, was to select popular cultural references that were familiar to teenagers and their parents. This strategy was productive when the cultural reference clearly expressed a particular activity (language-game) that had a family resemblance to tasks within a design process.

Participants were familiar with the ‘cool wall’ as an activity for sharing and critiquing artefacts’ personal appeal (be they cars or insulin pumps) and, as a language-game, this resembled the collation of related products for inspiration (e.g. via mood boards) often undertaken in the early stages of design.

Similarly the ‘X-Factor’ provided a language-game for identifying potential talent that aligned with a language-game identifying promising design ideas for further development, but also aligned with the common design studio practice of ‘crit’, i.e. subjecting ideas to critical analysis and collaborative development with colleagues. A common feature of both ‘X-Factor’ and of ‘crit’ is that ideas can be subjected to quite fierce and sometimes quite harsh criticism, but this is accepted as part of the playful environment. Thus ‘X-Factor’ provided a safe vehicle to allow this kind of critical assessment of design ideas, without participants feeling uncomfortable and damaging their personal relationships.

‘Dragons’ Den’ also provided a language-game for communicating and defending proposals as worthy of investment that matched a language-game in design of ‘selling’ the essential features of a design proposal to a client and thereby resolving practical details.

Participants’ familiarity with the popular culture language-games enabled them to ‘play’ relevant language-games in the design process because of the similarities between the games’ unwritten rules. Consequently the young people were able to participate in a design process that otherwise may have been difficult to understand.

However, not all of the popular cultural references we employed were effective. Although productive discussions did take place in the ‘Wallace and Gromit’ workshop, they were not facilitated by our use of this particular cultural reference. Participants were familiar with the animated characters and the illustration style but crucially the factory re-design activity was our invention and not an activity that arose directly from the cultural reference. It was not a familiar language-game that participants could ‘play’. The information factory (as a set of machines, conveyors and pipes) provided analogues of what was being designed but did not provide rules (written or unwritten) of how to do this reconfiguration. Likewise the Facebook personas were static artefacts with no associated activity for participants to engage in.

The lack of familiar language-games for certain design props was not always problematic, however. Although the Facebook personas did not afford ‘play’, they helped to make the issues presented engaging for participants and other stakeholders. In disseminating our work, the Facebook personas have often attracted attention from healthcare practitioners and researchers.

7. Conclusion

Our diabetes case study demonstrates that employing familiar popular cultural references can make participatory design activities more engaging. This is particularly important when working with teenagers who have few immediate incentives to participate in designing abstract and future services. This strategy was also effective for parents, which suggests that it could be applied for groups other than teenagers. However such cultural references are only productive if they express language-games that are understandable to participants and resemble useful language-games in the design process. Our case study suggests implications for others wishing to use popular culture-language-games as a broader strategy for engaging young people in participatory design:

- attend to the function of specific activities in the design process;
- select popular cultural references that reflect activities with similar functions and are both familiar to participants and embody language-games that participants can ‘play’;
- settings and props should be designed to both communicate the cultural reference and afford the playing of the language-game, e.g. gold and silver envelopes express both the theme and activity of the talent competition.

Sensitively applied, popular culture can enable teenagers to understand the language-games of design and consequently engage productively in designing.

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