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Our Year With the Glass: Expectations, Letdowns and Ethical Dilemmas of Technology Trials With Vulnerable People

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Our Year With the Glass: Expectations, Letdowns and Ethical Dilemmas of Technology Trials With Vulnerable People

JOHN VINES[*], RÓISÍN MCNANEY, AMEY HOLDEN, IVAN POLIAKOV,
PETER WRIGHT AND PATRICK OLIVIER

*Open Lab, School of Computing Science, Newcastle University, 89 Sandyford Road, Newcastle upon
Tyne NE1 8HW, UK*
[*]*Corresponding author: john.vines@ncl.ac.uk*

In this paper, we reflect upon the ethical dilemmas faced during our research exploring the potential of Google Glass as a self-care technology for people with Parkinson's. Our project involved two stages of research: an initial study that explored the overall acceptability and responses of people with Parkinson's to the technology; and a follow-up study that examined participants' experiences of the technology in more depth through further trials and a series of co-design activities. While our first trials were successful, leading to publication and subsequent local and national publicity, our follow-up trials were hampered by technical problems that were often out of our control. We highlight how participants' heightened expectations prior to the second trial, as a result of public discourse around the project, were difficult to meet. This led to our participants articulating their frustrations, feelings of lowered self-confidence, and in some cases a reduced sense of self-worth. We reflect on how the decisions and actions taken during the project led to these dilemmas, and how these relate to contemporary challenges in human-computer interaction research where there is increased focus on in the wild studies of technology use and a pressure to publicly disseminate the findings of research. In doing so, we offer an open and honest account of how a set of ethical dilemmas emerged while conducting technology field trials with a potentially vulnerable group, and offer guidance to future researchers finding themselves in similar circumstances.

RESEARCH HIGHLIGHTS

- We conducted 'in the wild' deployments of Google Glass with people with Parkinson's.
- There were several ethical implications of conducting this type of research, wherein the technology in question was still being developed and updated by its commercial manufacturer.
- Prior publicity about our project caused participants to formulate overly positive preconceptions around the technology.
- We reflect in detail on some of the decisions and actions taken during the project, and discuss strategies for researchers to take into account in future studies that might help anticipate, avoid and negotiate ethical dilemmas in the future.

1. INTRODUCTION

Human-computer interaction (HCI) researchers are increasingly engaging in 'research in the wild' and community-oriented research where engagements with participants occur at the scale of months and years, rather than hours (Crabtree *et al.*, 2013; Le Dantec and Fox, 2015). While historically HCI researchers may have conducted lab-based, controlled or tightly structured studies, the last decade or more has seen a growing interest in understanding how people experience living with prototype technologies in their everyday lives. These shifts are the result of a series of 'turns' within HCI whereby researchers and practitioners have: gone beyond the lab to conduct research in real-world settings; moved from the study of work environments to those of the home and moved beyond single desk-bound machines to study mobile, held and worn computing systems. Complementing these shifts, many public funders of research also emphasize the involvement of communities of users and further stakeholders in all stages of the research process (RCUK, 2014). This includes motivating research teams to raise public and industrial awareness of research projects (Vines *et al.*, 2013), sometimes through the timely publication of results and sometimes through public engagement and outreach activities.

While these shifts can be viewed in a positive light, they also raise a number of ethical challenges for HCI research. The quest to engage the public, especially when this involves working with the press and mass media, can place significant pressure on researchers who are unlikely to be experts in media work (Vines *et al.*, 2013). Media work can also lead to misrepresentation of the aims, objectives and outcomes of research, with journalists and editors discarding the details of a project in order to create newsworthy stories. Furthermore, working closely with communities and participants, as active contributors and co-creators of research and design, can raise concerns around informed consent and expectation management (Banks *et al.*, 2013), while also requiring researchers to be flexible in negotiating their own research interests in relation to the interests of others (Le Dantec and Fox, 2015).

In the field of HCI, we are only just beginning to concede that the types of research we conduct may not only be ethically challenging, but also raise specific difficulties that are not well dealt with by established ethical frameworks. While we have a discourse around the ethics of using digital technologies [e.g. discussions of privacy, trust, surveillance and worker deskilling noted in Urquhart (2014), Oulavirsta *et al.* (2012), Friedman *et al.* (2006) and Pritchard *et al.* (2014)], with few notable exceptions (Mackay, 1995) there has been little engagement with issues of research ethics. Very recently, however, there has been a new wave of discussion around the ethics of HCI research as practiced and published. For example, the highly publicized 'Facebook study', where researchers manipulated the algorithms of Facebook users' news feeds to present greater numbers of positive or negative communications, without consent, has raised questions over University partnerships with industry and the role of institutional ethical reviews [see Kramer *et al.* (2014) and Harriman and Patel (2014) for discussions of this]. There have also been ethical debates around public-facing and critically oriented design work in HCI, such as that raised by people's unwitting participation in a piece of speculative design work at the 2014 CHI conference that implied an elaborate sensor system was monitoring the venue toilets [see Tanenbaum (2014) for a brief discussion of this work]. Recently, there has been interest in the ethics of HCI research practice when involving close collaboration with participants, especially those who may be considered vulnerable in some way. For example, Waycott *et al.* (2015) reflect on the ethical challenges of deploying socio-technical interventions with socially isolated individuals. Munteanu *et al.* (2015) also highlight how the types of ethical issues identified during formal institutional research ethics processes do not always hold-up to the complexities of ethical concerns as they occur in practice. They argue that researchers should be prepared for situational ethical dilemmas and be supported in developing a range of tactics and sensitivities to respond to them in the field. This echoes debates in social science where there has long been an awareness that it is necessary to distinguish between procedural and anticipatory ethics and emergent ethics in practice (Guillemin and Gillam, 2004; Miller and Bell, 2002).

This paper contributes to this growing discourse around ethical implications and considerations arising within contemporary HCI research. We describe our experiences of a project where we worked closely with a community of people with Parkinson's, conducting 'in the wild' deployments of a new technology in the form of Google's Glass platform. This involved significant amounts of outreach and generated publicity based on work we had conducted prior to this project. An increasing wealth of research addresses how mobile and wearable technologies are being used for the tracking of personal health and wellness (Lupton, 2014) and the self-management and self-monitoring of conditions (Barlow *et al.*, 2002; Sha *et al.*, 2008) especially in the context of Parkinson's disease (de Barros *et al.*, 2013; Mazilu *et al.*, 2014; McNaney *et al.*, 2011; McNaney *et al.*, 2015a; Nunes and Fitzpatrick, 2015). As such, our project aimed to: (i) explore the acceptability of the Glass technology to people with Parkinson's; (ii) explore how comfortable they felt using and wearing this technology and a range of its default applications in their daily lives and (iii) co-create and design, with participants, ideas for new applications for Glass, based on their experiences of using the technology.

By reflecting on 'our year with the Glass', we explore and discuss the various ethical dilemmas that occurred throughout the project. Some of the ethical challenges we faced were expected and were mitigated by anticipatory steps taken by the research team and the governing research institution. Others emerged as a consequence of our engagement in

media work, the particular dynamics of working with a community of participants who were in contact with one another, and the great unpredictability of the technology being trialled. We explain how, while the results of our first stage of exploratory field trials with people with Parkinson's were highly positive (McNaney *et al.*, 2014), our later trials were plagued by problems related to the reliability of the Glass technology. Some of these challenges were anticipated—such as the system dropping connectivity to the Internet in certain locations, or batteries discharging quickly; others were out of our control—such as systems being remotely updated over-the-air during trials. While these problems led to fundamental breakdowns of the technology (e.g. failure to reboot following updates) or new usability problems (e.g. the operating system changing the interaction qualities of the device), some participants in the later trials experienced these as personal failures and inadequacies. In this paper, we detail how the confluence of actions and decisions made by us, our institution, media organizations, the developers of Glass and the participants themselves led to these dilemmas. In reporting these reflections, we highlight a number of challenges for the ethical conduct of HCI research, especially at a time when there is increased emphasis on conducting research in the wild and the compulsion to discuss and disseminate research to wide public audiences.

2. CONTEXT: PARKINSON'S AND TECHNOLOGY FOR EVERYDAY SELF-CARE

Our involvement in the Google Glass for Parkinson's project was a result of a series of studies, conducted over several years, where we have been developing technologies that support the self-management of Parkinson's symptoms (McNaney *et al.*, 2011, 2014, 2015a, 2015b). Our prior work is part of a growing contingent of research studying the potential for mobile and wearable technologies to support new practices of self-care and self-management for people with Parkinson's (de Baros *et al.*, 2013; Mazilu *et al.*, 2014; Nunes and Fitzpatrick, 2015). This relatively small area of research, focused on the specificities of Parkinson's, is influenced by a wider contemporary interest across HCI surrounding wearables, smartphones, 'apps' and sensor platforms for health and wellness tracking, monitoring and behaviour change (Barlow *et al.*, 2002; Sha *et al.*, 2008). As such, we envisaged our project as building upon both our own and others' prior work highlighting the potential for wearable technologies to improve the daily lives of individuals with chronic conditions, such as Parkinson's.

There were a number of assumptions made at the start of the project as to why Google Glass would be a suitable platform for exploring new self-care practices for people with Parkinson's. First, at a functional level, the Glass system with its array of sensors and micro-display provides a wealth of opportunities for collecting data related to bodily movement and for presenting this back to the wearer. We speculated that this might provide opportunities to build on prior work by exploring how context aware applications could provide prompts and feedback to those wearing the device—for example, to prompt an individual to take their medication if the system senses it is wearing off, or to provide an auditory cue to help with episodes of freezing of gait (both common challenges for people with Parkinson's that affect their independence). Second, at the time of our work Glass was widely perceived as a leading example of consumer wearable technology. As such, we also assumed that Glass might be more positively received as an assistive platform by people with Parkinson's, who in our prior work had reported feeling stigmatized and disabled by poorly designed, medically oriented devices (McNaney *et al.*, 2011).

Therefore, the first set of questions underpinning our research related to the degree to which novel wearable 'eyewear' platforms, envisioned as near-future consumer technologies, might be accepted by people with Parkinson's. Our first study investigated these questions through a workshop and a series of short field trials of the standard Glass technology with a group of participants with Parkinson's (reported in McNaney *et al.*, 2014). Acting on the findings of the first study, our second set of questions related to understanding and exploring some prospective uses for technologies like Glass to support the daily routines, self-care practices and ongoing independence of people with Parkinson's. These questions were examined in a second study, where further trials of the Glass technology were conducted, followed by co-design sessions with individual participants at the end of their trial. Critically therefore, our work neither was treated as a trial of a clinical intervention, nor was intended to feed into the design of one—rather, it was focused on overall acceptability and exploring the design space of self-care technologies. This had a number of anticipated implications for the ethical and consent processes surrounding our research, combined with other considerations resulting from the participants we intended to work with. We discuss these and other anticipated ethical challenges in the following section.

2.1. Anticipating ethical challenges

The focus of this paper is primarily on the unexpected ethical dilemmas that were experienced during the conduct of our trials—however, it is important to note that there were a range of ethical challenges identified prior to, and during, institutional ethics review and the design of the research. Perhaps the most immediate of these was that participants might be considered vulnerable as a result of their condition. Parkinson's is a progressive neurological condition that degenerates over time and typically results in a slow increase in symptom severity (Hughes *et al.*, 2000). While it affects between 7 and 10 million people worldwide (Parkinson's Disease

Foundation, 2014), the symptoms experienced by individuals can be diverse and highly heterogeneous. Tremor, rigidity and slowness of movement are the three most common symptoms. However, individuals might also experience symptoms that affect mobility such as freezing of gait, which is caused by difficulties with initiating movement and increases risk of falls (Bloem et al., 2004). There is also the potential for impaired speech, voice, masked facial expressions and swallowing problems that can impact communication with others and thus socialization (Miller, 2012). It is also known that there are a range of non-movement issues people experience, including fatigue, depression, anxiety and obsessive-compulsive behaviours (Berardelli et al., 2001). Another factor leading to the diversity of Parkinson's is the ON/OFF phenomenon. Over the course of a day, an individual may find that they suddenly switch between periods where their medication controls many of their symptoms (ON) to their symptoms being uncontrolled (OFF). A further feature of this side effect is known as 'wearing off' whereby an individual might find their medication does not last as long as it had previously and they begin to feel their symptoms return before their next dose is due (Stacy et al., 2005).

Given the range of possible symptoms and their potential impact on life, it is perhaps unsurprising that people with Parkinson's as a group might be considered vulnerable from an institutional view. Many experience some form of physical disability (even if this is only temporary) and frequently have support from carers. While many individuals are still active and entirely able to make independent decisions (such as being able to participate in a research project), the fluidity of their condition and its symptoms means their participation in studies has to be carefully supported. In our case, this meant when designing our study we took into account participants' medication cycles (the 'on/off' periods mentioned previously). For both of our studies, during deployments we carefully agreed times to meet, interview and phone participants that worked around these cycles. Our plans for the field trials across both studies included a series of structured interactions where the research team would check-in with participants to talk about how they were using the technology, to gauge if they were having problems and whether their participation was placing any additional burden on them.

A further set of anticipated concerns related to the prototype nature of the Glass technology. Although we had conducted extensive in-lab functionality tests on the Glass, there were still questions around how reliable the system might be 'in the wild'. For example, we were aware in advance of the studies that the technology had relatively poor battery life—lab tests of 'normal' use highlighted that a wearer would be fortunate to get more than 4 hours from the device between charges. We were also concerned about how usable the interface of the Glass would be to people with Parkinson's. Specifically, we suspected tremor and vocal difficulties (both typical symptoms of Parkinson's) could have implications for the primary interaction mechanisms for Glass. Also, in practice, we anticipated that it could be difficult to use the device while doing other day-to-day activities. These concerns were informed by prior work, which has highlighted how new self-care technologies can at once empower individuals but also amplify existing feelings of anxiety and exclusion (Storni, 2010). Furthermore, while our ambition was to study technology use 'in the wild', we had some concerns about how members of the public might react to participants wearing the technology. Our study design attempted to account for these concerns as we felt they had the potential to distress participants. To explore the issues to do with the usability of the system, our initial workshop in the first study (reported in McNaney et al., 2014) allowed us to gauge initial impressions of the usability of the system for a group of participants with a diverse set of symptoms. We also ensured that when meeting with participants during deployments the visiting researcher spent considerable time explaining how to use the system and going through a series of practice runs using specific applications. This was partly to allow participants to familiarize themselves with the technology, but also allowed the researchers to gauge how suitable the system might be for each individual to use. We also provided a simple instruction manual for participants to follow (the prototype Glass devices did not come with one), and also mains electricity chargers so participants could easily charge it at home. Finally, when meeting with participants we were careful to position the research as very exploratory, emphasizing that the purpose was to see how much and why they used the technology, how comfortable they felt wearing it in different places, and how appropriate it was for them to wear it doing different activities. We suggested that there were certain activities where it may be inappropriate to wear the system (visiting bathrooms, driving cars) but otherwise they should feel as though they could wear it as much, or as little, as they wished.

While our work was with a group of people who are normally defined in research by their 'clinical' label, the non-clinical nature of our work negated the possibility of recruiting participants through health clinics and the National Health Service.[1] As such, our research progressed through a standard institutional ethical review process for studies where potentially vulnerable participants might be involved, and we recruited participants via local support groups organized by volunteers of a national Parkinson's charity. Despite being separated into geographical areas, the individual support groups were interlinked through personal connections and group communications (in the form of newsletters) to the wider Parkinson's community. The support groups

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[1]In the UK, clinical research is governed under the NHS and must adhere to Medical Research Council Good Clinical Practice (GCP) guidelines (Medical Research Council, 1998). These guidelines cover details surrounding the informed consent of participants, the appropriate management of clinical data, including storage and confidentiality, and outline the roles of the investigators and institutions involved in the research.

themselves attracted what could be considered as relatively 'healthy', 'active' and 'engaged' members of the Parkinson's community. We did not target specific individuals to take part in the study, as might be in the case in clinical research where participants are identified and recruited through clinical staff. Rather, we provided some information about the study and were available for questions on a one-to-one basis. While this allowed for an unpressured opt-in policy, it also meant that we were recruiting participants who were particularly interested in, or had previously heard about, the project or the concept of Glass.

We submitted our designed protocols to our institutional research ethics committee, identifying these concerns and risks and responding to them. The protocol was then reviewed by two independent and anonymous colleagues, who subsequently provided written feedback and queries that we had to be respond to satisfactorily prior to approval. Researchers are required to inform the ethics board should any changes in study design occur during the research process. When designing our study, we took a 'worst case scenario' approach to allow us to prepare for negative eventualities. This was reflected in our considerations of the possibility that a physical accident might occur when using Glass, or that the discussion of symptoms and their impact might cause emotional distress in interviews or workshops.

2.2. Completion, publication and dissemination of first study

Following institutional approval, to explore the initial perceptions and overall acceptability of the Glass we conducted our first study. This involved a running a workshop with a group of people with Parkinson's followed by a series of short trials of the standard Glass technology with the same participants. As noted, this provided an opportunity to reveal any significant usability problems with this technology, both in a controlled workshop environment and in real-world settings. While these initial participants raised a number of concerns—particularly in respect to personal security while wearing the technology in public and the unwitting sharing of information—in general, their response to Glass was overwhelmingly positive. Despite our initial fears, all of the participants were able to interact with the device through the touch-sensitive panel on its side and via voice controls. During the trials, they started to appreciate the potential of the technology and commented frequently on how simple it was to use in comparison with their mobile phones. They also drew upon their experiences of living with Parkinson's to suggest a range of design opportunities for Glass-based applications to support self-care. The success of this initial research inspired us to write up the results with the qualification that these were short, initial studies of the technology with a small group of participants [published in McNaney et al. (2014)].

At the start of the project, an agreement had been established between Google (the manufacturers and developers of Glass who had provided us with the devices) and the researchers' institution not to publicize the research (except via peer-reviewed publications) or to demonstrate the technology to journalists. We understood this to be because, at the time of our first study, only a small number of research groups outside of North America had access to 'pre-production' prototypes of the technology and the company wished to focus publicity around a future launch of Glass in the UK. However, just prior to the official publication of our research, Google informed collaborators that they were happy for teams working on Glass to publicize their projects and any of their findings. We assumed this was, in part, because Google were preparing the launch of the Glass Explorer programme in the UK and were hoping good news stories about the technology might start appearing in the press.[2] The combination of this, the publication of our paper, and our institution's standard practice of creating press releases for newly funded research projects, resulted in a push for the project to be publicized in the local and national press. In a similar vein to that discussed in our prior work (Vines et al., 2013), this involved the researchers working closely with the University's media team to draft and redraft a press release, followed by interviews with news outlets and appearances on radio and television shows to talk about the project.

There were two key decisions taken during this publicity phase of the project that later had significant implications for the conduct of our second study. First, during the publicity work, we aimed to carefully explain the findings of our research in such a way as not to 'oversell' the results. Some members of the research team had previous experience of media work, where findings were elaborated upon or misconstrued by journalists and editors in the name of making a story more newsworthy (Vines et al., 2013). In an attempt to avoid some of these issues, we composed a press release[3] that was very general about the aims and ambitions of the research. We aimed to make it clear that it was 'very early days' for the research, and that we had only so far conducted 'initial studies' that 'have focused on the acceptability of Glass'. We also tried to communicate that the work was ongoing, that we were 'working on the next stage of the project' and 'still learning how it might be used'. At the same time, we were keen to explain 'how well our [initial] volunteers took to the wearable technology and the fact that they

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[2]At this time, which was between the end of our first study and the beginning of the second study, there were increasingly negative reports related to the Google Glass in the media, especially in the USA. There was an emerging popular term 'Glasshole' to describe people who wore the devices in public (Schuster, 2014) and there were also privacy concerns around the device (Hong, 2013). Perhaps as a consequence of this, restaurants and bars were starting to ban people wearing the device on their premises (Gray, 2013).

[3]Our original press release can be read here: http://www.ncl.ac.uk/press/news/legacy/2014/04/googleglassputsthefocusonparkinsons.html

could see the potential in it'. We also had to carefully negotiate a tension around the desire (from the institutional press team and journalists who later interviewed us) to provide concrete, yet hypothetical (as we were yet to develop anything), examples of how Glass might help someone with Parkinson's. To help with this, in the press release we said we would be exploring how 'motion sensors in Glass can be used to support people with "freezing", a behaviour caused by motor blocking, a common symptom of Parkinson's'. In a video produced alongside the press release, and in subsequent interviews with journalists, we also used the example of a medication reminder as a hypothetical Glass-based app. We chose this as it was something simple for audiences to understand, and because it was an idea expressed by the participants in the first study. Again, we were cautious to express that 'we were looking at' how these ideas could be useful and used language such as how the technology 'might' be valuable to people with Parkinson's in various ways. However, the care we took over the language was somewhat contradicted by the inclusion of a video of a mocked-up medication reminder Glass app being used by someone.[4] This short segment was included to make the ideas we were talking about clearer to the viewer. In hindsight, however, this very likely gave the impression that this was a working system that was ready to be trialled.

A second set of issues arose after we contacted our first study participants to explain the publicity work and asked if they wished to be involved in any way. It was at this stage that several participants highlighted that Parkinson's Awareness Week, a campaign run by a UK charity to raise public awareness around the condition, coincided with our plans. Some of our participants, and indeed the local support groups of which they were members, were particularly interested in leveraging the Glass project and the press interest it might receive as a way to build public awareness of Parkinson's. Therefore, several of the participants volunteered to take part in the publicity activities, appearing on local news with the researchers, not just to talk about their experiences in taking part in the study but to talk about their experiences of living with Parkinson's more generally. Two participants, in particular, contributed significantly to our press work, including working with the University press office to provide short 'case studies' as an addendum to the press release. In these case studies, the volunteers explained how the condition affected their routines and daily life. They were also more enthusiastic to talk about the opportunities presented by the Glass technology than we (the research team) had been. In their case studies, which were added to the end of our press release, they explained how they were 'complete converts' to the technology, and that 'the potential for someone with Parkinson's is endless'. While again the tone of the press release emphasized what the

technology *could* do, rather than what it *did* do, it was without doubt a highly positive portrayal of the project and the research.

In the period immediately following the publication of the press release, two members of the project team spent several days speaking to journalists, being interviewed for articles and appearing on regional television and radio shows. While for the most part news reports used direct quotes from the press release or video we had put together,[5] it was notable how some articles started to adapt and alter the description of the project. For example, one article in a popular national newspaper explained how 'the technology, which is not yet available in Britain, reminds the patients to take their medication, contacts relatives in an emergency and can even prevent debilitating episodes of paralysis—known as "freezing"'.[6] A popular online technology blog opened their article by claiming: 'First UK Google Glass trial gives Parkinson's sufferers more independence',[7] while another explained that we had 'developed software to help sufferers of the disease cope with and control some of the common issues they face'.[8] Local newspapers spoke with our volunteers, reporting one as saying 'for me the biggest benefit [of using the technology] was confidence'.[9]

While in some respects the different ways in which the research was described and characterized in some articles was disappointing, given the observations made in prior work around HCI in the media it was somewhat expected. However, we had not imagined the degree to which the representation of the research in the media, and by ourselves and our volunteers in the press release, would shape the next stages of our research. While our initial work was successful in a highly exploratory way, it was always intended to feed into a longer trial of Glass with a larger number of participants. This second trial was focused on capturing participants' experiences of using Glass to do specific types of activities that built on the themes and ideas identified in the initial study. At the end of these second trials our ambition was to conduct co-design activities with participants to reflect on their use of Glass in a structured manner and to iterate and refine the ideas developed with our first study participants. As this stage of work has not been published previously, we describe the study design in detail below. After this, we explain the ways in which our earlier findings and subsequent

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[4]See the video accompanying our press release for examples: https://youtu.be/e0tbbWIvMFs

[5]This article in the Daily Mail is an example of an article that was primarily based upon the wording of our press release: http://www.dailymail.co.uk/sciencetech/article-2600241/Google-Glass-brings-hope-Parkinsons-sufferers-lives-improved-smart-new-technology.html

[6]See http://www.telegraph.co.uk/news/science/science-news/10752873/How-Google-Glass-is-helping-Parkinsons-sufferers.html

[7]See http://www.engadget.com/2014/04/09/google-glass-parkinsons-uk-trial/

[8]See http://www.gizmag.com/google-glass-parkinsons-research/31564/

[9]See http://www.thejournal.co.uk/news/north-east-news/google-glass-offers-hi-tech-hope-6938329

work with the press converged with technical challenges in the second study to present a number of ethical dilemmas.

2.3. Second field trials: co-designing applications

Our second study was divided into two stages. First, as with our first study, we provided participants with a Google Glass (and a Google Nexus 4 mobile phone for Internet tethering purposes). This time, we left the devices with participants for a slightly longer period of 7–10 days each. At the start of the study, a researcher visited participants in their home to deliver the Glass and provides a demonstration of its use. Participants were also provided with the user manual that we had created to refer to if necessary during the field trial. As with our first study, participants were informed that they could use Glass as much as they wished, in any setting they felt comfortable in. We also provided a diary with activities for them to perform each day (Fig. 1). The diary had a recording device embedded within the pages for each day, allowing the participants to record short reflections on their experiences with Glass. These questions were, unbeknownst to the participants, related to activities that would be conducted in the co-design session at the end of each trial.

The second stage of the study involved a co-design session with each participant at the end of their field trial. We used participants' diaries to structure these sessions, where design activities were built into hidden compartments on each page (Fig. 2). Each activity was designed to support reflection on

Figure 1. Diary given to participants for field trial in phase 2 of the study, closed (left) and open (right).

the specific tasks we had asked them to complete during the week and to identify opportunities for designing new Glass applications. In creating our design activities, we were inspired by Sanders and Stappers (2012) 'say, do and make tools' for co-creation. As such, our activities had a dual purpose—first to engage participants in reflecting upon both their everyday life and their use of Glass, secondly to act as ways of encouraging 'talk' around the activities that would be recorded and used as part of our qualitative analysis. As with study one, this study design went through the standard institutional ethical review processes, and was approved with minor adjustments made around participant data storage protocols.

2.4. Participants

As with our first trial, participants were recruited via local Parkinson's UK support groups. Our eventual group was made up of 10 (five female, five male) participants with ages ranging from 49 to 80. All had mild to moderate stage Parkinson's and were independently mobile. Participants had a diverse range of symptoms; from hand tremor to significant issues with gait freezing leading to increased falls risk, with varying degrees of impact on their daily lives. While most participants were active and independent, several had additional issues to manage aside from their Parkinson's; Morris was managing multiple conditions, Allen was a primary caregiver and Ethel was experiencing anxiety. In relation to technology use, all participants owned a computer, although five reported using it infrequently and two relied heavily on a family member in order to use it.

3. OUR ETHICAL DILEMMAS

All of the co-design sessions with participants were audio-recorded and transcribed. All transcriptions were anonymized. The transcriptions, combined with our field-note diaries and completed co-design materials, were the corpus of data for analysis. Our analysis of these data followed a thematic approach. This method, outlined by Braun and Clarke (2006),
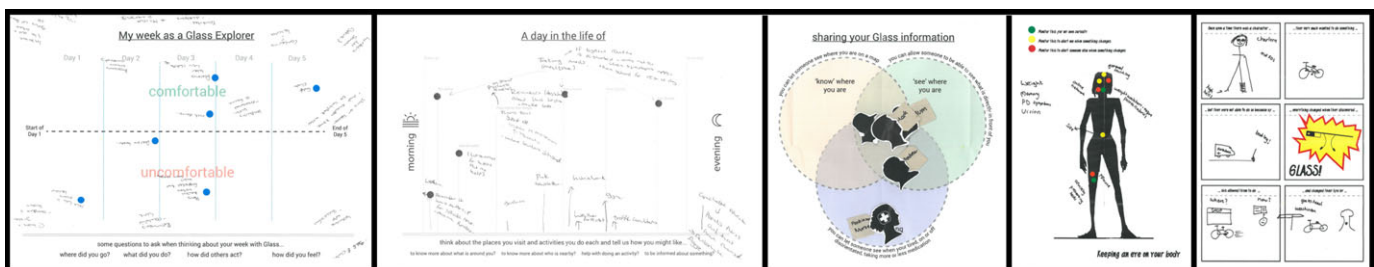

Figure 2. Examples of completed co-design activity sheets. From left to right: my week with the Glass, a day in the life of, significant others, body mapping and future self.

is a process of conducting bottom-up coding of the data in a way that does not attempt to fit data into a pre-existing coding framework. In our case, while our analysis of the data was inductive we were 'theoretically driven' to code in a manner that would identify the challenges, problems, breakdowns and ethically difficult issues that occurred during the field trials and in the data. This theory-driven, rather than data-driven, approach was taken as a result of our own concerns around participants' negative experiences while running these trials. These problems led to a number of participants withdrawing from the study, and eventually led us to bring our project to an early end. As such, in our analysis we wished to focus on the more problematic aspects of their participation in the study so as to understand these more fully and learn from mistakes made. Following Braun and Clarke, all of the transcripts related to the 10 participant interviews were coded, manually, at the sentence to paragraph level by one researcher, while a second researcher coded a subset of these data comprising five transcripts. Initially, 93 codes were generated across both of the analyses. Following this, the two researchers met to review codes and discuss agreements and disagreements in interpretation. A total of 66 codes were assigned to the data following this meeting. These were then grouped together around recurring themes across all of the participants (Braun and Clarke, 2006). As is common in constructivist approaches to qualitative research, the coding review process was not undertaken as a means to determine inter-rater reliability or objectivity of the analysis, nor to develop a prescriptive schema; rather it was to ensure that there was agreement among the research team that codes and themes were authentic to the data corpus [see Yardley (2000) for a discussion of this].

This analysis process led to the construction of four broad themes described in the following sections with extracts from the interviews and our observations from field-notes: *high expectations and initial letdowns*; *effort, time and withdrawal*; *hope and self-depreciation* and *risks and vulnerabilities*.

3.1. High expectations and initial letdowns

There were several underlying reasons why participants had a desire to take part in the second phase of the Glass study. We first met many of the participants by attending their regular local Parkinson's group meetings. It became clear at this stage that several group members had already heard about the project and were particularly interested in participating in order to try using the technology. As previously mentioned, following the first study we engaged in several media activities. Our first piece of work had also featured in the both the regional and several of the smaller local Parkinson's group newsletters. Also, many of the people attending these groups had heard about the project from other members who had taken part in the first study.

While there was no doubt that this widened awareness of our project meant recruitment for the second study was made simpler, we were immediately concerned about participants' expectations of the research, and what they thought they might gain from participating in it. When participants were recruited we were careful to emphasize the exploratory nature of our research, through both our verbal and written descriptions of what we were doing. In our participant information sheets we explained how 'Glass is a brand new technology' and that we were still aiming 'to identify whether Glass would be acceptable and usable to people with Parkinson's'. We went on to say that we were giving participants the technology to find out 'what you enjoyed, and what frustrated you' and how 'this will help us understand what aspects of the Google Glass people with Parkinson's find useful, enjoyable, frustrating or even pointless, and help us identify ways to improve the technology and create new ways of using it to help provide health/Parkinson's related help in the future'. Despite this, going into the trials there was a buzz of excitement from our participants around the study. For example, Ethel explained how at the start of her week with Glass she was 'too excited to take it in' and 'full of hope'. While in our initial meetings with Ethel, her excitement was in part because of the pleasure she sought in learning something new, it was also clear that she had set expectations on what the device might do for her. When first meeting Ethel, she had already considered in some depth how Glass might positively influence her life during the week ahead. She imagined it being useful for making phone calls, as she struggled with her phone due to tremor. She felt it would increase her confidence when walking outdoors by alerting her when she was at risk of falling: 'I couldn't see [*myself*] going out on the street with it to help [*me with*] finding directions. I'd go out in the street with it to stop [*me*] falling in the road.' In almost all respects, Ethel had constructed these potential personal use-cases based upon the reporting of the project in the press and the previous volunteers who enthused about the 'great potential of the device'. Similarly, other participants talked about their excitement about being able to try these 'magic specs' (Henry) with their 'endless possibilities' (Rory). While we tempered these expectations around the device—emphasizing how Glass was still a prototype, and that many of the envisioned applications were still some way from fruition—many of the participants were clearly still motivated to take part for some personal gain.

The high expectations and excitement around the potential of the Glass became problematic as participants took part in the field trials and attempted to use the devices on a daily basis. Early into the trials, it became clear to many participants that it was going to take them significantly more time to become accustomed to Glass than they had expected. A relatively minor issue that five participants had to overcome was that they wore prescription spectacles. We had expected this to be an issue for some and in our initial meetings with these

participants we established workarounds by showing them how to wear Glass over their own spectacle frames. A bigger challenge for participants was with some of the functional elements of Glass. Contrasting with our first trial, all but two experienced significant problems with interacting with the device. Some struggled in familiarizing themselves with the touchpad on the side of Glass frame, finding it 'fiddly' (Keith), 'too responsive' (Ethel) or 'unpredictable' (Rory). There was a similar unpredictability with speech recognition; some participants explained how on some days it would hear them perfectly, and on others it would not respond at all. Again, in some ways, these issues were unsurprising considering that speech and voice issues are common in people with Parkinson's. However, these were difficulties expected in our initial study yet for the most part were not experienced by participants in either the workshop or the first field trials, despite some having more severe speech problems. Furthermore, many of the issues participants were reporting could not be replicated when the researcher was with them, meaning it was often difficult to identify the cause of the problems. Despite these initial difficulties with using the device over the first several days with the Glass, participants explained that they 'wanted to persevere with it' (Keith) and would try again the next day.

3.2. Effort, time and withdrawal

As the trial progressed, the research team spent an increasingly large amount of time talking with participants about the problems they were having using the Glass and visiting them to debug the system. What became clear was that many of the problems participants were having stemmed from updates to the Glass operating system. During the period the study was conducted, unbeknownst to us, the operating system went through frequent over-the-air updates. These were impossible to stop without disconnecting from the Internet and thus severely reduced the functionality of the device at these times. Updates had several undesirable implications for participants during the trial. The most extreme of these was an inability of the device to reboot fully following new software installation—three participants reported that their devices would turn on, show a loading screen and then turn off, only to turn itself back on again. These installation problems required the researchers to reset the device, reinstall the operating system and re-add applications. However, as there was no information about these updates, each time the system was reset the older operating system was reinstalled resulting in further over-the-air updates occurring during later trials. On other occasions, when the updates did work it meant that the device still functioned but a range of its attributes changed (e.g. batteries discharged even more quickly, the list of voice commands altered, or it reorganized the cards displayed on the timeline that the wearer interacts with). As such, the instruction booklet provided became invalid, as did the demonstration performed by the researcher at the initial home visit.

These updates and breakdowns in expectations of how the device worked had significant impact on participant engagement. Despite the enthusiasm at the start of the trials, all but one participant bemoaned the huge amount of time, effort and energy that went into 'fiddling' and 'faffing' about with the device. Morris described how 'it starts to consume a lot of time'. As with other participants, he adopted a piecemeal approach to his engagement with the technology: 'Well, I've only done a couple of hours, and then put it down and try again later.' On two occasions, the amount of effort Glass required led to participant withdrawals from the study, with the first, Allen, noting 'he couldn't find the time to engage with it properly'. The second drop-out, Cara, so full of hope and expectation when we first met her, was so deeply frustrated with Glass following two updates in a week that she explained: 'I just want you to take it away, and be rid of it.' In Cara's case, the deep frustration and upset caused by the technology during her short time with it was palpable. In the case of these participants, they withdrew from the study with no barriers, as outlined in the ethical procedure. However, the levels of frustration they felt were shared by other participants who persevered with the project because, as said by Ethel, 'I didn't want to let you [*the researcher*] down'.

3.3. Hope and self-depreciation

It is clear from the above that many of the participants became deeply frustrated with the technology during the course of the trial. In most cases, this resulted in disappointment that Glass, which had appeared to offer such great potential, did not live up to expectations. However, several participants experienced frustrations with the system that affected them more personally. We mentioned Ethel's perseverance in the previous section. She expressed an extremely positive attitude at the start of the trial that became more subdued as she encountered multiple functional problems with the device. While conducting our design activities with Ethel, it became apparent that she had a number of anxieties in relation to her physical abilities, and was having issues with her own confidence. Much of this appeared to be rooted in her experiences following her diagnosis of Parkinson's. She had taken early retirement and had experienced a number of trips and falls in public as a result of her medication wearing off. As such, her great enthusiasm at the start of the study was related to a sense of hope that this technology would, at some point in the future, give her back some of the agency and independence she had lost. Through some of the challenges she experienced with the device, she became confronted with the possibility and probability that these expectations were unrealistic. However, more critically, she started to blame

herself rather than the technology for these failings: 'I was just rubbish; absolute rubbish.' Ethel continued:

> I just wanted it to work and I wanted it to be a success. But I don't know if I was too impatient or whether it was too sensitive. Because my right hand is good; my left hand is not. […] I think I overcompensate on my right hand. I'm a bit ham-fisted.

As Ethel spoke about her troubles using the device, she would continually return to blaming herself for lacking 'physical ability' or 'patience'—this was despite the researcher explaining that she was not alone in having problems with the Glass, and that her issues may have been caused by some unexpected problems with the software on the device. Ethel referred to the positive experiences she believed other participants were having:

> I had spoken to Laura […] She had it a few weeks ago. She was telling us how brilliant it was and what a great time she had. I think, 'Well, I must be thick if they had such a brilliant time with it. […] Here we go. Something else I'm meant to be doing and I'm meant to be successful at and I'm useless.

Our experience with Ethel highlighted the most extreme case of participants blaming themselves for what was, primarily, technology failure. She felt her struggles with Glass reflected a loss in intelligence: 'I've always classed myself as reasonably intelligent. […] So I should be able to take something in'. Her experiences during the trial had caused a number of existing concerns to surface and become more prominent. These problems were also echoed, albeit less severely, by others: 'I was obviously doing something wrong. […] You feel inadequate don't you when it's the machine' (Sue). Morris also noted: 'I couldn't get it to do what I wanted it to do, and sometimes when I moved it wouldn't move. That was probably me not being able to operate it properly.' These same participants expressed great joy and satisfaction when they were able to get it to work: 'it made me feel a bit better because I got something right at last.' (Sue); 'When I got Google to work […] I was sky high. I was chuffed to bits with myself.' (Ethel).

3.4. Risks and vulnerabilities

Perhaps unsurprisingly, some participants restricted their use of the Glass to their own home. In part this was down to fears of the device being tempting to thieves: 'I'd be frightened if I met somebody that knew what it was and thought, "That's quite valuable." […] I was frightened to go outside with it' (Ethel). Others who had similar concerns over personal security and sense of vulnerability when wearing the device carefully chose where they would and would not wear it in public:

> I chose not to go to certain places when I'm wearing it. I wouldn't go into [Town] on my own, but I would go to the [Shopping

Centre] on my own. The reason for that is, is it a prejudice or I don't know, but there are people who these days are just nicking mobile phones that are in people's hands and walking down and we were around an area that's a bit economically deprived, I feel less comfortable with that (Keith).

Beyond fears of being placed at greater risk, two of the participants felt that the physical presence of the device was a barrier to its use in public. For example, Laura felt that there was already a negative public perception due to the external symptoms of Parkinson's, and that wearing Glass would draw unnecessary attention exacerbating feelings of discomfort:

> People who already have a condition that draws attention to themselves, if they are already having difficulty dealing with that, they may have difficulty feeling that the Glass is going to attract attention to them.

Although our initial study had highlighted generally positive reactions to the use of Glass in public, we were unsurprised that some participants were deterred from wearing it due to feelings of vulnerability—either fears for personal security or fears of attracting attention and stigmatization. However, what was unexpected was the ways in which participation in the research activities themselves heightened certain vulnerabilities. The co-design activities, intended to structure reflection on the week's activities using the device, also purposely invited conversation around participants' personal circumstances and biographies. While for the most part these gave opportunities for participants and researchers to talk openly about personal aspirations, desires and concerns, in some cases it revealed personal details of participants' lives that made the sessions somewhat distressing. In one instance, when completing the 'significant others' design activity, which was designed to support participants in reflecting on the sharing of different types of data collected by Glass to people in their lives, one participant struggled to choose who their significant other would be. During the activity, this participant thought about choosing their partner, but discounted them as they did not think they would care. Following this, they reflected on how their adult child would wish to see collected data but then speculated that they had a busy life already and this would burden them further. It became clear during the activity that the participant was dealing with personal challenges including the breakdown of a long-term relationship with a loved one, and fears of being hard work for one of their children. Unexpectedly to the researcher—and perhaps to the participant—the co-design activity initiated a conversation about these problems in a way that they had seemingly been unable to externalize before. This was echoed with a number of other participants where the completion of activities that asked them to imagine their future selves afforded the opportunity to talk about their perceived deficits and incapabilities, although the intention of course was to focus on positive future states, not to talk about doubts in the present.

It is important to note that while we have discussed a number of issues that emerged around the vulnerability of participants here, most—including those who became distressed at other points in the study—also acted in ways that confounded an image of them being vulnerable. All of the participants were all physically active and mobile. In some cases participants' activity levels eschewed any image of them being frail or 'at risk'. For example, while Keith was adverse to wearing the technology in places he felt were 'dodgy', he did wear it while driving (despite our guidance not to do so). He exclaimed 'when it works the SatNav is fantastic!', and that 'it tells you all this interesting information about what's around you!'. Similarly, Gerry wore the Glass when he was riding his bike: 'it's great, but you just have to be careful not to let it distract you as you can fall off!'. What this highlight is the transience of the concept of 'vulnerability'. Social conventions of vulnerability relating to factors like age, physical disability, or having a health condition do not necessarily equate to how vulnerability is fluidly experienced in practice. At the same time, it is clear that at points all of the participants were susceptible to being vulnerable, especially when their medication was wearing off, when their moods dramatically changed in ways they could neither control or understand, or when negative experiences reinforced underlying anxieties and feelings of inadequacy.

4. REFLECTIONS ON THE ETHICS OF OUR RESEARCH

In this discussion section, we reflect on the challenges the participants faced and the ethical dilemmas we encountered as a result during our year with the Glass. In particular, we focus on some of the key decisions and actions taken by the research team, the participants and volunteers. In discussing these issues, we aim to provide guidance for future researchers conducting similar types of 'in the wild' work with potentially vulnerable participant groups. We acknowledge that such guidance only provides first steps in responding to challenges faced in our project, and we share them in the spirit of promoting further development and thought.

4.1. Was it correct to publish our first study when we did?

If we were to trace where our ethical dilemmas first manifested, we could choose the point where we decided to publish the findings of our first study. It might be argued that it was too early to publish that initial piece of work; it was based on a single group workshop and a series of short deployments with a small number of people. In the paper itself we did not attempt to disguise these limitations of the work, highlighting many of them explicitly; yet this first piece of work was still very well received by reviewers in the peer-review process[10] and despite sample size, study length and potential novelty effects, was published relatively unchallenged. However, if we assume that the publication of this first study was problematic for a moment, then it ties into ongoing discussions around publication practices within HCI and the wider discipline of computer science.

There has been a growing concern that the annual conference cycles within HCI are promoting the creation of research for publication, rather than the publication of research—or, in other words, there is a push for quantity over quality (Friedman and Schneider, 2015). There are wider contextual and systemic reasons why this might be problematic. Yardi (2015) comments on how publishing cultures within fields and disciplines often fuel and feed into cultures of assessment and evaluation within Universities and research institutions. Friedman and Schneider (2015) have noted how tenure-track assessment committees have been influenced by the publishing practices within computing disciplines by placing an emphasis on hiring candidates with long lists of publications at 'leading' venues, rather than those who may have a smaller number of 'significant' and 'impactful' publications. A similar predicament can be seen in the UK (where the authors are based), where the Research Excellence Framework (REF), an assessment exercise that occurs every 5–6 years, rates and ranks the publications of faculty members in terms of their significance and impact. The emphasis of the REF is to push for a small number of 'internationally leading' contributions. However, significance and impact is also determined through the number of citations submitted publications have—thus there is still a pressure to publish early (because the earlier the work out the more opportunity to be cited) or publish novelty (i.e. be the first to publish something that might then be well cited by others). While having different purposes, it is possible to see how these practices of assessing the value of a researcher's work can easily influence a 'numbers game' in publishing practices. It has been argued that such practices lead to researchers 'spamming' publication venues with an array of submissions, increasing drain and strain on reviewer pools, lowering acceptance rates and biasing incremental gains in knowledge and short studies, over significant or controversial contributions (Grudin, 2013).

It could be argued that the publication of our first paper is a symptom of some of these issues. Its acceptance and relatively easy progression through review, following the above arguments, could be a result of a weakened reviewer pool that privileges novel technologies while the limitations of the study itself were missed or seen as less problematic than they were. Indeed, reflecting on some of our motivations for submitting the first Glass paper, we imagined that it would be one of the first user studies of Google Glass, would be well

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[10]The paper in question was so well received that it was acknowledged with a Best Paper award, meaning it was in the top 1% of all submissions to the conference that year.

received by reviewers partly because of this and, if published, had the potential to be well cited by others. At the same time, we were confident that the platform had genuine utility as an assistive device, that other researchers would have similar ideas for how the system could be used in this way, and that our initial reported results around the acceptability of the device would be an important first step to that would be valued by other researchers working in this space. Despite the study limitations, we still judged our findings as valid and significant, especially as the insights around the perceived usefulness and acceptance of the device were so counter to what we assumed would be the case before conducting the initial workshops and trials.

In our case, what was perhaps more problematic was that our first study examined a technology that was undergoing rapid and dramatic functional change, and we had not accounted for this in our first published work. The Glass studied in our first trial was fundamentally different to the Glass that developed during our second study. Apps that previously worked were blocked, the spoken commands changed and the ways apps appeared in the system, and the modes of interaction required to use them, changed significantly. These all influenced our second wave of participants experiences of the device, especially those who were dealing with it during unexpected system updates. As such, the greatest limitation of our prior work being published was that it was fixed in a moment of time when a specific group of participants experienced a specifically configured technology. While Google Glass *as a concept* was acceptable to participants (a view that was still echoed in our second study), using it relied on a high level of consistency, which later iterations of the software were unable to deliver. However, the danger is that an archival publication such as ours makes it appear that 'Glass' itself is accepted by people with Parkinson's in all of its material and software forms—which it clearly is not.

The problem above raises a number of questions for researchers and the ways in which they present their research. It emphasizes the importance of being confident in your findings, while also considering how future variants of systems and the particular ways they are configured might influence human experience. But it also challenges existing norms of how papers are read and disseminated, and the role of archival databases in presenting work to audiences. While publications should always be located in a discourse and ongoing accumulation of knowledge, they also have strength in isolation. In this instance, there is no opportunity for us to edit, amend or even retract the results of this earlier work. At times like this, there might be a responsibility for publishers such as the ACM to offer opportunities for commentaries, responses or updated articles and findings, that can be published visibly alongside archival publications. Such capabilities appear to be particularly important in HCI and design-oriented work where often there are contextual and technical specificities to findings and, as in cases like ours, study limitations might only

be discovered post-publication. The provision of modes of publishing that allow for follow-ups from authors, reasonable amendments to prior work, and the addition of new findings would aid readers who might otherwise take results at face value, or not discover subsequent studies from the same authors published in different venues or archived elsewhere. This also places an onus on researchers to not let old work and its findings be forgotten, and to give details about any follow-up work, whether the work has ceased or is continuing and whether the earlier findings were subsequently contradicted. It also means we should be encouraging authors to publish their failings and where projects went wrong, which does happen in HCI (Gaver *et al.*, 2009) but very rarely. This would place further demands on peer-review processes—as community members we should accept that project failings, either in design, in enactment or in technical implementation, are as important to share via publications as our successes.

4.2. How could we be better at managing our own 'publicity'?

A further layer of complexity surrounding our ethical dilemmas was the role of the media and our publicity work in shaping participant impressions and perceptions of what the research would be about. The publicity work we conducted was done at the intersection of a number of 'timely' events that meant it was distributed near and far. It reached local and regional Parkinson's support groups due to the overarching charity's involvement in the research. It reached popular science press due to the upcoming results being published. It also reached the local and mass media because it was portrayed as a 'worthy' application of the 'soon to be publicly available' Glass technology. Perhaps naïvely, our engagement with the media was predicated on a desire to raise awareness of what we were doing in general and also to articulate a more positive presentation of living with Parkinson's for the awareness week. While we purposely avoided 'talking up' the contributions of our research given the exploratory nature of our work, the subtle wording of the press release was somewhat lost on a non-academic audience. This was hidden further when we talked about feasible future applications that could be developed for technologies like Glass to help people with Parkinson's. We intended such examples to act as 'hooks' (Eilders, 2006) and offer a way for readers or audiences to understand what the broader aims of the project were. It was also, based on our press team's guidance, a way to avoid getting lost in details of the science and talk about the narrative of the research. However, in doing so we presented a highly positive imaginary of what these technologies could do in the future, and how we might positively influence the lived experience of Parkinson's through this project. This was given even more authenticity by the case studies and accounts from our previous participants which, when

combined with our hooks, led to the subsequent reporting of the project as a completed enterprise with evaluated, working applications and positive results.

The public discourse surrounding our project clearly influenced the experiences of those participating in our second study. For some, their first contact with this project came from a combination of reading short reports on the findings of the first study in their Parkinson's group newsletters and through talking to the first study participants through intergroup meetings and social activities. Many of these participants had also looked up the research online—not only watching the official promotional material from Google, but also reading the publicity material surrounding the entire project. This promotional work—in Google's case created to either 'sell' the Glass concept, or in our case to 'sell' the value of our research for a public audience—may have led them to believe that they would be testing a finished and complete 'product'. Furthermore, based on the shared experiences of the previous participants, it was reasonable for our second group to expect to find it relatively easy to learn to use and access the technology. As such, even those participants who had limited experience with digital technology had high hopes and were strongly motivated to participate in the study, either because of the positive narratives they had encountered or due to an expectation that their wellness might be, at least slightly, enhanced through participating in the trial. These stories therefore influenced participants to move to a state somewhat akin to *therapeutic misestimation*—they overestimated the potential benefits they might gain from participating in a trial, despite being fully aware that this was not in any way related to their ongoing care practices (Horng and Grady, 2003).

Clearly, as researchers, we need to be extremely cautious about how we communicate the value of research to others. It is well acknowledged that researchers working in Universities are increasingly encouraged to engage with the public about their research (Grand *et al.*, 2015). Many influential bloggers and scholars have proclaimed the benefits for academics if they increase the visibility of their work and professional profile to public audiences (Dunleavy, 2015; London School of Economics, 2015). It would be wrong for us to suggest that we had entered the publicity work in an entirely altruistic manner, without consideration of the potential positive impact it may have on us professionally. However, we should equally be sceptical of publicity for the sake of publicity, and be aware that much of the publicity work performed by Universities may not necessarily be done to develop the careers of researchers, nor to communicate research outputs; rather it is primarily a means of fulfilling metric evaluations of an institution's 'mentions' in the media.

While currently practices of publicity, engagement and outreach seem to be treated as a means of broadcasting information, we propose instead that it should be seen as a dialogical process whereby we meaningfully engage with communities and groups who may have a stake or interest in the research. This might mean that rather than initiating publicity via press releases, or devolving it to journalists, bloggers or news corporations, we initiate it through conversations with those potentially most affected by what has been learned. This could have other benefits, such as providing a platform for setting expectations around the research. It would also be an opportunity for researchers and communities to engage in question and answer sessions in more private settings, untangling the purpose of the work and its potential value.

4.3. How can we better harness the will of advocates?

While the research stories created by ourselves, our institution's press office and the press were problematic, equally so was the enthusiasm of some of our prior participants to talk about the research with others. Those prior participants who had volunteered to engage in the media work used this as a timely opportunity to advocate for people with Parkinson's and heighten awareness of some of the challenges faced by those living with the condition. They also wanted to present the lived experience of Parkinson's in a less negative light. In doing so they acted as an advocate for the researchers' project; explaining why they had got involved and, by association, praising the future potential of the Glass. The work they did in public was echoed in conversations about the project at a local level, within their support groups and with other future participants.

Our experiences highlight how, while researchers have a huge amount of power and control in the design, definition and conduct of research, those who participate also have power and responsibility. Fisher (2006) notes how participants can make others vulnerable, in that they have the power to willingly deviate from a defined protocol, to break the confidentiality of other participants, to use technologies in contexts where it may be invasive or irresponsible, or simply talk to others about their experiences of participating in a study when it is unwise to do so. In control trials it is often the case that participants are asked not to talk about their experiences of a trial with others and thus avoid the potential for biasing results. While result bias was not really a concern with our exploratory work, it was clear that the talk between participants about the research, particularly when those participants were highly trusted members of the local Parkinson's community, set unattainable expectations. In hindsight, we perhaps should not have involved these participants so actively in our publicity work. However, their desire to take part in this was very much driven by their own agenda to support a national campaign. Considering how much time they had given to us, it felt only fair to give something back by supporting them with this.

Clearly, in these circumstances, while traditional institutional ethical and governance frameworks assume the researcher is in full control of a study, in our case power was shared to a

higher degree. It would be unreasonable, or at least impractical in the 'messy' (Le Dantec and Fox, 2015) context of working with a close-knit community, for participants to be told not to speak to others about the work. However, there are strategies we could have used to help these advocates think through the implications of doing so. In community-based participatory research not only is control of the project shared between 'professional' and 'non-professional' researchers (who may typically be framed as 'participants' in institutional ethics processes) but also ethics and consent are seen as equally co-productive in the research process itself (Banks *et al.*, 2013). The lesson from this work would be to incorporate group sessions prior to the conduct of individual field trials where we could collectively talk through what is being consented to in the research, openly discuss aims and ambitions of the research, and allow participants to demonstrate their understanding of what they are consenting to prior to studies commencing. In some ways this happened in the first study; our opening workshop acted as an opportunity for participants to question what we were doing for what reason, and to set shared expectations around what the outcomes of the research would be. This was a critical step missing in our second piece of work where, while we did meet participants prior to trials at support groups, our discussions were shorter and on a one-to-one or one-to-two basis.

Going a step further, we might wish to explore whether there are opportunities for proactive participants and advocates of the research to take on new roles and responsibilities and perhaps become co-researchers themselves. This would require discussing with them the responsibilities of information gathering and talking to others who might be taking a less active, albeit still important, role in studies. In doing so it would be critical to examine with more proactive participants their potential power and influence over others who live with a similar condition but may, for a range of reasons, have heightened vulnerabilities. If we consider future studies like ours in this more co-productive sense—in that co-researchers provide support for one-another—we might channel the enthusiasm expressed by these participants in new ways, and further value the significant contributions of those with the most to give.

4.4. What are the responsibilities of consumer platform providers?

While many ethics boards take concrete definitions of vulnerability based on the World Medical Associations Declaration to Helsinki (World Medical Association, 1964), the participants' experiences in our second study highlight how vulnerability is fundamentally relational and situational (as noted by Fisher, 2006; Mackenzie *et al.*, 2014; Nordentoft and Kappel, 2011). In other words, when people become 'vulnerable' is 'dependent upon the specific actions of scientists within

a specific experimental context' (Fisher, 2006). In our case, participants could be viewed as having continually changing vulnerabilities throughout the trial. We had expected that fluctuating symptom severity could mean a participant appearing engaged, enthusiastic and alert upon meeting the research team might feel less so during the trial. What we did not fully anticipate, however, was the way in which Glass would heighten some of these vulnerabilities.

Again, it is important to note that we did anticipate a number of potential risks from the trial of the technology with these participants and designed measures into our study to mitigate against these. Each device was robustly tested prior to being given to participants. The researchers spent time with the participants to take them through how to use the device. Each participant had a bespoke designed 'user manual' showing them how to use it. Researchers also enquired about any problems with the technology when checking-in on participants during the trial. However, we wish to highlight a subtler point that only emerged during the study: that it was the specific configuration of Glass as a *nearly product*, yet one that was still going through a significant amount of iteration and development and receiving remote updates from its developers, that heightened these vulnerabilities further. The high-fidelity design of the Glass was greatly appreciated by many participants across both studies. The perceived quality of the design made it less stigmatizing to wear, echoing our own previous work with people with Parkinson's (McNaney *et al.*, 2011). Yet the external production values of the Glass disguised the fact that this was still essentially a prototype undergoing radical iteration and testing. This was particularly true for the software underpinning the device and it was the frequent over-the-air updates to the operating system that caused the most distress, frustration and confusion to participants *and* researchers. That these updates were unexpected, would break other installed software, would often fail, or would change the conventions of interacting with the device caused yet more misery. It also meant the careful work we had put into demonstrating the system, producing detailed guidance and documentation on how to use it, and building confidence and belief in the participants, was undone.

As HCI continues to pursue studying smartphones and wearables and their associated applications, we should not forget that more often than not that these are based on systems provided by commercial entities who have great influence on what is built and published on their platforms, and how they are experienced by those who use them. With this comes a responsibility to ensure that systems are coherent and consistent with one-another. Not only is this in the spirit of usability best practice (Nielsen, 2002), but it also means participants, like those in our study, would not be at risk of experiencing a system design that has to be continually relearned or made familiar. It also comes with a responsibility to offer a choice as to whether an update gets installed or not, or whether part-updates are made available where background

processes might be optimized but interaction style and qualities remain compatible with prior conventions. There is also then a responsibility for platforms to be sustained and maintained. It is worth noting here that Google stalled their support of Glass as a platform after only 2 years of development. In this sense, the hopeful expectations extended to the platform by the Parkinson's community and ourselves as researchers have been lost, as the prospect of seeing Glass develop into a product has diminished. But there is also a consideration to ensure that the physical and computational forms of devices are in tune with one-another, avoiding situations where refined and sophisticated visual aesthetics are used to obscure underlying flaws in the software, or unwittingly give participants a false sense of security in the devices they are using.

4.5. How could we have better anticipated these dilemmas?

Our final reflections look back at the anticipatory ethics process we went through prior to conducting our studies. In HCI it has been recently acknowledged that anticipatory institutional ethics processes are often limited in supporting the pre-emption of ethical complexities when working with vulnerable people or in sensitive settings. This, it has been claimed, is often because such review processes can fail to account for the many complex and situational ethical dilemmas that can occur in practice (Munteanu *et al.*, 2015). Indeed, much of the discussed literature on relational vulnerability questions the virtue of anticipatory ethics; arguing that most institutional ethics processes exist to protect the institution from litigation and are more a form of risk management rather than ethical assessment procedure (Mackenzie *et al.*, 2014).

Rather than seeing institutional review processes as fundamentally limited, we believe that our local IRB could have played an even more active role in helping us think through the specificities and complexities of our proposed research. In our case, the review of our study design was conducted single-blind (the reviewers knew who we were, we did not know who they were) by colleagues from our faculty, based in different departments and schools. This is standard practice in many Universities to ensure that ethical assessments are not conducted by those too close to the researchers proposing the study design. However, with this comes some uncertainty over the appropriateness of reviewers in understanding the specificities of the context under study. This includes, in this case, the diverse vulnerabilities of the participants and the specific qualities of the technologies being deployed. As such, while our initial protocol did go into detail about what the researchers would do if participants became upset or distressed, and what we would do with personal data collected by the Glass, the reviewers' comments primarily related to how we would keep typical participant data (i.e. personal

details, interview data) secure and anonymous. While these are important issues, this focus on the regulations of data handling did little to prompt us to think more deeply about the wider potential for harm.

We end here by suggesting two adaptations to institutional ethics processes that might create opportunities for assessing and anticipating the issues presented by protocols like ours. First, we challenge the idea that study designs and protocols should be solely reviewed by an anonymous and distanced other. Instead we suggest that they be appraised by researchers that are disciplinarily closer to the proposers or have more specific domain expertise. In a single institution, it may be the proposers close colleagues (e.g. fellow members of a lab or research group) who will be best placed to understand the research context, the methods being used and most importantly the possible impact that these will have on participants. Or it might instead be clinicians or health researchers based in different schools and faculties that would come with stronger expertise in working with participant groups with specific conditions. Furthermore, our example highlights how there might be difficulties for reviewers given the complexity and novelty of the technology under study, or a general unfamiliarity with co-design methods. Therefore we also suggest augmenting existing internal ethics processes with informal but documented conversations where proposers and reviewers meet to discuss their protocol, go through materials relating to methods and demonstrate the technologies being trialled. We would consider this important in our case as it would have aided the reviewers to have hands-on experience with the Glass, to understand its nuances, and to talk through with us the potential challenges its deployment might bring for the proposed participant group. While this process was done informally among the research team and their close colleagues, undoubtedly having such a conversation with, for example, a local ethicist or qualitative health researcher would have aided thinking through these implications in more detail.

Second, even if we did incorporate the above suggestions into institutional ethics processes, there is some doubt still whether the specific problems faced by the participants would have been anticipated. Meeting a local ethicist or Parkinson's expert may have raised questions about how to structure the deployment of the technology, but it would have been unlikely to highlight how the system itself might be remotely changed during our study. Conversations around the proposed study design would have done little to think through the 'bigger picture' of the project, including prior engagements with participants and publicity and media work. Furthermore, there is an inherent danger that in introducing further institutional processes we burden academics and staff with further work to compete within their already limited time and resources. With this comes new risks that protocols become accepted without having been attended to in detail, or that risky and exploratory work becomes unnecessarily punished and rejected due to open-endedness and ambiguities as it fails to meet norms.

Therefore, our experiences here suggest the importance of not just sharing ethical dilemmas through academic publication, but within and across institutions as a resource for future study designs. For example, experiences such as ours could be translated into storyboards or scenarios that are presented to researchers prior to designing their own protocols. In doing so, it may prompt questions around: how proposed work is building on previous engagements with participants; how researchers might help set mutual expectations around the research and negotiate these in practice; how the team may consider the bigger picture of a study and the impact publicity may have on participant experiences; or perhaps instead engage researchers in questioning and responding to how they might create more flexible study designs that account for emergent participant needs. Doing so may be particularly important in fields such as HCI where research is often being conducted on the fringes of different areas of expertize, and often in ways that are exploratory and with novel systems and technologies. In embedding such stories and scenarios within internal ethics processes, we would not intend to prescribe what is right or wrong in specific situations, or stop potentially risky or innovative research from happening, but rather to aid researchers in anticipating the wider implications of the work they do, and to relate their own work to the prior dilemmas of others.

5.   CONCLUSION: ENDING ON A POSITIVE

In this paper, we have reflected at length on a number of the ethical entanglements we encountered during the conduct of a year-long project evaluating and trialling the Google Glass technology with people with Parkinson's. For the purposes of this paper, we have focused on what went wrong in our second trial, and how the failures in the technology gave rise to a range of other problems inherent in the design of our study (in its broadest sense) and in how we had determined the vulnerability of the participants. We have provided a series of reflections on these ethical dilemmas that we hope will be valuable to researchers engaging in similar work to ours in the future. At the same time we are very aware that our suggestions may have further ethical side-effects (e.g. what if adding further burdensome processes leads to rubber-stamp approval in order to expedite institutional review processes?). We acknowledge that our suggestions may in themselves be problematic but they are provided with the intention of offering first steps into these complex issues that we hope future research will expand and develop further.

While we have emphasized these negative encounters in this project, it is important to stress that there were a number of positive outcomes as well. Although a number of participants had poor experiences during the study, all still enthusiastically engaged with our research. We are now working proactively with the Parkinson's support groups to talk about the challenges we had with this research and are using this as an opportunity to define the aims, objectives and ambitions of future research projects with participants prior to their commencement. Also, despite the barriers to using the Glass that many participants faced, the study still revealed a range of interesting insights in relation to self-monitoring and self-tracking systems, and the role wearable technologies might play in supporting the daily lives of people with Parkinson's in the future. Much of this has fed into our next phase of design and development work for the Glass platform, where we developed a single-function application that was locked into the system, and did not require Internet access, thus avoiding the software challenges faced in this work (McNaney *et al.*, 2015a).

These positive notes, however, were somewhat overshadowed by the problems participants faced and the negative experiences these provoked. Through sharing these experiences, we wish to contribute to the emerging discourse around the ethical dilemmas inherent in some contemporary HCI research, in the hope of inviting further discourse and open discussion of how to better manage these challenges in the future.

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