

The Design and Evaluation of Novel Technologies for the Self Monitoring and Management of Parkinson's Symptoms

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Abstract

This thesis explores how digital technologies might better support people with Parkinson's (PwP) to take control of their condition, by engaging in self monitoring and management practices. The specific focus of this thesis is around issues managed by Speech and Language Therapists (SLTs) (namely drooling and speech and voice changes). Three case studies were used to explore the ways that different technologies might be configured to aid the self monitoring and management of these speech and drooling symptoms.

The first case study describes an evaluation of *PDCue*, a wrist worn device to assist the self management of drooling through the use of a temporal cueing method, to increase swallowing frequency. This study showed evidence that drooling can be behaviourally self managed through cueing—like other symptoms of Parkinson's such as gait freezing—and proved a viable first step towards re-considering the use of additional medications as a first option for drooling treatment. However, whilst this study proved successful in understanding the ways in which a simple, temporal cueing technique might support drooling management, it opened up questions around the ways in which PwP might use technology to actively think about and understand their condition through self monitoring, and use this information to support self management practices further. In response, the second case study describes the design and evaluation of *LApp*, an application to support both the self monitoring and management of vocal loudness issues through the use of an in-situ cueing approach. The Google Glass was chosen as the platform to run the cueing method on, due to its technical capabilities as a multi-sensor, wearable platform, to analyse a constant stream of audio and provide real time visual prompts to support the wearer in increasing their volume at times when it is needed in conversation. This study highlighted how participants saw value in *LApp* in supporting their loudness issues, but also noted a desire for participants to understand more about their speech and the SLT strategies that they were required to do in order to improve it. The third case study drew upon this desire for increased understanding by developing and evaluating *Speeching*, which employed crowdsourcing through a smartphone application to support the self monitoring of speech and voice changes, through the provision of human feedback, and the subsequent effect that this feedback had on self management practices. This study yielded positive responses

from participants, who valued the anonymous feedback from the crowd and the support that this provided them in configuring their home based speech practice.

A final discussion chapter draws the 3 case studies together and discusses the lessons learned throughout the research. It discusses the overall research questions for the thesis in detail and describes the implications of the research for the wider HCI and medical communities. A framework is presented which aims to visualise the levels of agency that the studied technologies afforded and the levels of responsiveness required by participants to make sense of, and implement the information being provided by the devices in order to facilitate a change to the self monitoring and management practices. Through the design and evaluation of the described technologies and a synthesis of the findings across the span of the research, this thesis explores the ways in which PwP, with a diverse range of symptoms and related physical, social and emotional issues, might value digital technologies and their potential to facilitate new forms of self monitoring and self management in their everyday lives.

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Collaborations

The work described in this thesis is the result of a number of extensive collaborations, without which the research could not have been conducted. I had the pleasure of collaborating with a range of people who implemented the designs derived from each study to develop the technologies used in the evaluations.

Chapter 4 describes the Parkinson's disease cueing (PDCue) device. This device was designed through a user centred design process, led by myself, and developed by Karim Ladha, Cas Ladha and Daniel Jackson prior to the conduct of the PhD research. The research reported in this thesis describes the process I took to evaluating the PDCue, as a device to support the self-management of drooling problems through repeated cueing, through the collection and analysis of relevant quantitative and qualitative data. Chapter 5 describes the Loudness Application (LApp) which was developed by Ivan Poliakov, who provided fundamental technical support throughout the entire process of the wider Google Glass project. The case study described in the thesis focuses on the work I conducted around investigating the acceptability of Google Glass as a technology platform for PwP, and explores the design and initial evaluation of LApp. Finally, chapter 6 discusses Speeching, a crowdsourcing platform for aiding the self-monitoring and management of speech and voice issues in people with Parkinson's. Paul Dunphy provided months of his time collaborating closely with me on the design of the initial Speeching platform, he developed the first iteration of the platform which was used in our preliminary work. This platform was further progressed by Mohammad Othman for the second stage of the study which implemented the self management aspect of the system. Dan Richardson developed the application which was vital for the collection and upload of speech data from the participants, and for the presentation of feedback and therapeutic direction.

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Chapter 1

Introduction

1.1 Overview

Speech and Language Therapy (SLT) is an allied health profession concerned with the assessment, diagnosis and treatment of a range of both communication and swallowing disorders. Speech and Language Therapists (SLTs) manage a broad range of patient groups within paediatric and adult services (e.g. early language development, additional needs, movement disorders, stroke, traumatic brain injury) and work within a wide range of settings (e.g. schools, homes, care homes, hospitals, prisons). A large component of an SLT's role, when providing therapy to a patient, is to measure clinical change—that is, the outcome or effect of the therapy on clinical goals and the service user's life. This is to ensure that the patient is receiving the best possible care from the health service and that they are satisfied with the outcome of their therapy. Assessments to measure clinical change quantify a patient's performance on a variety of tasks and permit comparisons to be made to 'the norm'. SLTs are responsible for delivering a range of evidence based therapeutic interventions to support the clinical needs of their patients, relating to improving communicative ability and managing swallowing dysfunction. The ultimate goal of any therapeutic program is for the generalisation of principles learned in the clinical context to the patient's everyday life. This is facilitated by the gradual practice of principles learned in clinic (e.g. such as sustaining increased volume on the vocalisation of 'ah' or re-learning a set of verbs) to the practice of more functional activities (e.g. extending practice to functional phrases which are meaningful to the patient, such as "can I have a cup of tea?" or "let's go for a walk"). Despite providing a core allied health service within rehabilitative and long term care—particularly in acquired or degenerative neurological conditions—SLT, like many other services, has been affected by funding cuts to the National Health Service (NHS). A recent survey suggests that over 80% of services have faced negative impacts in terms of staffing, reduced scope of services and in 8% even an abolishment of services altogether (Harulow, 2013).

One client group seen within an SLT's caseload is people with Parkinson's (PwP). Parkinson's is a progressive, neurodegenerative condition affecting around 5 million people worldwide (Olanow, Stern, & Sethi, 2009) with around 1 in 500, or 127,000 people, in the UK alone (Parkinson's UK, 2015c)¹. Aside from Alzheimer's disease (with around 850,000 affected in the UK) (Alzheimer's Society, 2015), Parkinson's is the most commonly experienced neurodegenerative condition worldwide (Tanner & Goldman, 1996). Research has suggested that an estimated 90% of all those affected by Parkinson's will experience speech and voice changes at some point in their condition (Ho, Iannsek, Marigliani, Bradshaw, & Gates, 1998; Miller et al., 2007). Changes in speech and vocal quality have long been documented in Parkinson's research (Kent, 2000), with common characteristics including a reduction in volume and alteration to prosody (stress and intonation patterns in speech) associated with a tendency to speak on one loudness level (monoloudness) with little variation in pitch (monopitch). Imprecise articulation and short rushes of speech may also be typical. In addition, perceptual vocal quality can become impaired, largely due to imprecise closure of the vocal folds, leading to a hoarse, rough, breathy or tremulous speaking voice (Holmes, Oates, Phyland, & Hughes, 2000; Skodda, Grönheit, Mancinelli, & Schlegel, 2013; Skodda, Visser, & Schlegel, 2011; Skodda & Schlegel, 2008; Skodda, 2011; Tjaden, Sussman, & Wilding, 2014).

Another significant symptom mentioned by people with Parkinson's (PwP) and managed by SLT services is sialorrhoea, or drooling. An early study, carried out by Edwards et al (Edwards, Pfeiffer, Quigley, Hofman, & Balluff, 1991), found drooling to be a problem in 70% of people with PD, in both the later stages of disease and in early patients prior to drug treatment. It is thought that daytime drooling is experienced by approximately 50% of all Parkinson's patients (Kalf, De Swart, Borm, Bloem, & Munneke, 2009).

Perhaps unsurprisingly, SLT is an important clinical service in the lives of many PwP, although it has been found that less than 40% will have access to SLT services in the first place (Miller, Deane, Jones, Noble, & Gibb, 2011). For those who do receive SLT, there is a need to integrate learned principles into their everyday life, without the support of the clinician, in order for therapeutic practices learned with clinical sessions to be extended and maintained in everyday life. Consequently, independent home practice is an important

¹ A full discussion of Parkinson's and its related symptoms—including a detailed account of speech, voice and swallowing changes—will be outlined in chapter 2 (section 2.1).

aspect of treatment. In addition, repeated and long-term training of functional SLT materials (i.e. high intensity of therapy) has been argued to promote neuroplasticity, reduce neurodegeneration and lead to remapping of damaged motor pathways (C. Fox et al., 2006), making continuous practice outside of the traditional 1 hour of SLT per week (often for a block of 6 weeks) even more important. However, motivating individuals post-therapy to carry out the practice of tasks when at home is a key barrier to generalisation of therapy into everyday life. It has been well-acknowledged that those receiving SLT are heavily supported by their therapist during the program, and once it is over motivation can wane—in many cases treatment effect does not persist long-term following discharge from a therapy program (Wight & Miller, 2015).

Emerging literature around notions of self monitoring and self management highlight the concepts as both highly complex and interrelated. Indeed, it seems that self monitoring and management can often be discussed interchangeably within health literature alongside the umbrella term of self care (Riegel & Dickson, 2008). However there are subtle differences which define them as separate. Self care is a generalised term, which encompasses any practice that involves looking after one's self. This might be as simple as maintaining personal hygiene, ensuring the body is hydrated and nourished or as complex as managing a complicated health concern (Department of Health, 2009). Self care is the term often used to describe self monitoring or self management practices.

However, Riegel and Dickson (Riegel & Dickson, 2008), begin to unpick the terms by contrasting them in tandem. They first considered self management, describing both self care and self management as involving *"a proactive process, compliance with professional advice, close attention to one's body and appropriate coping behaviour"*(p.191). In isolation, the process of self-management is often related to notions of patients taking control of their symptoms—this could be, for example, through medication, exercise or lifestyle changes—without continuous input from a clinician. Wilson et al (P. M. Wilson, Kendall, & Brooks, 2006) highlight a distinction of self management as being a practice whereby patients somewhat take on the role of the professional by engaging in tasks that would traditionally be conducted by a clinician (such as modifying medication doses). Contrastingly, self monitoring, in the context of health, relates to the continuous monitoring of data or symptoms in order to aid understanding around one's conditions, and thus support informed decision making around these changes to medication or lifestyle practices. Often patients

will self-monitor symptoms to facilitate a conversation with a health practitioner around the effectiveness of medication, therapy programmes, or the ways that lifestyle changes might have an effect on their condition (Wilde & Garvin, 2007). The practice of self monitoring can be as simple as becoming consciously aware of how an element of a treatment might be influencing or impacting upon symptoms, keeping a paper diary for review, or wearing a digital technology to monitor symptoms.

Lupton (Lupton, 2013) critically reflects on this latter point surrounding the use of digital technologies to monitor symptoms. Herein the complexities of self monitoring as a patient driven activity become even more apparent. On one hand, Lupton describes the process of self monitoring of symptoms as being an empowering act for the patient, by allowing them to further understand their condition. However she highlights the difficulties that can arise from the attainment of this knowledge; the frustration and feelings of self doubt that can emerge if awareness centres around the fact that a condition is deteriorating, or in worse cases, where a self monitoring technology becomes the continuous reminder that one is experiencing ill health. Self awareness is already a prominent issue in Parkinson's, in that self monitoring of one's own performance on a range of sensory and motor behaviours (e.g. volume regulation) becomes impaired. As such, there is a need for sensitivity around the design of self monitoring and management technologies which might bring otherwise unconsidered issues to the forefront for the individuals using them. Additionally, Lupton discusses the fact that, as much as self monitoring is conducted in order to inform health advice directed by clinicians, there is a danger that patients can simply become submissive 'recorders' of their health, as opposed to actually being informed and involved in the decision making process. Unless there are ways to support patients in actively understanding the health data that they collect, they can simply remain passive targets of technology usage, where it is the clinician who interprets the data and provides direction.

This thesis explores the design and evaluation of self monitoring and management technologies for PwP which support different levels of self care agency, by examining the different ways that people with Parkinson's might respond to and value different technologies and the modes by which they support self monitoring and management practices.

1.2 Research Context

This thesis seeks to investigate how digital technologies might support the self monitoring and management of SLT issues within the context of Parkinson's care. It builds upon research within the field of Human Computer Interaction (HCI), which has contributed to an expanding body of work exploring the potential for digital technology to support people in the monitoring, tracking and management of health conditions.

With an increase in the numbers of mainstream digital systems, there has been a rise in levels of public awareness surrounding self monitoring and management technologies within the context of personal health. Currently, the majority of mainstream consumer technologies are placed within the 'fitness' bracket (e.g. jawbone², fitbit³), to support improved health through increasing levels of activity. However, there is much potential for the advancement of specified self care technologies linked to chronic health conditions; an area that remains relatively underexplored. Interest surrounding the development of consumer systems to help monitor and manage specific health conditions is beginning to grow, with automatic sensing systems being employed to support self monitoring of aspects such as glucose levels in a people with diabetes (e.g. Google's smart contact lens⁴), or respiratory symptoms linked with asthma (e.g. ADAMM, a wearable automated device for asthma monitoring and management⁵). These wearable systems support patients in the monitoring of chronic conditions by providing objective data on symptoms, while supporting self management through the interpretation of such data to allow for self administration of medication.

Previous work within the area of digital health technology for Parkinson's has focused on technologies to aid symptom management. For example, de Barros explored the use of mobile applications to support everyday Parkinson's issues, such as medication adherence and on/off fluctuation tracking (de Barros, Cevada, Bayés, Alcaine, & Mestre, 2013); Krause studied the use of digital gaming using the Microsoft Kinect platform to support home practice of speech volume issues (Krause, Smeddinck, & Meyer, 2013); and Mazilu et al (Mazilu et al., 2014) looked at the symptom of gait freezing (caused by a block in the motor pathway controlling walking which causes a person to feel like their feet are stuck

² <https://jawbone.com/>

³ <https://www.fitbit.com/uk>

⁴ <http://googleblog.blogspot.co.uk/2014/01/introducing-our-smart-contact-lens.html>

⁵ <http://healthcareoriginals.com/>

to the ground) and the use of body worn sensing to provide in-situ metronomic prompts, to help PwP to restart their gait after a freezing episode.

While there is much potential for technology to support PwP, the condition itself is particularly challenging to investigate, manage and design for due to its complex and heterogeneous nature. PwP can experience a vast range of physical and cognitive symptoms that can have transient periods of increased severity, as well as dealing with emotional issues relating to social stigma and embarrassment surrounding their Parkinson's (discussed in chapter 4, section 4.2). A number of these socially stigmatizing symptoms (for example; drooling, speech deterioration, unsteady balance, and freezing) have the potential to be improved by well-designed technologies that could aid in the discreet and personalized provision of cues and strategies to help overcome them (e.g. Mazilu et al., 2014; McNaney, Lindsay, et al., 2011; Nieuwboer et al., 2007). However, managing the heterogeneity of both the condition and the variability across individuals gives rise to a variety of complexities in terms of how to design and evaluate digital technologies with such communities.

This thesis proceeds from the basis that, while PwP might benefit greatly from the design of new technologies to support self monitoring and management, there has, thus far, been relatively little empirical study of their potential advantages for this group. The thesis therefore first aims to gain an understanding around how self monitoring and management is discussed within clinical and HCI literature, in order to ascertain where the complex condition of Parkinson's is currently situated in the domain. Following this, the thesis describes three case studies, within which novel digital technologies were designed, developed and evaluated in order to support new self management and monitoring practices for PwP. Each of these case studies focuses on the development of self monitoring and management technologies for specific issues managed by SLT services (i.e. drooling and speech intelligibility), as well as exploring the current challenges that are faced when attempting to integrate these types of technology into real-life contexts, outside of the clinic.

The findings of these three case studies leads into a discussion around the ways in which specific types of technology might be valued by PwP in supporting self monitoring and management practices and how different types of technology might promote agency surrounding self care practices. The discussion also explores how certain types of digitally

mediated support (such as cueing, or the provision of feedback around a symptom at a certain point in time) might be suited to particular symptoms and not others.

1.3 Research Questions and Contributions

The main research question for this thesis is *what role might digital technology have in supporting the self monitoring and management of Parkinson's symptoms, specifically relating to speech and drooling?* In order to fully explore this question, this is broken down into four sub-questions:

- 1 How is the monitoring and management of Parkinson's symptoms, using digital means, understood within the HCI and wider medical communities?
- 2 What types of feedback are required to provide PwP with a sense of agency when using self monitoring and management technologies, in terms of increasing their understanding of their condition and facilitating them in making a positive change which will help manage their symptoms?
- 3 What are the current challenges for the integration of self monitoring and management technologies into the daily lives of PwP?
- 4 How might PwP be engaged in the design of feasible technical solutions to facilitate self monitoring and management practices for PwP?

1.3.1 Thesis Structure

The thesis is organized as follows: Chapter 2 (Background) provides a review of literature relating to Parkinson's and developments in HCI research towards self monitoring and management technologies. The chapter begins with a discussion around Parkinson's and its associated symptoms, to provide a deeper understanding of the condition. It then moves on to discuss the specific symptoms being explored in the thesis – in particular speech changes, and how they are managed within SLT practice, and drooling and its management.

The chapter then goes on to review HCI literature around self monitoring and management technologies within healthcare more generally, and Parkinson's specifically, before concluding with a discussion around technologies in SLT.

The outcomes from the background literature review are two-fold: First, it provides a basis with which to understand Parkinson's and the complex symptoms that can be

experienced, with a specific focus on speech and drooling. Second, it uncovers the current literature surrounding monitoring and management of Parkinson's symptoms, using digital means, in order to explore the gaps within the research area and provide a basis upon which to build an understanding of the approaches to research within the domains that have been successfully explored.

Chapter 3 (Methodological approach) provides an overview of the methods that were used throughout the thesis. It describes the user centred design approaches that were taken, as well the methods employed in the evaluation of the developed digital technologies. This chapter provides a theoretical grounding for the chosen methods and orientates the work amongst current perspectives around user centred design practices and the conduct of feasibility trials. Each of the described case studies were exploratory, feasibility trials employing different study designs in order to respond to the research questions being explored and the different qualities of the technologies being designed and deployed with participants. The process of designing each study was iterative, building on lessons learned within each of the case studies to explore novel ways of working with PwP.

Chapter 4 (Self Management of Drooling) describes the first case study. In this chapter the *PDCue* is introduced, a simple wearable device that cues the wearer to swallow more often, with the aim of aiding the self management of drooling issues. The chapter discusses the findings of an evaluation of *PDCue*, where a mixture of methods including self report, diary use and the conduct of standardised baseline assessments, were used to capture and compare the before and after effects that using the device had on drooling problems. The study reaffirms existing evidence that temporally cued self management⁶, wherein cues are regularly provided to the wearer to remind them to bring about a change in their behaviour (in this case swallowing more often), are particularly of benefit to PwP (Nieuwboer et al., 2007a). Findings show that the vast majority of participants perceived a positive effect to their drooling following the use of the *PDCue*, with not only improvements to drooling but also levels of improved social confidence. However, the temporal cueing method that was used only provided insight into a relatively passive method of supporting self management, with participants receiving no feedback about their drooling, when it was

⁶ In this context, temporally cued self-management is the process of receiving a regular prompt to carry out an activity which does not require the user to interpret any data. This is akin to receiving a medication reminder.

occurring or how the implementation of the prompted swallow affected their drooling. As such, there were still questions surrounding how PwP might be engaged to actively think about and understand elements of their condition through processes of self monitoring, and how this might then impact on their self management practices. This led on to the second case study, which modified the cueing approach to explore these elements.

Chapter 5 (LApp on Glass) concerns the second case study. It details the design, development and evaluation of an application on Google Glass intended to support cued, in-situ self monitoring and management of vocal loudness. This followed an initial acceptability evaluation of Google Glass as a technology platform and its appropriateness for PwP. The chapter discusses the design and evaluation of the application, with an aim to uncover the value that participants placed upon in-situ prompting of their speech during everyday conversations, whereby participants were prompted to increase their volume as and when it had sunk below a given threshold. In this sense, the technology supported a deeper understanding around *when* volume was too low, allowing for ‘on the spot’ reflection and interpretation of this information in order to bring about a change. The app then provided visual feedback to represent that sufficient change had been made to increase the volume to normal levels, providing instantaneous clarification that the individual had appropriately self managed the issue. The findings from this study support previous findings around in-situ gait cueing [e.g. (Mazilu et al., 2014)], which show the method to be a feasible way of managing movement symptoms in PwP. However, the study also highlighted how participants appropriated the LApp as a means to practice their speech and increase their confidence, outside of the in-situ context.

The third and final case study is presented in chapter 6 (Crowdsourcing as a Method for Enhancing Self-Monitoring of Speech and Voice in Parkinson’s). This chapter built upon the desire of participants in case study 2 to use technology to practice their speech independently, by exploring new ways of directing this activity through the presentation of individualised feedback around issues with speech commonly faced by PwP. The chapter describes the design and evaluation of Speeching, a smartphone application to facilitate the self monitoring of speech and voice changes through the provision of feedback obtained through a crowd of anonymous workers on crowdsourcing platforms, and the subsequent ways that this feedback was interpreted and used by participants to support home based

practice. The chapter first describes the process of developing and testing a range of crowdsourcing tasks with three types of crowd: SLTs, local novice listeners and novice listeners recruited anonymously via an online crowdsourcing platform, and compares their ratings to that of two experts in Parkinson's speech. Once the appropriate tasks had been decided upon, the chapter then moves to the development of the Speeching system, which was evaluated with PwP. The chapter discusses the value that participants placed on receiving human rated feedback on their speech and how this encouraged them to practice their speech more often, in an attempt to see positive changes in their ratings from the crowd.

Chapter 7 (Discussion) provides a synthesis of the findings from all three case studies and discusses the challenges and benefits of the technologies that were trialled. It provides a commentary on the implications of the research, for both clinical and HCI research practice, as well as discussing the limitations of the studies which might need to be considered in the future. The chapter ends by presenting the conclusions in the context of the individual research questions that were explored. It points to some directions for future work which arose in response to the findings from the individual case studies and discussions. As will be seen, there were several issues highlighted throughout the discussion around; designing systems on generic technology platforms; the levels of difficulty that PwP can have with these devices due to their condition (at times relating to technical literacy); and the affordances that need to be made to account for these issues in future research.

Figure 1 provides a visual overview of the 3 case studies and their relation to the research questions.

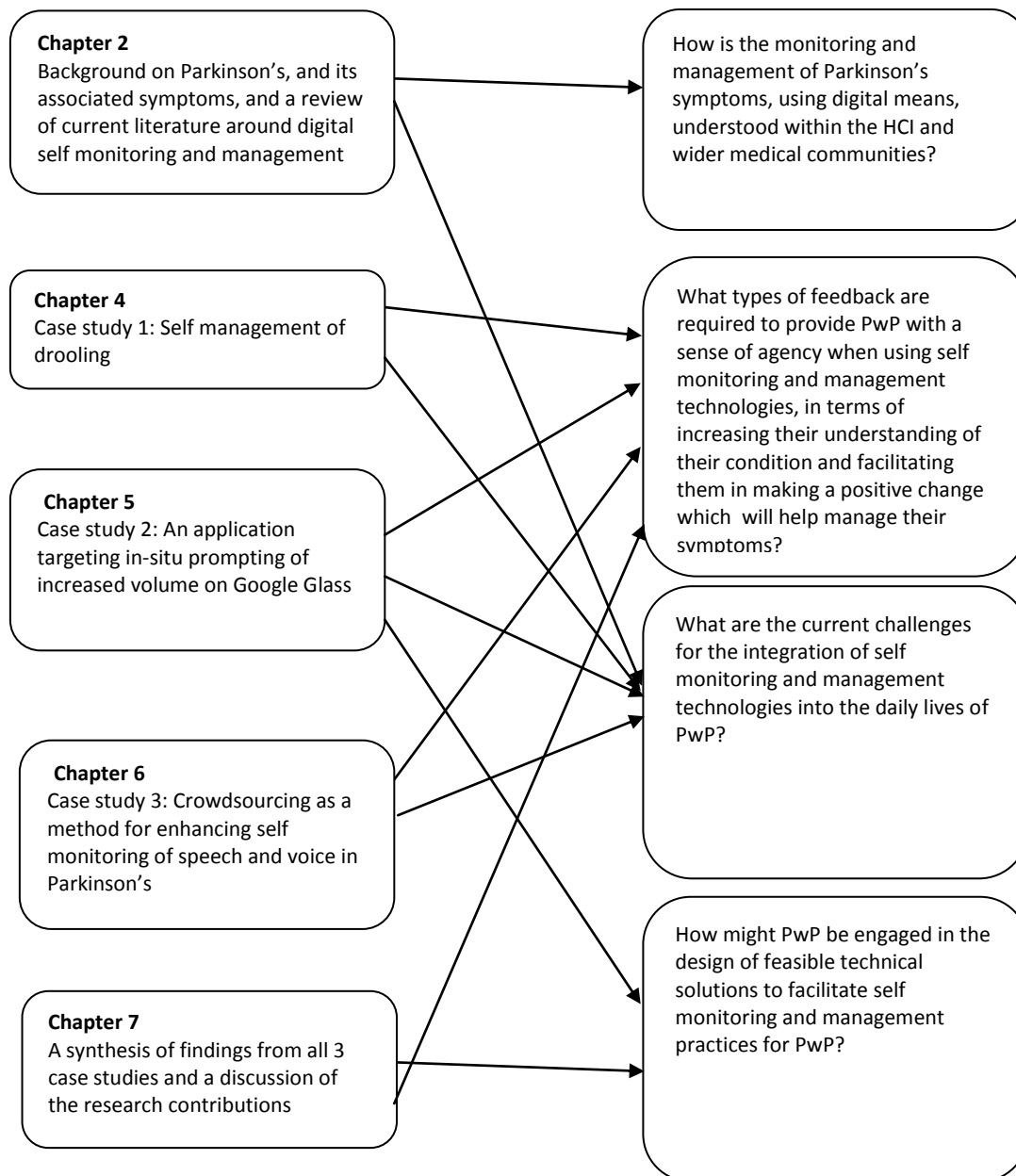


Figure 1: Visual overlay of the case studies presented within this thesis and their relation to the research questions

1.4 Contributions

Through these seven chapters and the process of responding to the research questions, novel contributions of knowledge to the field of HCI and the wider clinical research community are made. The primary contribution is an enhanced understanding of the ways that digital technology could support new ways of self monitoring and management for

people with Parkinson's. This is formed from a series of four smaller and more specific contributions:

- Through a synthesis of diverse literature, drawing from multiple domains of medicine, HCI and speech and language sciences, this thesis offers new knowledge around the ways in which Parkinson's and digital self monitoring and management are represented within the HCI community. It highlights several gaps in the literature which provide insight into opportunities for future research.
- Through three distinct cases, the PhD research offers empirically grounded insights into the ways in which technologies can be designed to aid self monitoring and management of Parkinson's symptoms, as well as how these technologies are then experienced and valued by PwP.
- Guidance is offered to future designers of self monitoring and management systems, encouraging reflection around the different types of monitoring information that can be presented to participants and how this might be subsequently responded to and used in different ways.
- Finally, the thesis offers a deepened understanding of the relationship, and distinctions between, both the clinical and personal needs that must be encompassed within digital self monitoring and management systems for health, and the complexities that arise through the heterogeneous nature of Parkinson's as a condition which is expected to degenerate over time.

1.5 Prior Publications

The thesis contributions have directly extended the body of research within the design and development of self monitoring and management technologies for people with Parkinson's. In a continuing process the work has been disseminated to a wider audience through both workshop and conference presentations, as well as publications in archival proceedings and journals. The thesis work has thus far been presented for discussion at:

1. McNaney, R., Othman, M., Richardson, D., Dunphy, P., Amaral, T., Miller, N., Olivier, P. & Vines, J. Speeching: Mobile speech assessment to support self-monitoring and management for people with Parkinson's. *In Proceedings of CHI 2016: San Jose, CA* p.7-12.

2. Vines, J., McNaney, R., Holden, A., Wright, P. & Olivier, P. Our Year with the Glass: Expectations, letdowns and ethical dilemmas of technology trials with vulnerable people. *Interaction with Computers special issue in co-constructing meaning: Ethics Matter(s) in design research*. doi: 10.1093/iwc/iww017
3. McNaney, R., Poliakov, I., Vines, J., Balaam, M., Zhang, P. & Olivier, P. (2015). LApp: A speech loudness application for people with Parkinson's on Google Glass. In *Proceedings of CHI 2015: Seoul, Korea* p.497-500. **(Honourable mention award)**
4. McNaney, R., Balaam, M., Holden, A., Schofield, D., Jackson, D., Webster, M., Galna, B., Barry, G., Mhiripiri, D., Rochester, L. & Olivier, P. (2015). Designing for and with people with Parkinson's: A focus on exergaming. In *Proceedings of CHI 2015: Seoul, Korea*, p.501-510.
5. McNaney, R., Vines, J., Roggen, D., Balaam, M., Zhang, P., Poliakov, I. & Olivier, P. (2014). Exploring the acceptability of Google Glass as an everyday assistive device for people with Parkinson's. In *Proceedings of CHI 2014: Toronto, Canada*, p.2551-2554 **(Best paper award)**
6. Vines, J., McNaney, R., Lindsay, S., Wallace, J., McCarthy, J. (2014). Designing for and with vulnerable people. *Interactions*, 21 (1) p.44- 46.
7. McNaney, R., Miller, N., Walker, R. & Olivier, P. Designing for the person living with Parkinson's: A focus on wellbeing beyond functionality. In *Proceedings of Digital Economy 2014: London, UK*.
8. McNaney, R., Lindsay, S., Ladha, K., Ladha, C., Schofield, G., Ploetz, T., Hammerla, N., Jackson, D., Miller, N., Walker, R., Olivier, P. (2011). Cueing for drooling in Parkinson's disease. In *Proceedings of CHI 2011: Vancouver, Canada*, p.619-622.

1.6 Summary of Chapter 1

This chapter has provided an overview of the focus of this thesis, including an introductory discussion of self monitoring and management and the differences between the two concepts. The research questions that will be explored throughout the thesis were described, as well as an overview of the contributions that the thesis provides. The next chapter focuses on an understanding of Parkinson's and discusses the literature relating to self monitoring and management technologies both in the wider context of digital self monitoring and management for health and in Parkinson's more specifically.

Chapter 2

Background and Literature Review

This chapter provides a review of the current literature relating to Parkinson's and the management of its symptoms, and recent work in the field of HCI on self monitoring and management technologies. The overall aim is to explore how the monitoring and management of Parkinson's symptoms, using digital means, is understood within the HCI and wider medical and digital health communities. The opening section sets the scene by describing Parkinson's, its associated symptoms and how they are typically managed within clinical practice. This is used to provide an understanding of the condition and highlight the complexities of living with Parkinson's. The chapter then moves to speech, voice and drooling changes in Parkinson's and the impact that these can have on daily life, to add context to the SLT focus of the research. Following this the practicalities of SLT and how the profession manages Parkinson's is discussed, followed by a review of the HCI literature around digital technologies for the self-monitoring and management of a range of chronic health conditions and how Parkinson's in particular is represented within this literature. The chapter concludes with a discussion around how digital technologies have been adopted in the field of SLT more generally, and SLT for Parkinson's specifically.

2.1 Understanding Parkinson's

2.1.1 Parkinson's and its Associated Symptoms

Parkinson's is a complex, progressive neurodegenerative condition, associated with a depletion of dopamine-producing neurons in the brain. Dopamine is one of the neurotransmitters responsible for facilitating transmission of nerve impulses between parts of the brain involved in the initiation of movement and control. Therefore, as the neurons die and dopamine levels reduce so does the ability to control movement (Lotharius & Brundin, 2002). Parkinson's is known to affect approximately 5 million worldwide (Olanow et

al., 2009)⁷. The condition is generally associated with older age, with worldwide figures placing most diagnoses in people over 50 (107 cases per 100,000) and persons aged 80 and above being most susceptible (1903 cases per 100,000) (Pringsheim, Jette, Frolkis, & Steeves, 2014). However, more younger adults are being diagnosed with the condition - 1 in 20 new diagnoses are under 40 in the UK (Parkinson's UK, 2015c) and an estimated 4% are under 50 in the USA (Parkinson's Disease Foundation, 2015). As a degenerative condition, symptom severity is expected to increase over time (around 10-20 years) (Hughes et al., 2000).

The three major movement, or motor, manifestations of Parkinson's are rigidity, stiffness, tremor (involuntary, rhythmic back and forth movement, for example in the hands, head or jaw) and bradykinesia (slowness) (Jankovic, 2008). These symptoms can have a huge impact on carrying out daily activities such as washing, dressing, feeding oneself, writing a note or household chores. Similarly, carrying out leisure activities or driving can also be affected. These factors can interact to impact on life enjoyment, independence and relationships with family and friends (Chapuis, Ouchchane, Metz, Gerbaud, & Durif, 2005).

There are a range of other symptoms that also lend to the overall impact the condition can have on a person's life. Problems initiating movement (or hypokinesia) can lead to episodes of (gait) freezing. Here movement is suddenly halted, especially when additional attention is required—such as manoeuvring through a narrow space or turning. In turn this can lead to an increased risk of falls (Bloem, Hausdorff, Visser, & Giladi, 2004). Issues with arm movement can also affect balance.

Speech and voice are also typically affected, with approximately 90% of PwP experiencing a voice problem at some point following diagnosis. Alongside difficulties initiating facial movements, which can cause a mask-like facial expression (whereby the face can often seem emotionless), this can lead to many communication issues that can impact on socialisation (Miller, 2012). Distress, embarrassment and social isolation are reported within the Parkinson's population as a result of having speech and voice changes. In a study by Miller (2008) on 104 PwP, the authors found there was a strong perception of negative impact on communication when PwP compared how they perceived themselves as

⁷ not to mention undiagnosed statistics from developing countries and people dying with possibly undiagnosed Parkinson's

communicators before the onset of Parkinson's compared to after (Miller, Noble, Jones, Allcock, & Burn, 2008)⁸.

A range of non-motor symptoms are also common among PwP, including: fatigue, which can cause everyday difficulties with completing daily tasks or managing one's life; compulsive behaviours— such as excessive spending or gambling—which bring their own difficulties within family dynamics; inhibition or disinhibition, often sexual, which can lead to embarrassment and distress; and a range of autonomic dysfunctions, such as impaired temperature control or incontinence (Berardelli, Rothwell, Thompson, & Hallett, 2001; Shulman, Taback, Rabinstein, & Weiner, 2002).

Cognitive decline (e.g. slowing of thought processes, memory loss, hallucinations, difficulties with dual task performance, which involves the completion of two tasks at once, such as walking and talking) is also frequently observed in PwP. The presence of anxiety and depression, alongside significant negative changes in emotional wellbeing, are also identified to be highly prevalent (Menza, Robertson-Hoffman, & Bonapace, 1993; Shulman et al., 2002).

From this brief overview of the range of symptoms and manifestations of the condition, it is clear to see that Parkinson's is both complex and multifaceted. The next section discusses how the symptoms of Parkinson's might be typically managed and how this can bring about its own set of difficulties.

2.1.2 Managing Parkinson's Symptoms

Motor aspects of Parkinson's can generally be well controlled by medication, but finding the right combination of medication can be a lengthy and continuously changing process. There are several types of medication that can be used to treat the symptoms of Parkinson's. Dopamine replacements (Levodopa) involve increasing the amounts of dopamine in the brain, while other drug treatments used stimulate parts of the brain on which dopamine acts (dopamine agonists) or block the further degeneration of dopamine (inhibitors) (Parkinson's UK, 2015a). An important aspect of pharmacological management of Parkinson's is the ON/OFF phenomenon. PwP can experience periods when their symptoms are controlled by

⁸ In a further section of this chapter (section 2.2), the types of possible changes in speech and voice are unpicked to provide some insight into the types of symptoms the participants who were involved in the case studies might experience. The case studies also provide some first-hand accounts of the social and emotional impact that speech, voice and swallowing changes can have.

the medication they take and they feel as though they are functioning well (ON times). However, these can quickly transition into periods of severe symptoms (OFF times), which has been likened to the turning on and off of a light switch (Parkinson's UK, 2015a). This phenomenon often worsens the longer that an individual has been using medication, and thus requires people to be continuously monitored to allow for medication readjustments when they are needed. The often unpredictable nature of these ON/OFF periods can make the undertaking of daily activities difficult and be a further barrier to social participation, with individuals often planning their day around times when they think they might be ON versus OFF, so that they are not out and about or in public when experiencing an episode of, for example, particularly bad stiffness (hypokinesia) or slowness (bradykinesia).

Another element leading to the complexity of Parkinson's is that not all PwP will have the same symptoms, or experience them to the same degree in the course of the condition. In fact, the scope and variability of symptoms among individuals is vast. Although hugely important, medication is only a small part of managing Parkinson's. Individuals work with a multidisciplinary team of clinicians (neurologists, specialist nurses, physiotherapists, occupational therapists, SLTs, psychologists), to develop personalised plans of care with functional goals related to improving quality of life. This usually includes a range of therapies to provide an individual with a set of strategies and exercises to retrain functional abilities related to daily life (e.g. improving safe walking to minimise the risk of falls, improving the clarity of speech to aid participation in conversation).

These therapeutic interventions typically involve clinical input, however it is generally viewed that the patient should take control of their care themselves and continuously conduct home-based practice of therapeutic tasks. This ensures that gains are maintained and positively impact on everyday activities. However, it has been noted that motivation for many people can wane heavily post-therapy (Nijkrake et al., 2007). For example, in many cases treatment effect does not persist following discharge from a therapy programme (Green, Forster, Bogle, & Young, 2002; Wight & Miller, 2015). Quite often these challenges relate not only to issues of motivation, but also boredom surrounding the repetition of tasks or simply difficulties in completing therapeutic practice in and around daily routines. This highlights a need to explore methods of encouraging people to take control of their health and facilitate better self management. Technology, in this sense, can offer the potential to provide alternatives for assisting the self-directed management of health conditions.

The initial sections in this chapter have provided an overview of Parkinson's, its related symptoms and how they are clinically managed. In the following sections, the focus is shifted specifically towards speech, voice and swallowing changes in Parkinson's to provide context to the case studies, which focus on these symptoms.

2.2 Speech and Voice Changes in Parkinson's

Changes in speech and vocal quality have long been documented in Parkinson's research (Canter, 1963, 1965; Darley, Aronson, & Brown, 1969a; Logemann, Fisher, Boshes, & Blonsky, 1978). Alterations in respiration are associated with an impairment in sustaining appropriate loudness/voice intensity levels. Added to this, people with Parkinson's have an impaired perception of how loud they are speaking—i.e. they feel as though they are shouting when in fact they might be speaking at a normal level (Ho et al., 1998). This can make the maintenance of therapy gains particularly difficult.

PwP also experience changes to laryngeal function (responsible for the manipulation of pitch and volume). Perceptually vocal quality becomes impaired due to incoordination and weakness in vocal fold closure, giving a hoarse, rough, breathy or tremulous speaking voice (Ferrand, 1997; Holmes et al., 2000; Skodda et al., 2013, 2011; Skodda & Schlegel, 2008; Skodda, 2011; Tjaden et al., 2014; Tjaden, 2008). The laryngeal changes can be associated with the production of a monotonous and low voice and lack of amplitude variation. This is heard by listeners as monoloud speech with no differentiation between stressed and unstressed syllables. A loss of fine control of vocal cord tension also leads to a loss of frequency variation, heard as monopitch, speech lacking in intonation, which can be interpreted as a voice lacking in feeling or emotion. In addition, bradykinesia (slowness) and muscular incoordination cause alterations to tongue and lip movements giving the presentation of a slurred quality to the individual's speech, as well as altered respiratory patterns, which lead to the individual speaking in short bursts. In addition, impairments in sustaining sufficient sense of effort for voice or speech mean that often speech may trail off in terms of intelligibility and volume on longer speech utterances.

Speech and language problems can interact in multiple ways to cause difficulties for a PwP in making themselves understood by speaking partners. In turn this may lead to distress and embarrassment, particularly when speaking with strangers (Miller et al., 2011; Miller, Noble, Jones, & Burn, 2006). A reduction in the functional ability to communicate effectively,

as well as the accompanying tendency to avoid social situations, can directly impact on the wellbeing of a person—especially so when we consider that conversation is typically conceived as being the core of social activity. This can cause multifaceted difficulties in aspects of everyday life such as the maintenance of relationships, self-confidence and stress management (Keyes, 1998; Ryff, 1995; Wade & Kendler, 2000). The presence of anxiety and depression, alongside significant negative changes in emotional wellbeing, are identified to be highly prevalent in PwP (Wade & Kendler, 2000), again emphasizing why maintenance of communication ability is extremely important. Miller et al (Miller et al., 2008) studied the perception of changed speech pre and post Parkinson's diagnosis in a sample of 104 patients and 45 carers, and the impact this had on their lives. They found individuals reported a *"sense they have lost control in communicating, are less confident, find it difficult to get their message across, with consequent frustration, feelings of inadequacy and sense of loss of independence"*. They go on to conclude that *"these feelings may lead to withdrawal from communicating, passing over the burden of communication to carers, independent of any objectively measured decline in underlying speech skills"* [p.19]. Miller et al found that, although only a moderate correlation, greater levels of depression were associated with an objective decrease in intelligibility and a greater perception that speech had negatively changed following Parkinson's diagnosis. A further finding by Miller et al (Miller et al., 2006) in another piece of research was that PwP felt their speech issues caused a negative effect on their communication ability, highlighting the embarrassment at, and fear of, other people's reactions of their Parkinson's, causing a barrier to communication and withdrawal from social interaction. In addition, a feeling of being ignored or 'left out' during conversation was found to be a major factor in feelings of loss of dignity in older adults generally (Woolhead, Calnan, Dieppe, & Tadd, 2004).

This initial overview of the clinical literature has explored the speech and voice changes that might be experienced in Parkinson's. It has provided insight into the multitude of problems that can combine to form a speech impairment and the impact that experiencing speech and voice changes might have. The following section outlines how issues like these might be treated within current SLT practice.

2.2.1 Speech and Language Therapy for Parkinson's

Diagnosing speech issues in Parkinson's can be a complex process. As an example of the type of process that might be observed, a therapist will listen to a range of single words, sentences and longer samples of speech. These are produced by the individual by asking them to read a word or piece of text, describe a picture or engage in free flowing discussion about a topic. The therapist will measure the changes experienced by the individual—whether this be for example, volume control, alterations in speech rate, vocal quality such as excessive breathiness, or a combination of a variety of issues. To accomplish this, the therapist uses a range of standardised assessments to objectively measure voice and speech status, alongside non-standardised methods such as rating scales completed based on subjective clinical judgement. Often recordings of the PwP speech will be made as a reference point against which to measure later changes.

The process described above is a highly idealised practice, and one that raises a number of issues in the reality of conducting SLT work. One of the main issues arising with the diagnosis and subsequent management of speech and voice issues in Parkinson's is the fact that SLTs are highly specialised and experienced in listening to Parkinson's speech. It has thus been argued that their familiarity can lead to underestimation on rating scales of the extent of a change (Miller, 2013). One way to mitigate this in the clinical assessment of intelligibility is to have 2-3 listeners to rate a speech sample and taking the mean score as a more representative rating. However this is not always possible in a busy clinic (Ziegler & Zierdt, 2008a). There is also the added issue that intelligibility scores obtained within one-to-one clinic sessions rarely match real world intelligibility outside of the clinic when a person might be carrying out other tasks (Bunton & Keintz, 2008). PwP may also be susceptible to a possible Hawthorne effect⁹, causing speech patterns to improve under the direct observation of a therapist compared to typical occurrence in real world contexts. As a result, there are still great challenges for SLTs to gather more ecologically valid data about their patients.

In an attempt to mitigate these issues and ensure that individuals are able to sustain a change made in clinic into their everyday life, one of the core focuses of SLT is providing people with the necessary skills to self monitor and subsequently self manage their speech

⁹ Whereby individuals modify their behaviour as a direct response to an awareness of being observed

once they have been discharged. One example of a treatment programme that might be delivered is Lee Silverman Voice Treatment (LSVT) — a training programme which is carried out by a SLT who has to be certificated by the LSVT Global (Ramig et al., 2001). The main aim of LSVT is to improve the individual's volume through a progression of tasks (single sounds, words, sentences, natural conversation), in an attempt to transfer the skills learned in clinic into their everyday life. Drawing upon issues pertaining to PwP inability to accurately estimate their vocal loudness, an element of LSVT also involves re-calibrating a person's loudness perception and reinforcing a 'typical' loudness in day to day life. The extremely intensive programme (both clinically at 4 sessions per week for 4 weeks, and in terms of home practice, with daily practice expected) has been shown to be effective by the creators of the technique (Ramig, 2001). Subsequent studies, from the same research group, have even shown that the effort involved in speaking louder also influences other areas affecting the quality of communication, such as intonation (C. Fox, Morrison, Ramig, & Shapir, 2002) and facial expression (Spielman, Borod, & Ramig, 2003). However, the gains made during treatment can often be difficult for people to maintain outside of the clinical setting, and speech issues often regress back to being disordered, as motivation to complete home practice of SLT exercises wanes (Wight & Miller, 2015).

Technology has been shown to offer benefits in this context as it offers the potential to aid the self-directed monitoring and management of speech. Remaining for now with the example of volume, Krause et al. proposed the use of a digital game to help PwP practice LSVT tasks at home (Krause et al., 2013). The game asked users to use their voice to break glasses, with an opera singer as an avatar. This provided an objective monitor of their volume and a range of gamified targets to apply themselves towards. Halpern et al (Halpern et al., 2012) also discuss the development of the LSVT Companion¹⁰, which is a technically simple, yet expensive¹¹, digital system aimed at supporting LSVT treatment and individual practice in the home. The system allows the clinician to deliver personalised plans remotely and provides a space for users to practice their speech and track their progress. However, the fact that this system involves an interaction with the therapist brings into question

¹⁰ <http://www.lsvtglobal.com/products/category/software>

¹¹ The LSVT companion is a piece of software costing \$659 for the clinician version and \$299 for the patient version.

whether or not users would remain motivated to continue their home practice if this feature were to be removed.

While these examples highlight the potential for technology to bridge the gap between therapeutic sessions and home practice, or to provide new motivational frameworks for PwP, this is still a relatively underexplored area. Differing from these prior examples, this thesis explores the concept of supporting self monitoring and management practices within the context of SLT, however without the need for clinical input. Case studies 2 and 3 focus on speech (chapters 5 & 6), while case study 1 (chapter 4) looks at the symptom of drooling, another issue which is managed within SLT. In order to situate this chapter, the following section discusses the cause of drooling and its impact on the people who experience it.

2.3 Drooling

Drooling (clinically known as sialorrhoea), or excessive loss of saliva from the mouth, is reported as a significant symptom of Parkinson's, with over half of all individuals reporting diurnal (daytime) drooling—a figure which rises even further when nocturnal drooling is taken into account (Kalf et al., 2009). Drooling is associated with muscle rigidity and bradykinesia (or slowness of movement) in the oral¹² and pharyngeal¹³ structures (Nóbrega et al., 2008a). People experiencing drooling issues fail to swallow saliva in sufficient volume or regularity, despite a normal amount of saliva production. In a study by Nóbrega et al. (Nóbrega et al., 2008a) using objective measures, changes in the oral stage of swallowing were seen in 100% of people experiencing drooling problems (n=16), and in the pharyngeal stage in 94% of patients. They also found a correlation between drooling severity and swallowing problems (or dysphagia), in that, people with the worst dysphagia had the worst drooling. In an early study by Edwards et al (Edwards et al., 1991), drooling was found to be a problem in 70% of PwP, in both the later stages and early stages of the disease.

¹² Oral structures are found in the mouth cavity and refer to the tongue, palate, lips, cheeks etc. In the process of swallowing (oral stage), the oral structures are responsible for forming the bolus (ball of food, liquid, saliva) which is to be swallowed.

¹³ The pharyngeal structures are found towards the back of the throat and include the base of the tongue, the pharynx and the epiglottis (which closes off the airway while swallowing) etc. In the process of swallowing (pharyngeal stage), these structures are responsible for passing the food into the oesophagus whilst protecting the airways.

Drooling can be exacerbated when concentrating on other things, such as watching television or reading a newspaper. In such instances, swallowing is decreased due to the attentional demands of other tasks and this leads to excessive pooling of saliva. These types of activities are also when patients, or their carers, often complain of problems with drooling (Kalf, Smit, Bloem, Zwarts, & Munneke, 2007). Perhaps unsurprisingly, drooling can have huge physical, social and emotional impact on the individual experiencing the problem (Kalf et al., 2007). It can have associated issues with eating (as saliva acts as a lubricant during chewing and swallowing (Chou, Evatt, Hinson, & Kompoliti, 2007)), speech oral hygiene (excessive escape of saliva around the mouth paired with wiping it away can cause broken skin and sores to form; saliva contains antibacterial proteins which are important for dental hygiene (Chou et al., 2007)) and social contact with others. As such, simple everyday activities like going for a meal with friends or speaking to a shopkeeper can become a great source of embarrassment for the PwP and can lead to feelings of stigma.

Most current treatments for drooling in Parkinson's are aimed at decreasing saliva production, predominantly with the use of drugs. However, these can have serious cognitive side effects such as memory loss—which can be a significant problem already for PwP—or even hallucinations (Hyson, Johnson, & Jog, 2002). Another treatment option used to decrease saliva production is Botulinum toxin (Botox) injections into the salivary glands. However, this is generally a painful and short-term management option that must be repeated every three to six months. Meningaud et al. (Meningaud, Pitak-Arnnop, Chikhani, & Bertrand, 2006) extensively reviewed the modalities of treatment for drooling problems and maintained that it is important to propose, where feasible, more non-invasive treatment options, such as behavioural cueing methods, before drug therapy is considered¹⁴.

The previous sections within this chapter have situated the clinical context of this thesis within the literature and provided an overarching understanding of Parkinson's and the specific speech and drooling symptoms that will be the focus of the case studies. The following section looks at how digital technologies are currently used in the self monitoring and management of health in general, and then more specifically Parkinson's, in order to position the work within the wider context of the field of HCI.

¹⁴ Chapter 4 presents a case study which explores this concept of behavioural cueing using a digital device, and presents a case for its clinical effectiveness on a cohort of 30 patients.

2.4 Representation of Parkinson's in the HCI Literature

The role of digital technology in healthcare has been widely explored since the introduction of organized telemedicine programmes in the late 1950s (Ryu, 2010). With recent growth in the ownership of mobile phones, personal computers and more recently smartphones and portable tablets (Ofcom, 2015), there has been a growing appreciation of the role that technologies can have in enhancing self monitoring and management practices. The following sections provide an overview of how digital technologies are currently being used to support self monitoring and management of health and how Parkinson's is positioned within the associated literature.

2.4.1 Tracking Health

As consumer technologies such as smartphones and tablets are becoming more widely available and affordable to the general public, we are seeing a rise in the appearance of health and wellness applications on mobile and wearable technologies. These devices now have the technical capabilities to collect, collate and make sense of a range of data pertaining to health and fitness. Commercially available devices provide opportunities to capture, for example, movement data via built in accelerometers and gyroscopes, or heart rate using light sensors which monitor the blood flow through the veins in the wrist (e.g. the wrist worn Fitbit¹⁵ or Polar¹⁶ devices which track daily steps, count calories burned during exercise, monitor sleep patterns). Many of these devices communicate collected data to accompanying applications on mobile handsets, to aid those using them in the monitoring of their data both in-situ and over time.

As a result of the growing popularity of wearable health technologies and the increasing use of mobile technologies for health, the HCI research community has engaged widely in the 'quantified-self movement' (Choe, Lee, Lee, Pratt, & Kientz, 2014; Estrin, 2014). Work studying the design of personal informatics applications (Rooksby, Rost, Morrison, & Chalmers, 2014) has highlighted a range of self-tracking practices around the use of sensor and data logging platforms. In these instances, those using a range of data-logging and collecting technologies engage in practices of monitoring aspects of their own life, sometime through curiosity, sometimes to change certain behaviours or routines, or

¹⁵ <http://www.fitbit.com/uk>

¹⁶ <http://www.polar.com/uk-en>

sometimes to better personal performance in certain domains. A recent report from the Pew Research Centre (on 3,014 adults) noted that approximately 69% of all US adults tracked at least one health indicator for themselves or a loved one, and that those with a chronic health condition were more likely to track their health regularly (S. Fox & Duggan, 2013). It was also highlighted how the majority of people conducting health related self-tracking did so for their own or a family member's benefit, and did not share this data with clinicians. Of the 69% adults engaging in tracking activities, 60% of these were tracking weight, diet or exercise routines.

Considering the rise in this quantified self movement and the generalised increase in visibility of monitoring or self tracking technologies—as well as increased familiarities around the interpretation of personal data which is positioned alongside these technologies, It is perhaps unsurprising that self care has emerged as a particular area of interest. However, there are certain intricacies that come into play when considering the self directed analysis and interpretation of specified health data (for example, lung function, blood glucose levels, or motor ability) which might be the focus for self-monitoring.

Lupton describes the complexities which can arise when users of these types of self monitoring technologies are provided with data that suggests their *“health is suffering, or if these data conflict with their own subjective and phenomenological interpretation of their state of health and wellbeing, this can be unsettling and anxiety – or fear—provoking”* (Lupton, 2013) (p.264). Particularly in the case of Parkinson's, where symptoms can be transient throughout the daily drug cycle, and indeed the severity is expected to increase over time, this is a perspective which needs to be fully considered in the design of self monitoring and management systems, in order to understand the role that these types of technologies might play in supporting Parkinson's. In a 2014 magazine article, Sara Riggare (Riggare, 2014), a researcher with Parkinson's who blogs about her experiences with self tracking (www.riggare.se) describes the practice as *“the most powerful weapon I can wish for in my battle against Parkinson's”* (p.13). She describes how, in a typical year, she spends one hour with her neurologist receiving clinical guidelines about her condition, spending 8,765 hours engaging in self care. Riggare discusses tracking as a way to monitor and better understand her condition and her reactions to medication. In a later blog post however she calls to question the “burden of tracking”(Riggare, 2015), describing how continuous monitoring of her Parkinson's takes time and planning, particularly when considering

complex medication routines and further practices such as regular exercise which help to manage motor symptoms. To borrow Lupton's phrase, Riggare is very much a "digitally engaged patient" (Lupton, 2013). However, her unusually young age of diagnosis (32 years), her scientific background (engineer and self care researcher) and general interest in digital technology place her very much in the minority of 'typical' Parkinson's patients. In this sense, her own experiences—as a digitally engaged patient—of 'burden' and 'effort' again highlight the importance of the careful design of self monitoring and management systems for Parkinson's, to ensure that the technologies being developed can be seen as tools to support self care practices, as opposed to weighing patients down with information and laborious tasks.

This thesis aims to uncover these complexities in order to facilitate the design of digital systems which speak to the specificities of Parkinson's and the needs and values that interplay to encourage the instigation and continuation of self care. The aim was to design technologies that would fit easily into the everyday lives of participants, without becoming a burden. There have been several previous attempts within HCI literature to explore self monitoring and management technologies for Parkinson's, which will be described in the following section.

2.4.2 Self Monitoring and Management Technologies for Parkinson's

The specific ways technologies might support Parkinson's in self care practices remains relatively underexplored in the HCI literature. The vast majority of computing literature on Parkinson's has focused on issues related to the assessment and diagnosis of motor aspects of the condition (Arora et al., 2015; Cai et al., 2014; T. Khan, Nyholm, Westin, & Dougherty, 2014; Martens et al., 2013; Westin, Dougherty, Nyholm, & Groth, 2010). For example, Westin et al. (Westin et al., 2010) describe the development of a touch screen based system to provide in-home motor testing on a range of condition relevant measures, including traditional finger tapping and spiral drawing tests as well as self-reported patient information via a diary. In a recent piece of work, Arora et al (Arora et al., 2015) went a step further and described the development and evaluation of a smartphone application to assess a holistic battery of tests including voice, posture, gait, finger tapping and response time, all of which provide information towards the initial diagnosis of Parkinson's and the disease state of a person already diagnosed with the condition at a given time. Arora et al.

were able to distinguish Parkinson's patients from controls to a high degree, suggesting that their system could be effectively used in the remote assessment of Parkinson's within rural and hard to reach areas.

A small amount of HCI research has explored the design of technologies for the self management of Parkinson's. For example, de Barros et al. (de Barros et al., 2013) developed a suite of mobile applications to help PwP manage and track day-to-day aspects of their condition—such as ON/OFF fluctuations, medication reminders, and daily diary and data sharing features with clinicians. They found that, during the design phase, participants particularly valued having an 'all in one' solution to help them manage their Parkinson's. However the authors focused their evaluation on usability testing of their apps and did not reflect on the impact that their use had on participants' lives. Moving more towards a rehabilitation technique, Mazilu et al (Mazilu et al., 2014), describe an in-situ prompting system for episodes of gait freezing. The system functioned using an ankle worn sensor that detected freezing episodes and provided an auditory metronomic prompt, on a mobile phone, to facilitate gait initiation and continuation. This method has similarly been used in a large clinical trial on 153 patients by Nieuwboer et al (Nieuwboer et al., 2007) using temporal prompting (where prompts are simply programmed to go off within a specific time frame and do not rely on interpreting a data stream from the patient) with significant effect. Indeed, gait in general is an element of Parkinson's which has been widely explored, often through the use of accelerometers (inertia movement sensors) to help monitor and give situated support for gait management (e.g. (Bächlin et al., 2010; Casamassima, Ferrari, Milosevic, Rocchi, & Farella, 2013; Mazilu et al., 2014)). Often examples of such work rely on using machine learning techniques to detect episodes of freezing and providing 'cues' that aid PwP to continue their movement. Unlike Nieuwboer et al.'s work, Mazilu et al. (Mazilu et al., 2014) highlight the benefits PwP gain from in-situ cueing over continuous cueing, which can become habituated over time.

The examples of work described above add significant understanding towards how self monitoring and management of Parkinson's is understood within the literature and provide a starting point for understanding the ways that technologies might be configured for Parkinson's symptoms. However, they all focused their research questions around usability of the designed systems and ways in which objective clinical goals were met. There are still unanswered questions around how PwP might interpret and make sense of data

being provided by these types of technologies, and a lack of research focusing on obtaining experience rich qualitative accounts of the impact digital technologies might have on self monitoring and management practices in everyday life. In addition, there is currently very little knowledge about how the specific symptoms of speech and swallowing might be supported. The following sections provide an overview of how technology is being currently used within SLT and, specifically, SLT in Parkinson's.

2.4.3 Technology for SLT

The use of digital technology in the field of SLT is longstanding. One of the key areas where technology has impacted on SLT has been in the development of Augmentative and Alternative Communication (AAC) systems. AAC is a general term used to describe methods of aided communication. These can be through general non-verbal strategies such as gesture or body language, the use of picture books or communication charts, or through a range of different technologies which can act as a substitute vocal communication aid (Glennen & DeCoste, 1997). The types of technologies used for AAC are diverse with varying complexities—from equipment with simple text to speech functions, picture based 'buttons' that relay messages when pressed, to eye-gaze technology for those who are physically unable to physically interact with a system. However, these specialized technologies are often expensive and frequently require the attainment of external funding, or for individuals (or their families) to fund these privately in order to use them in the long term. It is unsurprising, therefore, that there has been a recent rise in the development of AAC apps that can be simply purchased and downloaded from commercial app platforms and installed on personal tablets and mobile devices, which also brings advantages in terms of cost, updateability and ongoing sustained use.

However, the interest in mobile applications for SLT extends further beyond the AAC domain. Recent work has started to explore the role technology might play in supporting clinical practice within therapeutic contexts, with a wide range of research being conducted into the development of digital tools to support SLT. Many of these applications are aimed at children, often to enhance the enjoyment of speech therapy tasks through the gamification of tasks and to facilitate home practice (Bastanfard, Rezaei, Mottaghizadeh, & Fazel, 2010; Fardoun, Kateb, & Paules Cipres, 2014; T. Lan, Aryal, Ahmed, Ballard, & Gutierrez-Osuna, 2014; Parnandi et al., 2013). However, there has also been work aimed at adults who are engaging in SLT programmes, mainly around aphasia—a communication impairment

affecting the expression of, or comprehension of, spoken and written language (Allen, McGrenere, & Purves, 2008; Kuwabara, Shimode, & Miyamoto, 2010; Piper, Weibel, & Hollan, 2011; Stapleton, Whiteside, Davies, Mott, & Vick, 2014; Williams, Moffatt, McCall, & Findlater, 2015). For example, Piper et al (Piper et al., 2011) described the Write-N-Speak system, which builds upon traditional paper-based therapy techniques, employed by many SLTs, to deliver customizable and interactive paper-based resources such as worksheets, stickers and photographs which can be loaded with personally meaningful and useful content audio. Moving away from the specific clinical therapy sessions and into the everyday lives of the patients, Kane et al (Kane, Linam-Church, Althoff, & McCall, 2012) described TalkAbout, a context-aware system which allowed users to access relevant word lists dependent on their location and conversation partner. Within a similar area, Williams (Williams et al., 2015) explored the potential for providing in-situ support for the access of vocabulary during conversation, using head-mounted wearable technologies such as Google Glass and wrist mounted touchpads for easy navigation.

Specific to Parkinson's, there is emerging research on the use of SLT apps to improve vocal loudness. Eglin¹⁷, for example, has developed a voice training application to treat PwP with volume problems, which includes a 'feedback-meter' to encourage reflection around self perceptions of volume (a well-know issue for PwP, as discussed above in section 2.2) (Parkinson's UK, 2015b). Krause et al (Krause et al., 2013) also focused on providing a visual representation of achieving an adequately loud voice but in their case in a playful way. The authors explored the potential of a Microsoft Kinect-based game in facilitating the home practice of vocal loudness exercises, using gamified modifications on different practice tasks to encourage a level of enjoyment whilst reaching SLT goals. Their participants showed significant improvement when practising their loud voice with the game compared to the original volume they had during the calibration phase of the study. However, the authors suggest that there is much further work required to explore how these types of games might support longer term motivation towards home practice in the future. Although these studies highlight how digital technologies can be useful for supporting the practice of speech within people's homes, there is still little known about the motivations that might drive PwP to engage in these types of systems over traditional SLT practice.

¹⁷ Roger Eglin's work is yet unpublished but the application (speech tool) is available for PwP to download and use via the app store:
<https://itunes.apple.com/WebObjects/MZStore.woa/wa/viewSoftware?id=807115217&mt=8> .

The research described above demonstrates clear opportunities that technology could bring within the domain of SLT; however, much of the focus thus far has been around supporting the clinical practice of the SLT and in repurposing more contemporary consumer mobile technology platforms to perform the job of more expensive equipment, or indeed to remediate older paper-based activities and therapy tools. Within the context of Parkinson's, interest around supporting home practice of vocal exercises is beginning to emerge. However there is little understanding around how digital systems might be used to motivate and support self monitoring and managing practices, by encouraging PwP to engage with meaningful data to reflect upon their symptoms. The work in this thesis explores this concept by covering a spectrum of technologies using different feedback mechanisms—from passive cueing, requiring a basic response to a prompt, to active interpretation of feedback, encouraging self directed changes to practice behaviours.

2.5 Summary of Chapter 2

This chapter has provided necessary context around Parkinson's and its complexity as a condition, both in terms of experiencing it as a PwP, and within the design of digital technologies. The chapter discussed the current literature surrounding self monitoring and management technologies currently being explored within health and Parkinson's, more specifically, in order to provide insight for the upcoming case studies. Before moving onto the case studies, however, the following chapter will describe the specific methodologies that were chosen and employed across the course of the research, to situate the reasoning behind the selection of methods used in each individual case.

Chapter 3

Methods

Chapter 2 provided an overview of Parkinson's, its related symptoms and the ways in which the condition is managed clinically, both within Speech and Language Therapy (SLT) and more generally. It further presented an overview of current literature on self monitoring and management technology for Parkinson's and the wider health domain. This served to provide insight into the thesis aims around understanding how self monitoring and management practices surrounding speech, voice and drooling might be digitally supported in PwP. These issues will be examined in further detail within the case studies.

This chapter describes the individual methods taken in this research, the rationale for choosing these, and how they were applied with a Parkinson's community. The following chapter is structured as follows. It will first discuss the user centred design (UCD) approach taken in this research and the practices around UCD that are currently being employed in health research; and for UCD with the Parkinson's community more specifically. It then provides an overview of the specific methods that were applied to each case study, before moving to discuss the recruitment process that was taken during the research and some of the challenges that were encountered.

3.1 User Centred Design (UCD)

The research reported in this thesis follows a user centred design (UCD) approach in the design and evaluation of novel digital technologies for PwP. UCD involves a set of principles and methods in which target end-users inform how the design of a technology takes shape. Users can be involved in the design process in a variety of ways, from consultation about their needs during requirements gathering, as participants in usability testing, as well as a deeper participatory involvement throughout the entire process (Abrams, Maloney-Krichmar, & Preece, 2004). Since the mid 1980's, UCD perspectives have developed in ways to position the user at the forefront of technology design. In Norman and Draper's 1986 seminal work (Norman & Draper, 1986) it was argued that, while computing systems had until that point required inside knowledge of coding languages, future systems (based on graphic user

interfaces) needed to be more widely accessible, usable and should augment the daily activities of those who live with them. Their goal to “*understand the fundamental principles behind human action and performance ...[and] devise systems that are pleasant to use*” (p.32) created a starting discourse around the ways that technology could be designed to account for user needs. Participatory design (PD), a movement that originated during the 1960s and 1970s in Northern Europe and Scandinavia, also rose to popularity around this time as a way to promote democratic involvement of workers in the design of computerised versions of previously manual industrial processes (Bødker, Ehn, Sjogren, & Sundblad, 2000). These approaches emphasised co-operative methods for developing technologies through involving participants as co-designers. PD places a focus on bottom-up, grass roots design, with participants being involved at each point in the design process, from idea formulation through to trialling and evaluation. As technologies become more pervasive and ubiquitous, we are seeing increasing examples of person, or human centred design (HCD)—whereby the focus is placed more upon how the social, emotional, economic and behavioural elements of the person impact on their use and value perceptions of technology, as opposed to just focusing on how people directly interact with a specific technology (Ritter, Baxter, & Churchill, 2014). Furthermore, Wright and McCarthy (Wright & McCarthy, 2010) introduced the concept of experience-centred design (ECD), an approach to design that seeks to gain a holistic understanding of the lived and felt life experiences of the person being designed for (or with), taking into account their past, present and anticipated futures. While UCD, PD, HCD and ECD all offer different conceptions, understandings and perspectives around “the users”—and indeed come with their own historical roots and methods—they all share an ambition to place the intended user of a technology as a key agent within the design process.

Working closely with people in the design of technology—particularly within the domain of healthcare where the technology being designed is intended to bring about a clinical change—is needed in order to gain an understanding of the person’s lived experiences and the elements of life that are important to them. Without this insight, it is difficult to foresee how they might experience and value a health technology being thrust upon them, changing the ways that they engage with their condition. In the context of self monitoring and management, user involvement is even more important, as a critical factor surrounding these technologies is the individual’s motivation to use it in the first place, and

to continue using it, without support from a clinician. If systems are poorly designed, difficult to use, or simply difficult to integrate with the person's daily life, then this can be a barrier to long-term engagement. More importantly however, is the fact that these technologies have the potential to change the ways that individuals may view their condition. On one hand, self monitoring and management technology can empower people to take control of their condition, dispersing somewhat from the dynamic that the clinician is the single actor leading their care. However, they can also become a cause for concern and frustration, acting as a reminder of 'ill health' or fuelling anxieties that a conditions might be degenerating (Lupton, 2013). Given the focus of the research presented in this thesis on people with Parkinson's, these complexities are even more important, due to the prevalence of individual symptom fluctuation which is common in the condition. As such, involving participants in the design process, to understand their individual circumstances and experiences was considered of critical importance throughout the research.

The case studies described in this thesis had a strong focus on specific symptoms (drooling and speech) and there were already clearly formulated ideas around the types of issues that the technologies might address. However, there was a need to understand how the technologies might be adapted or developed, in order to fit into PwP daily lives. As such, the design of each of the technologies followed an iterative UCD methodology. This involved running workshops and informal design activities with participants in order to generate design requirements and subsequently evaluate the developed systems with end-users. The technologies designed for use in the case studies drew from a range of traditional UCD methods (described below) to both gain an understanding of participants and the specific symptoms that they were experiencing, and to begin to acknowledge the specific needs and values of PwP that might introduce barriers and/or create enablers towards the uptake of a new technology into their lives.

3.1.1 User Centred Design in Health and Care

There is a wealth of research which has implemented UCD within a variety of health and care settings (for instance, Fitzpatrick and Ellingsen (Fitzpatrick & Ellingsen, 2012) provide many examples in their review of computer supported cooperative work in health care). Designing in mental health contexts has received a large amount of interest (e.g. Coyle & Doherty, 2009; Lindsay, Brittain, et al., 2012; Robinson, Brittain, Lindsay, Jackson, & Olivier,

2009; Slegers, Wilkinson, & Hendriks, 2013; Thieme et al., 2013; Wallace et al., 2013; Wallace, Thieme, Wood, Schofield, & Olivier, 2012). For example, Thieme et al (Thieme et al., 2013) describe a particularly complex project, conducted with women experiencing learning disability and personality disorders in a medium secure forensic hospital unit, exploring the engagement of the women in the personalised design of a set of interactive artefacts designed to promote mindfulness practices. The authors, although they worked closely with hospital staff in the construction of the design concepts, describe the complexities of working within the setting and the safety, ethical and organisational issues of the research that they were required to design a technology suitable for use by the women and in that complex context. One area of mental health which has received particular interest is dementia care. For example, Slegers et al (Slegers et al., 2013) worked alongside people with dementia and their caregivers to develop a system that would allow caregivers to track the different variables that might influence meal times, such as personal preferences, and also physical and environmental factors. The authors describe three phases in their method. The first involved carrying out ethnography to gain an understanding of the lived experience of dementia and the everyday struggles that might occur in a typical day, which they developed into stories. The second phase involved bringing caregivers and a person with dementia together in a naturalistic context (a participant's home) in order to collaboratively brainstorm ideas for possible interventions using the previously created stories as prompts. They then conducted low fidelity prototyping sessions with professional caregivers for the eventual system that was used. The authors reflect on the importance of involving all stakeholders at each point in the design process, to ensure all project partners maintain a sense of ownership over the developed design. In another project, Wallace et al (Wallace et al., 2012) describe the design process surrounding an interactive art piece, Tales of I, which was commissioned for a hospital specialising in the assessment and treatment of people with severe dementia. The authors used interviews and workshops with staff, alongside observational visits to the site, to gain an understanding of the practices around engaging with people with dementia and the spaces that were the focus of daily life on the unit. They used these insights to construct a home-like space, in the style of a living room, where staff and clients could spend time together, watching one of many differently themed videos (i.e. showing video footage of nature) that were displayed through a cabinet that was specifically designed to resemble an old-fashioned television. The playback of videos was triggered

through an RFID that was embedded at the underside of a small resin globe when the globe was placed on top of the TV cabinet. The authors found increases in intimacy and interpersonal relationships between staff, clients and family members which was facilitated by the experience of spending time together in the space. They discuss the importance of stepping away from 'the mental health condition' in question and instead suggest taking into account the environment and people surrounding the person in order to allow for designs which allow natural interactions to emerge. Lindsay et al (Lindsay, Brittain, et al., 2012) discuss the importance of creating an empathic relationship between designer and participants when working with people with dementia in the design of assistive technologies to support independence. The KITE (keeping in touch everyday) process they describe advocates the use of an initial exploratory session to facilitate the development of an empathic understanding of the lived experiences of participants, through the sharing of personal stories of what it is like to live with dementia, to help bridge the gap between designers and participants. They describe how recruitment of existing groups and caregivers, made up of people who already know one another, can facilitate this sharing of personal narratives in a comfortable and sympathetic space. The authors also discuss the importance of reviewing design ideas throughout design workshops and describe it as important to ensure that the design team's interpretation of participants' views are accurate.

Another application area of UCD in health has been into service design. For example, Bowen et al (Bowen, Dearden, Wright, Wolstenholme, & Cobb, 2010) describe the development of a toolkit which facilitated the use of UCD methods in collecting and analysing stories around hospital experiences from patients and staff at a UK hospital. They describe how their engagement with stakeholders over the course of several months allowed for positive changes to be made within the hospital setting, by allowing participants to articulate issues around their patient experience with staff and identifying shared benefits from making changes to service provision and delivery. Suggestions like improving signage to toilets, making information in appointment letters clearer, and improving the road into the hospital were put forward by the patient group and implemented by the hospital to enhance the patient's attendance experiences; providing patients a voice with which to reach out to the institution.

These examples provide insight into the types of overall approaches and methods of engagement that can be used to involve different stakeholders in health and care technology

design processes. However, given that Parkinson's comes with its own set of complexities (e.g. speech problems, ON/OFF fluctuations, mobility and dexterity issues), there are considerations and adaptations that must be made to traditional UCD methods in order to engage PwP in the design process. As was highlighted in the understanding Parkinson's section (2.1), Parkinson's is a complex condition which presents in a heterogeneous set of symptoms within each patient. As such, there are challenges when designing digital technology with this community, to ensure that the resulting system will be both accessible, usable and easily integrated into PwP lives. In addition, there are already well documented challenges [e.g. (Lindsay, Jackson, Schofield, & Olivier, 2012)] around designing technologies with older adults (+65), an age range which describes the vast majority of PwP. The section below describes the previous literature around designing technologies with older adults and then moves specifically to designing for and with PwP.

3.1.2 Designing with Older People

There is wealth of HCI literature exploring design methodologies with older people (e.g. Lindsay, Jackson, et al., 2012; Lindsay, Brittain, et al., 2012; Massimi, Baecker, & Wu, 2007; Newell, Gregor, Morgan, Pullin, & Macaulay, 2011; Robinson et al., 2009; Vines et al., 2012; Vines, Blythe, Dunphy, & Monk, 2011; Wallace et al., 2013). Lindsay et al (Lindsay, Jackson, et al., 2012) highlight that, whilst engaging older users in the design process can have its challenges (such as envisioning intangible concepts relating to technology which might not be familiar to older people), their unique and diverse input is vital for effectively designing technologies targeting the older population, thus the approach taken in design must augment their capabilities not hinder them. Lindsay et al. describe their 'Open Architecture for Accessible Services Integration and Standardization' (OASIS) approach, which employs the use of "invisible design" (Briggs et al., 2012), a method which inspires novel ideas around how a technology might look or function through ambiguous reference to a version of the technology, which is never actually seen. Invisible design draws from methods pioneered by Newell et al (Newell, Morgan, Gibson, & Forbes, 2011), which describes the use of professional interactive theatre and professionally produced narrative videos as "powerful tools for raising designers' awareness of the challenges technology presents to older people" (p. 602) by encouraging empathy with user groups through the provision of unique insights into user perspectives. Low fidelity prototyping is also used at a later stage of the OASIS

method to develop the target technology according to the users' requirements and enable discussion around aesthetic qualities relating to the device in question.

Another paper describing a particularly interesting design method is that by Vines et al (Vines et al., 2012), used to engage older users in the design of future banking options. Their approach involved the use of a set of provocative 'questionable concepts' cards which served as a way for participants to think about future methods for banking in new and interesting ways. This method opened up a space for participants to criticise, re-iterate and make suggestions upon purposefully ambiguous and unfinished design ideas. Similarly, Frohlich, Lim and Ahmed (Frohlich, Lim, & Ahmed, 2014) describe a process of re-designing product concepts with older users within a focus group (or 'sandpit') context, as a way to promote creative discussion around the intended use and functionality of product ideas. They used an active re-design approach, whereby participants were shown demonstrations of semi-functional, tangible, yet ambiguous, conceptual prototypes— which were the authors' responses to challenges older adults might face with technology as defined by the literature—and were asked what they wanted to keep, lose or change about the concepts. This process of re-designing the product concepts within the workshop settings, and alongside supported input from the designers, differs from the work presented by Vines et al (Vines et al., 2012), which allowed participants to focus on their own perceptions of design concepts individually, at home, before bringing their critiques and comments into the group setting. In this case, it allowed participants to see their re-imagined concepts take shape as they collectively developed their ideas and, it could be argued, led to a greater level of overall positivity with the design concepts being formed.

Newell et al. (Newell et al., 2011), outlined and explored a new design paradigm related to 'Designing for Dynamic Diversity' which they explain centres around an understanding that older people have significantly different and dynamically changing needs. They aimed to celebrate, rather than attempt to homogenise older people within the design process by understanding the key experiences related to ageing which might impact on technology design. They introduce a framework called User Sensitive Inclusive Design which asks designers to seek out diversity among older users to allow for a wider sensitivity of different abilities in the eventual design of technologies. This is particularly relevant when considering Parkinson's given the highly heterogeneous nature of the condition and is, indeed, one of the reasons why limited inclusion criteria were imposed on the recruitment

efforts throughout the work. Related to this work, a paper by Massimi et al (Massimi et al., 2007) looked at developing mobile phone technologies with older users. The authors present a set of considerations around how to adapt methods within the design process so that they are better suited to a heterogeneous group of users with varying difficulties, for example cleverly pairing participants to overcome deficits and enhance participation, ensuring that tasks are adaptable to ensure that there are alternative methods to participation in activities, or simply effective group facilitation by the researcher to minimise people talking over one another and enable equal participation. Some of these considerations are particularly relevant to the case of Parkinson's whereby there will undoubtedly be a highly variable group of people with varying difficulties, one possible issue being the presence of speech or voice issues which might limit participation in group discussion. Poorly designed technology can lead to a multitude of issues, relating to usability and unrealistic expectations of the way they might be integrated into daily life. This can ultimately cause frustration and disengagement with the technology. In the case of self monitoring and management for healthcare, where the technologies being designed might reveal something about the person's personal care, their health and might be influencing their behaviours, it is particularly important to identify an appropriate design to ensure that the individual using these systems is not negatively affected (Lupton, 2013). When considering technologies for Parkinson's, particularly given that there is little available work which has specifically focused on the community, we must consider the very specific accessibility issues, and personally centred needs and values of, what is, a highly heterogeneous group. The following section explores some existing examples of design work conducted with PwP and the approaches that were employed.

3.1.3 Designing for Parkinson's Symptoms

Aside from age, there are a range of heterogeneous difficulties related to Parkinson's which cannot always be accounted for in a one-size-fits-all consumer technology. These relate for instance to motor symptoms that can cause issues with physical access to consumer technologies; symptom fluctuation that can cause issues with integrating technologies into daily life; or cognitive decline that can cause issues with learning to use complex systems. Furthermore, it is important to also consider PwP as individuals with independent lives, unique experiences, and desires and needs. An example of a paper which focuses on

designing for diversity and individual need is that by Balaam et al (Balaam et al., 2011), which discusses the employment of a bottom-up, design-led method to developing bespoke technologies to motivate users with stroke, who had upper limb mobility issues, to practice rehabilitative exercises in the home. The authors illustrate the importance of viewing each patient as an individual during the design process, each experiencing different social, emotional and practical factors within their home lives, which can impact upon their motivation to practice rehabilitative tasks at home. They also highlight how motivation of the patient can waver when faced with carrying out rehabilitation exercises alone in the home, when compared to rehabilitation carried out in clinical settings, wherein the patient is heavily supported by the therapist. The research emphasizes the importance of using participatory methods to understand the user engaged in the design process. This concept of maintaining motivation is of particular relevance to the design of digital self monitoring and management tools as the individual user is ultimately the person who will deliver the intervening change in response to system provided prompts or feedback. In order to explore the motivations that drive users towards making a positive change we, as designers, must first gain an understanding into the lived experience of having a specified symptom or condition and it is only through discussion with the person living with the condition day-to-day that we can truly gauge the social and emotional impact which drives motivation, or lack thereof.

In relation to designing for people experiencing communication issues, which is a key focus of this PhD research, it is worth drawing on some of the literature focusing on aphasia; an acquired disorder (following neurological damage, e.g. from traumatic brain injury or stroke) affecting spoken and/or written comprehension and/or production of language. Although the focus of this literature surrounds language, and not speech quality (which this thesis research focuses on), there are insights into the ways in which design research can be conducted with those experiencing limited communication. For example, although their research focused on working only with technology literate aphasic individuals, which in itself differs from the work presented in the thesis, McGrenere et al (McGrenere et al., 2002) discuss several insights towards engaging people with communication difficulties in design. They focused on using individual informal interviews to outline the specific needs of participants, which are then used to inform the design of prototypes (paper based low fidelity, leading to software based medium fidelity). The authors found that even highly

technically literate aphasic individuals had particular difficulties engaging with low fidelity prototypes, exhibiting an inability to consider how they might interact with the conceptual 'system'. They advocate focusing on the development of medium fidelity prototyping as a way to provide concrete examples of the ways in which a system might look or function, to allow participants to show, rather than tell, what they are doing with a system, thus bypassing the need for complex expressive output.

Galliers et al (Galliers et al., 2012) provide a wider reflection on the challenges they experienced with the participatory design methods they used to engage people with aphasia in the development of a computerised gestural therapy tool. The authors describe how issues relating to the participants' aphasia, such as impaired comprehension, impaired ability to understand conceptual information, difficulties with information retention and retrieval, easy distraction, and physical difficulties relating to stroke had an impact on the planning and conduct of the design process. The authors, similarly to McGrenere et al., advocate the use of high, over low, fidelity prototypes to provide concrete examples of system designs and describe how methods employing hands-on activities, that employ skills outside of language production, can elicit insightful observations around user behaviour. Finally the authors used traditional SLT approaches to supporting communication, such as assuring the availability of alternative means of expression in the form of pictures, flashcards and symbols, to ensure that all participants were able to contribute their ideas and opinions within the group format.

Finally, Wilson et al (S. Wilson et al., 2015) describe a long term engagement with people with aphasia in the co-design of digital therapeutic tools. The authors describe their creation of tangible design languages (manipulable, non-verbal design representations) to help give voice to people with aphasia within the design process. They describe the importance of using pictures to support understanding and expression, without the need for verbal expression, using demonstration (from facilitators) as a means to explain activities and interactions required by participants, and using tangible prototypes as a way to provide concrete representation of design ideas.

Although aphasia differs to the speech issues experienced in Parkinson's (a motor speech disorder characterised by dysarthria which affects the clarity, not the content, of the speech), this bank of literature shows that people with communication difficulties can be given voice in the design process through careful facilitation and support. In addition, there

are a many cognitive difficulties associated with later stage Parkinson's that can lead to similar language difficulties. As such these insights could be employed to support these types of participants. In general, HCI literature specifically related to Parkinson's is relatively limited and research related to designing for and with Parkinson's remains even more so underexplored. Specifically, there are no guidelines around how to conduct a design process with a group of PwP, particularly in relation to managing contingencies which might arise around specific Parkinson's symptoms such as speech issues, mobility difficulties, and so forth.

As of yet, the literature that actually describes engagement of PwP in the design process surrounding health technologies is very limited (Assad et al., 2011; de Barros et al., 2013; Mazilu et al., 2014). Of those few existing examples, only one outlined a design process wherein PwP were more fully involved (the work of de Barros et al (de Barros et al., 2013) which is described further in the section). For example, in a study by Assad (Assad et al., 2011), the authors took a systems based design approach, which only minimally involved PwP, to explore the development of a suite of exergames for home-based rehabilitation of movement related symptoms for Parkinson's. Participants trialled off-the-shelf digital games and provided feedback on their experience, alongside researcher observation. Whilst this allowed the authors to gather requirements for their game, they did not unpick the intrinsic needs and values of their participants that might influence their motivations to use such games at home. In addition, findings have shown evidence that critiquing existing technologies prior to idea formation can lead to a fixation on previous designs and impede the creativity of participants (Davidson & Jensen, 2013). Similarly, in a study by Mazilu et al (Mazilu et al., 2014), the authors used a questionnaire and semi-structured interview approach to inform the design of a wearable sensor-based system to treat freezing of gait episodes. Again, whilst appropriate for requirement gathering, the authors were more interested in sensor placement, comfort and usability, and did not focus on the needs and aspirations of the participants. One example of engaging participants more fully in the design process comes from de Barros et al (de Barros et al., 2013), who described their UCD approach to develop a set of mobile phone applications to aid in the daily self-management of Parkinson's. The authors discuss how they took an iterative design approach, modelled on Robinson et al (Robinson et al., 2009), which involved a process of exploratory meetings to identify the design space; design meetings which involve the use of prompts to begin to

explore the design space; and re-iterative design with participants. Unfortunately, being one of the only design papers specifically related to Parkinson's, de Barros et al. do not reflect on the successes and challenges of their design process and approach, which highlights a need for more critical appraisal and awareness of design methods for Parkinson's, and the development of recommendations for designers and researchers working with this particular group.

While each of the case studies presented in this thesis are focused on deriving insights into the value that PwP place on different configurations of self monitoring and management technologies in supporting their self care practices, the case studies also aim to bridge this gap in the literature by providing reflections around the challenges and successes of designing these types of technologies with PwP. Several distinct phases were involved in the design of each technology. At first, workshops were used to gain an understanding of the Parkinson's symptom under study and the associated impact it had on participant's lives, as well as gaining insight into the technological features that were most important to participants. This was followed by iterative prototyping to develop technologies that met the participants' requirements; and finally, the conduct of real world deployments of the technologies to allow participants to experience using the technologies in their everyday lives. Following the deployment, interviews were conducted to capture participant insights into the ways that the technologies might be integrated and used in their daily lives. The UCD methods used in this research were largely discussion-based; scoping participants' experiences of Parkinson's of technology, and co-developing design requirements that would call to the values and needs that they expressed.

This section discussed perspectives in UCD and some examples of UCD methods used within the domain of health technology design generally, and Parkinson's more specifically. The following section will describe the particular methods that were employed in the design and evaluation of the technologies in each of the case studies.

3.2 Case Study Methods

As noted, each case study had three distinct phases: initial design requirement gathering workshops, iterative design of the technology and in the wild implementation and evaluation of each technology that was developed. Each study drew on a range of UCD methods which allowed for the development and evaluation of technologies that met the

needs outlined by participants during initial discussions around specific symptoms, as well as allowing for exploration of the value that each technology might have for assisting in the self monitoring and management of SLT issues in PwP. Below, the methods employed within each case study are described in detail, discussing both the design and evaluation stages of each case. Please note that individual ethical approvals were obtained for each stage of each study, through the NHS Research Ethics Committee (REC) for case study 1 and through Newcastle University REC for case studies 2 and 3.

3.2.1 Case Study 1: Self Management of Drooling

The first case study, described in detail in chapter 4, explored the design of a cueing device to aid in the self management of drooling (also termed sialorrhoea) problems in PwP. The focus of this case study was to develop a non-invasive means of helping people manage this issue, employing a device which would deliver regular physical cues, in a manner that was acceptable and accessible to participants, to remind them to swallow their saliva more often and thus reduce their drooling.

3.2.1.1 Design Methods

The approach that was used in the design of the device that was used, the PDCue, was loosely based around the KITE approach, described in Lindsay et al (Lindsay, Brittain, et al., 2012), which has already been discussed in section 3.1.1 (a visualisation of this approach can be viewed in Figure 2). This approach was chosen due to its focus on the creation of an empathic relationship between the design team and participants, in order to yield an environment that would allow users to speak openly within design sessions. The initial exploratory meeting and initial design meetings were combined into half day workshops, with three groups of participants: the first group consisted of 2 PwP and 2 carers, and the other two groups of 3 PwP and 1 carer. The initial exploratory session, which made up the first half of the workshop, aimed to gain an understanding of the impact of Parkinson's, and in particular drooling, on daily life in order to gain initial insights into the intricacies of the condition. Following this, the design element of the process involved using prompts for discussion around everyday technology use (from telephones to falls alarms) and the issues and successes that participants had experienced. The focus then moved to discussions

around the types of features that would be important to the group when considering a cueing technology as part of treating their drooling.

The final phase of Lindsay et al.'s process involves an iterative design process with smaller groups of users in additional workshops. However, as the intervention element of the study had already been determined in advance, this process was adapted to involve a real-world deployment as opposed to a workshop, and focused on one person from each of the three groups. A functioning prototype was deployed with each group member for one week and, drawing from their feedback, a second reiterated prototype was re-deployed with the same participants. This process worked particularly well with the group of participants who took part and allowed for a deep understanding of the complex needs and values that might be assigned to a digital technology to treat, what became clear to be, a particularly stigmatising, frustrating and embarrassing symptom. The in-the wild deployments, that

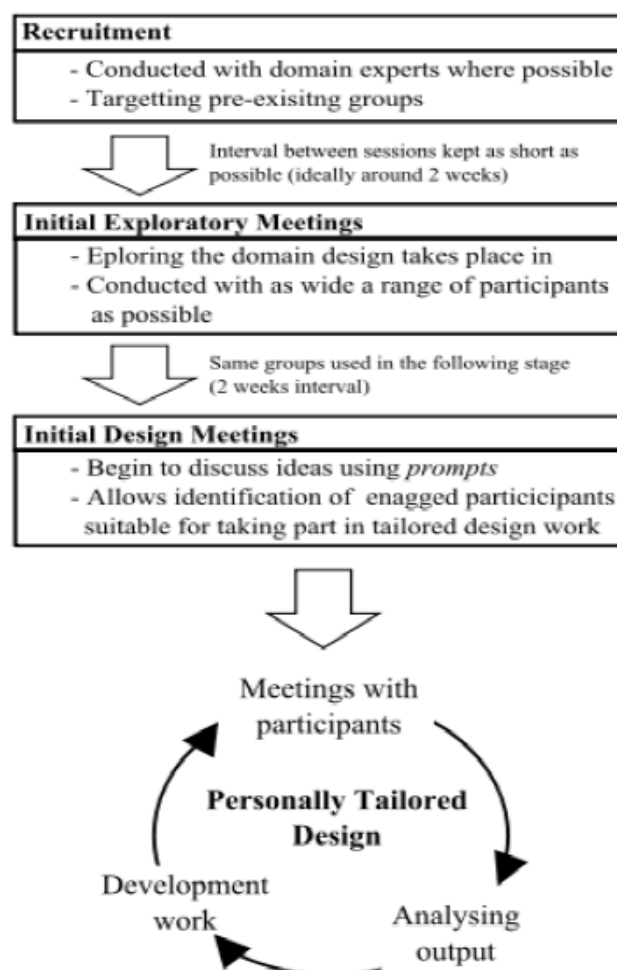


Figure 2: A visualisation of the KITE approach as presented in Lindsay et al (Lindsay, Brittain, et al., 2012)

formed the iterative design process, drew upon the commentary about living with drooling expressed during the workshops and gave real life insights into how the device might be accepted, used and talked about within participant's social lives.

3.2.1.2 Clinical Effectiveness Trial Methods

Following the final design of the PDCue, the first case study went on to evaluate the possible effectiveness of the device in supporting the self management of drooling problems. This stage employed a clinical trial methodology which is a formalised trial procedure, governed by the National Health Service (NHS), which follows Good Clinical Practice (GCP) guidelines¹⁸ (MRC, 1998). Clinical trial study designs are peer reviewed by a committee to ensure that the intended evidence collection is feasible and ethical. Trials can be conducted using a host of methods, however there are structured, evidence based study designs which fall into a hierarchy of evidence. For example Evans (D. Evans, 2003) suggested a framework for ranking evidence evaluating healthcare interventions, in which systematic reviews and multicentre studies are ranked the highest, with randomised control trials (RCT) ranking just below and, for example, single case studies ranking lowest. So, when trialling a new intervention, a multi-centred trial, whereby the intervention is being tested within multiple sites around the country, accounting for variances in economic status, environmental changes and individual difference between services is deemed to have a generalisable level of evidence for a clinical population. However, before applying for funding for these large, and expensive, multi-centre trials it is essential to perform smaller pilot trials, used to give evidence that an intervention works, and to ensure that the study design would be feasible to use on a larger scale.

The first case study presented in chapter 4 is a single-centre, randomised control, stage 1 pilot trial with 30 participants. The methods used followed closely with the randomised control trial format, whereby study participants are split into two or more groups, one of which receives a treatment, while the other receives different treatment or a placebo. Outcomes for each group are measured before, after and often during follow-up meetings at a designated time after the study has ended. The results are compared between

¹⁸ Good Clinical Practice (GCP) guidelines aim to ensure that patients are safeguarded when participating in clinical trials and that the data which is collected is of a high standard and communicable quality, which adds scientific integrity to the trial and credibility to the data (MRC, 1998). The GCP guidelines cover details surrounding the informed consent of participants, the appropriate management of clinical data including storage and confidentiality and outlines the roles of the investigators and institutions involved in the research.

the separate groups to analyse treatment effect¹⁹. The details of this protocol are discussed in more depth in chapter 4, section 4.4.

3.2.2 Case study 2: LApp on Glass: An Application Targeting in-situ Prompting of Increased Volume on Google Glass

The second case study addresses the symptom of reduced vocal loudness, a prominent issue experienced by PwP (as noted in (Ramig et al., 2001)). The LApp case study, described in detail in chapter 5, examines the design and evaluation of an application built for Google Glass, that aimed to support the self monitoring and subsequent self management of vocal loudness, through the provision of in-situ visual prompts provided to the participant in the context of their everyday life. This study focused on how participants valued and used the system in a meaningful way, as a means to support their speech in everyday routines and activities. The primary focus was around exploring how novel consumer technologies (in this case Google Glass) might be used to support new ways of cueing PwP, as and when participants required a prompt, to support self management. It looked at how the monitoring of these prompts, which gave participants information about *when* their voice was too low, could support reflection and enhanced understanding around their individual volume difficulties and the amount of effort required to produce their loud voice in order to manage them. Given that Glass was essentially a beta prototype released by Google to uncover issues and possible use cases of the platform prior to public release, there were several methodological adaptations that had to be made in order to explore its use with PwP. As such, prior to designing an application for Glass, it was first important to ensure that PwP would accept and be able to use the novel platform. The following section describes the methods that were used in an acceptability study for Glass as part of the design process.

3.2.2.1 Exploring the Acceptability of Glass

The intentions of the primary phase of this case study were formed around understanding how the Glass might be accepted and adopted within the lives of PwP, relating to, for example: sense of stigma; levels of training required to use the technology and the impact this might have on its uptake; personal acceptance of the Glass as an everyday technology; and perceptions around its usefulness as an assistive device for PwP. In the first phase of the

¹⁹ <https://www.nice.org.uk/glossary?letter=r>

case study, a workshop was held with 5 PwP and 2 carers to introduce participants to Glass and gather information on their initial perceptions of the technology. Following this, a real life deployment of Glass was conducted with 4 of the PwP who took part in the initial workshop, to gather people's experiences of using it as a consumer technology and to uncover whether their initial perceptions of the device were founded with the reality of its use. This deployment served to test whether or not the platform was usable and acceptable to PwP. As the intention of the second stage of the case study was to develop an application for Glass, it was important to ensure the hardware was accessible to the intended application users. It was also important to conduct in-the-wild deployments as opposed to observing lab-based experiences because the technology was so novel and visually apparent. This may have given rise to feelings of discomfort when using it in public—although it should also be noted that Glass was intended for the consumer market, thus potentially overcoming issues around stigma associated with medical devices. It should also be added here that participants were informed that they did not have to use Glass in public if they preferred not to. A full discussion of the study design and findings are described in Chapter 5 (section 5.4.1 and 5.4.2 respectively).

3.2.2.2 Designing LApp

Following a successful first phase, the second phase of the case study involved the design of an application to aid the in-situ prompting of loudness (LApp). This design process involved participants in the early phases and evaluation of the design. It took a similar approach to the design workshop in case study 1, which had previously worked well to engage PwP in the design process. Seven PwP experiencing volume issues were invited to a workshop to share their lived experiences of volume issues, as well as the discussion of personal strategies being employed to overcome these issues. A paper prototyping activity was used to facilitate discussion around the types of features that might be desirable in an application to prompt vocal loudness, with the researcher clarifying arising ideas in a visual format. Finally, participants explored 3 scenarios, all based around PwP experiencing issues with their volume in different settings, and were asked to consider the use of an application in these situations. The use of scenarios was aimed at engaging participants in discussion around imagined use cases of the app and how it might fit into their daily lives. It can often be difficult for participants to imagine their use of a system which is yet to be developed, so by

placing the focus onto a scenario, the pressure of imagination is reduced and the designers and stakeholders are able to share a common 'experience' (C. Putnam, Rose, & Johnson, 2009).

Following the design workshop, the Loudness application was developed and pilot tested with a group of people without Parkinson's, in order to gather feedback around the app and its general usability prior to evaluating it with PwP. Participants in this stage were able to provide useful information surrounding basic interaction problems with the app and the device as a whole prior to evaluating the system with individuals with Parkinson's. Following iteration of the device from this stage the LApp was deployed with 6 of the original design phase participants in an exploratory manner, that is to say participants were advised that they could use the application however much, and in whatever settings, they wished in order to uncover the ways that the system might be integrated into their daily lives. This feasibility study followed an in the wild field study approach, which, as described by Rogers (Rogers, 2011), aims to explore *"how people come to understand and appropriate technologies on their own terms and for their own situated purposes"* (p.59). Unlike in-lab testing, which is very much dominated and controlled by the researcher, an 'in the wild' study design allows for an appreciation of the many idiosyncratic differences that make up each individual participant and their day-to-day lives. In order to uncover how each participant experienced LApp, they were interviewed following the field trial using a semi-structured questioning methods (i.e. where questions aim to probe experience as opposed to obtaining a specified response, for example, "tell me about your time with LApp") to elicit experience rich discussion (Rogers, Sharp, & Preece, 2011). A mixture of quantitative log data from the device and qualitative interview data, allowed for a picture to develop around the value that PwP might place on an application like LApp and initial attitudes to in-situ prompting on novel platforms such as Glass. Chapter 5 includes full details of the design workshop and the findings that were derived from it as well as the pilot and field trials.

3.2.3 Case Study 3: Crowdsourcing as a Method of Enhancing Self Monitoring and Management of Speech and Voice in Parkinson's

The final case study, described in chapter 6, shared a similarity with case study 2 in that it was exploring the domain of Parkinson's speech. This second case study continued to explore issues of vocal loudness and was further expanded to also investigate a number of

additional speech and voice features that are commonly impaired in Parkinson's (volume, rate and pitch variance). More specifically, this study focused on understanding how speech and voice can be monitored over time by PwP and whether the provision of timely, non-automated feedback about their speech, derived from other people, could be a positive motivator in encouraging PwP to self manage their speech and voice. The study introduced a novel way of obtaining this speech feedback using crowdsourcing and, due to its exploratory nature, required several innovative methods in order to scope its potential for PwP.

The Speeching system presented in this case study was made up of two components; a smartphone application provided to participants—which was used to collect speech samples, present feedback from the crowd and provided tools to facilitate the practice of speech; and an online service linked to a pre-existing crowdsourcing platform to obtain speech ratings from an anonymous crowd of workers. The design and subsequent evaluation of the system involved several key stages and drew from lessons learned in the previous LApp case in order to inform its design. Given that even the feasibility of the crowdsourcing method was unknown, and that the app itself involved a therapeutic practice element, this case study focused heavily on the involvement of a clinical expert in the design phases, before trialling the app and crowdsourcing method with PwP in the final stages of the project. As such, this case study focused on the design of a complex self monitoring system, but was grounded in clinical knowledge, with carefully developed, clinically relevant data around speech and voice being collected.

3.2.3.1 Assessing the Appropriateness of the Crowdsourcing Method

The intention of Speeching was to explore the use of crowdsourcing to obtain relevant feedback around speech and voice, which could be communicated back to the person using the application. However, it was first vital to gain an understanding around whether or not a crowd would be able to provide the necessary information required, through the presentation of simplistic crowdsourcing tasks. Crowdsourcing in itself is defined as the outsourcing of mini-tasks to an online network enabling a larger task to be completed (Wolters, Isaac, & Renals, 2011). In this case the larger task was the analysis and feedback provision around speech and voice changes in PwP, a process usually performed by an SLT. As such, it was necessary to explore whether or not members of an online crowdsourcing

platform would be able to provide good quality ratings of speech that would be equivalent to an expert's rating. This was the first question explored during the design process.

The first step involved working alongside an expert in Parkinson's speech to identify the types of measures that would normally be observed by an SLT working with PwP during the therapy process. As such, the primary system requirements gathering step in the UCD process involved the participation of a clinical stakeholder, and not PwP themselves, as was the case with case studies 4 and 5. Through a series of meetings with the expert it was possible to outline the main areas that were measurable in SLT practice and gather information around the standard ways that these were completed. The next step involved synthesising this information to develop a set of simple crowdsourcing tasks. A full discussion of the process of developing the crowdsourcing tasks is described in chapter 6 (section 6.4.1.1.2).

The next step was to validate the crowdsourcing method. In order to do this, a gold standard comparison was conducted (Versi, 1992). This approach involves obtaining a measure, which is considered to be the best possible outcome, and using this as a comparison to judge the accuracy of measures collected during the study. Gold standard comparison is a method that is widely used in both clinical [e.g. (Flamand-Roze et al., 2011; Pearson, Jackson, & Wu, 2014)] and machine learning research (e.g. (Choi & Bakken, 2006; Wiebe, Bruce, & O'Hara, 1999)) as a way to benchmark new methods against current guidelines for best practice. In the case of this study, the gold standard was obtained from two highly experienced experts in Parkinson's speech. Their ratings were used as the gold standard against which to compare all other ratings. Again, full detail of the study specific methods that were used are provided within the chapter itself (section 6.4.1).

3.2.3.2 Designing the Speeching Application

The design process employed when developing the Speeching application was slightly different to those used in the previous case studies, as workshops were not held with participants. There were several reasons for this. Firstly, this case study built upon the work conducted in case study 2. The information that would have been sought around participants' experiences of monitoring and managing their impaired speech had already been collected during the LApp workshops (described in chapter 5). Similarly, the LApp workshop had provided clear insights for the direction of a speech and language application

and the types of features that participants desired. Whilst the two apps were very different in terms of functionality, with LApp providing an in-situ prompt for vocal loudness and Speeching providing a way to monitor and practice speech and voice issues, the core insights surrounding the ways in which applications to support self monitoring and management of speech might be integrated into the daily life of PwP experiencing speech issues were very similar. In addition, the practice element of Speeching, an identified feature of importance during the LApp workshops and evaluation, required the expertise of a clinical expert, to ensure that the tasks designed would target the required speech issues being monitored. As such, the clinical expert who took part in the initial design of the crowdsourcing tasks was involved in the iterative design of the application, informing on its content and design features. Individuals with Parkinson's were, however, involved in the evaluation of the system (6 PwP, 4 of whom were involved in case study 2).

Drawing on the methods successfully employed in case studies 1 and 2, Speeching was deployed with participants 'in the wild' to allow for insights into how participants integrated the Speeching system in their day-to-day lives; how often they used the system; to what extent they integrated the system into their established speech therapy practice; and how they interpreted the feedback being presented to them. Quantitative log data was collected from the Speeching servers to provide insight into the ratings that participants were obtaining, and how these might have changed over the course of the week, as well as how often they submitted data for feedback. Finally, a semi-structured interview was conducted to capture the individual experiences of participants and their perspectives on the system for supporting self monitoring and management of speech in everyday life. Details surrounding the design of Speeching, the study specific evaluation design, and the findings from this trial are presented in Chapter 6 (sections 6.5.1, 6.5.2 and 6.5.3 respectively).

3.3 Qualitative Data Analysis

Within and throughout each case study qualitative analysis was carried out at key stages; on data collected during the initial design phases of the PDCue and LApp case studies—which involved design workshops—to inform the development of the prototypes; and on the interview data collected during each study after the field trials, to evaluate the technologies

being explored. While the case studies grew and developed from the knowledge obtained from previous cases, they were all distinct in terms of the research questions they explored.

As such, the qualitative data analysis process that was chosen involved the implementation of thematic analysis, which allows the researcher to look for expected themes within the data, compiled following the review of existing literature or previous experiences (reflecting a deductive approach). However, the method is sufficiently open in the sense that it allows for the observation of newly emerging themes (reflecting its inductive qualities). Following Braun and Clarke's method (Braun & Clarke, 2006a), the transcripts were coded, manually, at the sentence to paragraph level, which involved reading each sentence of the data and looking for potential themes or patterns and then re-reading the paragraph, or extract, to see if any further themes or patterns were evident in the context of the conversation. Each individual code was written down and numbers were assigned consecutively to the highlighted extract of the interview, across all participants, that the code had been applied to. This allowed for the researcher to develop a quick referencing system, to search for specific extracts of each interview. Following this, the coded data was then reviewed, to search for recurrent themes across all of the participants. In contrast to thematic analysis, methods such as Grounded theory (Glaser & Strauss, 1967) involve the generation of new theoretical knowledge from data, using methods which constantly compare analyses as the project progresses.

The previous sub-sections explored in 3.3 have looked at the case specific methods that were employed during the course of the research. The following section concluding the chapter, will now discuss the processes involved in recruiting participants to take part in each of the studies.

3.4 Participant Recruitment

There are multiple challenges when recruiting participants into health research. Firstly, it can be a difficult and time-consuming process to gain access to clinical groups, and even when access is granted it can be challenging to recruit a representative sample of participants. Technology-based design research can pose its own unique set of problems during recruitment, particularly when involving participant engagement at an early stage of the design and development process when the ideas might be more vaguely formed. There is

also the added complexity around this research's focus on working with and designing for PwP; for example, the community is made up of many older people who might be unfamiliar with technology and therefore be less interested in partaking in projects surrounding the design of digital systems; participants often have complex medication routines and fluctuating symptoms; or may suffer of a number of additional health conditions to their Parkinson's. In an attempt to manage these complexities, the recruitment process ensured that potential participants felt confident that they did not require prior knowledge of technology to take part, and that help and guidance would be provided throughout the study, if did decide to partake. In addition, the design workshops were carefully constructed to alleviate any of the associated issues arising for many PwP, relating to mobility and mediation routines. This simply involved elements such as ensuring that chairs had arms to support sitting and standing; that essential facilities such as toilets were accessible; that water was available for participants to take medication as and when required; and so forth. In addition, the researcher had the knowledge and skills necessary to recognise and facilitate common issues associated with Parkinson's. For example, assisting a participant to move again if blocked in a freezing episode or ensuring conversations were equally distributed throughout the discussions for participants with delayed or particularly quiet speech production.

Due to the different methodologies employed in each of the case studies, there were also different methods taken towards recruitment. The first case study (PDQ) was a clinical trial, and with this came a supported environment for the recruitment of participants through patient databases. As the study had been through favourable NHS ethics approval and met the requirements of GCP, it was possible to formally recruit participants through the Parkinson's clinics in Newcastle, North Tyneside, Sunderland and Gateshead NHS Foundation Trusts, in accordance with the clinical trial context of the study. This involved not only the researcher being involved in recruitment, but also staff members within each trust identifying and providing information to appropriate potential participants. In contrast, case studies 2 (LApp) and 3 (Speeching) were not governed by the NHS—rather, Newcastle University were responsible for governing the ethical validity of the studies—and so the process of recruitment was slightly more difficult. In these cases, participants were initially contacted and met through Parkinson's UK, a charity which provides support and

information to PwP and their carers²⁰. Throughout the timeline of the research, contact was made with a total of 7 separate Parkinson's UK (PUK) support groups within the local areas of Newcastle, Tyneside and Northumberland. These groups meet approximately once a month to engage in sessions, providing information and support to members, offering insights into new developments in Parkinson's care (through talks given by various speakers) as well as a regular setting for its members to socialize, and also raise money for PUK. As these support groups are used by often large numbers of PwP, they provided a valuable space for highlighting the projects within the Parkinson's community. In addition, the social element of the sessions allowed for individuals to discuss queries they might have had on a one-to-one basis with the researcher. The recruitment process first involved making initial contact with PUK to gain approval to approach their members. Visits were then made to the local support group sessions to discuss the project aims and the inclusion criteria and to allow for the collection of contact details of interested participants. These could then be used to contact participants individually to discuss the project and answer any questions they might have. Each of the three cases studies aimed to recruit a group of participants whose demographic would reflect a range of age, gender and symptoms to explore different life experiences and everyday variables during both the design discussions and the field trial evaluations. As such, there were no exclusion criteria relating to any of these variables (age, gender, stage of Parkinson's). One requirement, however, that was stipulated was that participants taking part in each study felt that they were experiencing the symptom in question (drooling, speech volume, general speech issues), to ensure that they could share views on how the technologies designed might support them in their everyday practices relating to these specific symptom. Although this process allowed for opt-in recruitment of interested participants, it had its own issues in terms of the scope and variability of participants who took part in the studies, as it involved recruiting from an already socially active group of people, who had a personal interest in the research topics. This is opposed to the on-the-spot identification of a wide range of 'patients' within clinical practice, who may or may not be socially active, which is how recruitment was carried out in case study 1 (PDCue). This is discussed and reflected upon in further detail in chapter 7. Please note that descriptions of participants and their comments are denoted throughout the thesis with the case study number and participant identification code (e.g. cs1p1, cs2p4 etc.).

²⁰ www.parkinson's.org.uk

3.5 Summary of Chapter 3

This chapter first explored general perspectives and approaches in UCD, before moving on to descriptions of examples of UCD in healthcare generally, and Parkinson's more specifically. It then described the individual design and evaluation methods that were employed in the 3 case studies that will be presented in the forthcoming chapters. Finally, the chapter presented the recruitment methods that were employed and the different processes that were undertaken when recruiting from the NHS in comparison with Parkinson's UK. The next chapters will describe the individual case studies, all of which explore the potential for novel digital technologies to support the self monitoring and management of speech and drooling in PwP. Chapter 5 begins with the design and evaluation of the PDCue device (a digital wrist worn device which provides regular cues in order to prompt the increased swallowing frequency), and its potential for supporting the self management of drooling for PwP.

Chapter 4

Self Management of Drooling

The previous two chapters have focused on situating the upcoming case studies within the previous literature, in the context of related clinical and HCI work (chapter 2- Background) and the approach to the methods which were taken in each case study (chapter 3- Methods). Chapter 2 highlighted how people with Parkinson's (PwP) face a range of challenges in their day-to-day lives, in relation to their condition, and went on to discuss the symptom presentation of drooling and speech and voice issues, which are managed by Speech and Language Therapy (SLT) services. The overarching aim of the upcoming three case studies is to explore the role that digital technology might play in supporting the self monitoring and management of these issues with PwP.

The first case study, presented in this chapter, looked at how digital technology could support the self management of drooling, by providing a regular cue to remind the wearer to swallow more frequently. In increasing the quantity and regularity of swallowing, use of the device aimed to subsequently reduce drooling, by decreasing the amount of saliva being held in the mouth at a given time. This chapter begins by explaining why drooling was selected as the first case study, highlighting the need for a carefully designed and validated behavioural cueing method to support the self management of drooling issues. It will also highlight how there is an increased need and desire for viable alternatives for those patients wishing not to engage in additional medical intervention (such as Botulinum Toxin (Botox) or pharmaceuticals). The chapter then goes on to introduce the technological intervention that underpins this case study: the *Parkinson's disease Cueing device* (PDCue). PDCue is a wrist worn cueing device that provides its wearer with a regular cue, a vibration, intended to remind them to swallow with greater frequency and thus reduce drooling. The chapter concludes by discussing the results of the study, which showed a significant decline in both drooling severity and frequency following participants' use of the device over a 1 month period.

4.1 Drooling in Parkinson's

In chapter 2 the thesis described, in detail, drooling as a symptom of Parkinson's (see section 2.3). In summary; drooling during the daytime is reported by over half of all patients experiencing Parkinson's (Kalf et al., 2009). It is caused by a failure to swallow the saliva with sufficient volume or regularity, leading to a pooling of the saliva in the oral cavity (mouth) (Nóbrega et al., 2008). This reduced swallowing frequency is associated with changes in the muscular activities that bring about the swallowing procedure that occurs with the onset of Parkinson's. The oral muscles and those that trigger the swallow are affected by similar patterns of muscle rigidity and bradykinesia (or slowness of movement) that affect other larger muscle groups in PwP (such as those that control walking), thus causing similar issues around the coordination and initiation of the complex groups of muscles involved (Nóbrega et al., 2008). The earlier discussion of the literature also highlighted how there can be a range of physical, social and emotional impacts associated with the experience of drooling. The escape of saliva from the mouth can lead to issues around eating and oral hygiene—as saliva acts as a lubricant during chewing and swallowing and contains proteins with antibacterial effects that protect the mouth from infection and dental caries. Continuous wetting of the mouth and chin coupled with excessive wiping can also lead to sores, which can become painful (Chou et al., 2007). Difficulties with speech, embarrassment within social activities and impacts on emotional wellbeing are also reported to be prominent impacts (Aarsland, Andersen, Larsen, Lolk, & Kragh-Sørensen, 2003).

Most current treatments for drooling in Parkinson's are aimed at decreasing saliva production, predominantly with the use of drugs. However these can have serious cognitive side effects such as memory impairment—which can be significant problem already for PwP—or hallucinations (Hyson et al., 2002). Another treatment option used to decrease saliva production is Botox injection into the salivary glands, but this is generally a painful and short term management option which must be repeated every three to six months. Meningaud et al. (Meningaud et al., 2006) extensively reviewed the modalities of treatment for drooling problems and maintained that it is important to propose, where feasible, more non-invasive treatment options, such as behavioural cueing methods, before drug therapy is considered—due to the potential complications surrounding oral health (e.g. gingivitis, tooth destruction, tongue crusting) if saliva production is reduced.

Cueing is simply, by definition, “to give information or a reminder to someone” (collinsdictionary.com, 2015). Cueing for aspects of Parkinson’s such as gait and drooling—through the implementation of a system of temporal cues, wherein the participant was simply provided with temporal, or time-controlled, auditory or haptic prompts to change their behaviour—have been used successfully in the past (e.g. (Marks, Turner, O’Sullivan, Deighton, & Lees, 2001; Nieuwboer et al., 2007)). Within the literature studying gait cueing, it has been observed that the provision of a cue brings about the execution of a new motor plan that facilitates walking and suppresses the impaired motor plan currently inhibiting the intended movement (Bötzel & Schulze, 1996; Georgiou et al., 1993; Sarma et al., 2012). Although there has been no research, as yet, into the neurological effects of cueing on other motor activities, such as drooling, the concept of cue provision for this symptom as a behavioural management option has been studied. In a paper by Marks et al (Marks et al., 2001), the authors used a (now) commercially available device, in the form of a brooch, which emitted an auditory cue (a short ‘beep’) at regular intervals to remind the wearer to swallow. They found this process of cueing for drooling yielded positive results for a small number of participants (6). Although the device was found to be effective in the control of drooling problems, their small sample size did not provide sufficient information around the effectiveness of the intervention on a wider population of PwP, nor did the authors discuss the acceptability of the technology they trialled with their participants. A further study by Marron et al. (Marron, Robinson, & Walker, 2004) showed that wearers of the same drooling brooch reported several aspects that reduced its acceptability. For example, hearing impaired participants could not use the device. The product used also incorporated a switch to turn the device on and off, yet some users needed assistance to operate this due to fine motor skill degeneration resulting from Parkinson’s.

As such, there was a need to develop a more appropriately designed cueing technology, and for a more thorough evaluation of the value that a technology of this kind might have for PwP experiencing drooling issues. The following section focuses on the development of the PDCue, a novel cueing technology designed with PwP using UCD methods. This approach allowed for the design of a device which was not only functional for PwP, but that also met some of the social and emotional needs of the user group, in terms of minimising stigma and embarrassment associated with drooling and medical technologies more generally.

4.2 The PDCue

The design of PDCue was conducted during a collaborative research project prior to the conduct of this PhD²¹, published at CHI 2011. However, in order to contextualise the PDCue and its role in the case study, a summary of this earlier design work is provided here. The PDCue design process aimed to overcome some of the identified design limitations with the ‘drooling brooch’ technology described by Marron et al. (Marron et al., 2004) through a structured UCD process. The project explored the design of a cueing device and, to address issues related to the device’s potential acceptability, involved working with PwP during the design process. The design process had two stages; first an exploratory scoping and design stage, and second a high fidelity iterative design process.

Twelve participants, 8 PwP and 4 caregivers, took part in the scoping stage of the study. The scoping stage was used to gather qualitative accounts from participants about everyday experiences related to their Parkinson’s and drooling, as well as uncovering specific issues that might affect accessibility and usability, such as hand tremors making small buttons difficult to operate. Analysis of the discussions from the scoping stage revealed several recurrent themes. The consensus in the opinions expressed throughout all of the groups led to a set of design requirements being formulated. The eventual design of the PDCue came in the form of a wrist-worn device. The PDCue functioned by providing a vibratory cue at frequent intervals (once per minute, determined by a Parkinson’s expert) to remind the wearer to swallow their saliva more frequently, with the hope that drooling would be subsequently reduced. Its features included; a casing to ensure it looked like a standard wrist watch, deemed important by participants in order to ensure discretion, as to not incite conversation about their drooling when wearing their cueing device; a Velcro strap to ensure ease of use, as participants reported difficulties using traditional watch straps; a single, easy to use button to switch the cues on and off and to change the intensity of the cues (by pressing and holding the button to access the settings and releasing when the desired setting—on, off, low, medium, high cueing intensity). This button did not require fine motor ability, an issue described by participants when trying to use buttons on other

²¹ McNaney, R., Lindsay, S., Ladha, K., et al. (2011). Cueing for drooling in Parkinson's disease. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 619-622). ACM. The hardware and software of the device were developed by Karim Ladha, Dan Jackson and Cas Ladha, who brought it through its multiple iterations and into its final state.

technologies; and a vibrating motor to provide a discreet, vibratory cue, deemed to be the most desirable cueing modality by participants.

Following the design phase, a PDCue prototype (figure 3a) was developed and deployed with 3 of the PwP who took part in the initial work, to explore the usability and acceptability of the device within the context of the participants' everyday lives. Participants trialled the device for 1 week and took part in an interview to discuss their experiences. The main themes to emerge from these interviews were around the 'bulkiness' and 'ugliness' of the device. The device was iterated (figure 3b) to reflect the participants' comments and deployed again, using the same study design. Interestingly, when the device became more discreet and aesthetically pleasing, participants experienced an increase in their perceived effectiveness of PDCue, despite the functionality of the device not changing between the iteration phases. This demonstrated the importance of having a desirable device that people wanted to interact with. This echoes findings by both Shinohara & Wobbrock (Shinohara & Wobbrock, 2011) and Parette & Scherer (Parette & Scherer, 2004), whose research describe issues surrounding assistive technologies and how these lead to feelings of stigma. Both describe social acceptability and device aesthetics as being key factors in making devices less stigmatising to users, who are often found to abandon technologies that they attribute negative feelings towards, regardless of functional benefit. This was also a finding in the design phase for this case study, where one participant described a 'feeling disabled' by her falls alarm, which she chose not to wear at home, even when alone²².

Some final insights from participants led to a further iteration of PDCue (figure 3c), to make it more compact and include a digital display, which made it look more like an everyday digital watch. This was the version of PDCue used in this case study.

The first section of this chapter has provided a summary of drooling, as a symptom of Parkinson's. It then went on to establish the need for the upcoming case study by discussing both the need for a well designed cueing technology that was usable and desirable to PwP, to support the management of drooling issues, and the need for wider evaluation of digital cueing for drooling. Finally, it described the iterative design of the PDCue device, which forms the technology of interest within this case study. The remainder of the chapter is

²² Shinohara & Wobbrock suggest that designing for mainstream devices, which have social acceptability at their core, could be a way to alleviate public misperceptions around how people with disabilities use assistive technologies. Indeed this was the thinking behind the next case study, which focused on Google Glass, a (mostly) socially well perceived novel technology that was seen to be the 'next big thing' in wearable computing.



Figure 3: The progression of the PDCue design. a) First design following the scoping stage (top left); b) second iteration that was preferred by participants (top right); c) final version used in the PDCue trial (bottom).

concerned with an evaluation of the PDCue device, as a means to support the self management of drooling. It describes a randomised clinical pilot trial involving 30 PwP. The following section describes the study design that was employed in this randomised control trial, including the recruitment of participants and the study specific methods that were used.

4.3 Study Design

The clinical trial described in the following section took approximately two years to complete and followed a mixed-methods approach, collecting both quantitative and qualitative data. Quantitative data were collected in the form of clinical assessment scores and self reported daily diary scores, which focused on numerical figures relating to frequency and severity ratings of drooling. Qualitative accounts around the experience of using the PDCue and its impact on drooling within the context of participants' everyday lives were also collected in the form of semi-structured interviews upon completion of the trial. The following section will discuss the ways in which participants were identified and recruited into the study. Following this the section describes the randomisation methods that were employed, and then details the study specific methods used in this case study.

4.3.1 Participants and Recruitment

The inclusion criteria of this study sought participants who had; 1) a diagnosis of Idiopathic Parkinson's, as identified by a neurology consultant, or consultant with a special interest in Parkinson's, in accordance with the UK Parkinson's Brain Bank criteria (Daniel & Lees, 1993), 2) an acknowledged drooling problem, either observed by a clinical professional within a Parkinson's clinic or through self report from the patient themselves and 3) achieved a Mini Mental State Exam (MMSE) score of 24 or above (Hoops et al., 2009), identified by the researcher upon initial contact with the patient. The MMSE is discussed in detail in section 4.4.2.

Participants were primarily recruited via the regular Parkinson's clinics at Northumbria Healthcare NHS Foundation Trust (NHCFT) and several other Participant Identification Centres (PIC)²³ in Sunderland, Gateshead and Newcastle upon Tyne NHS Foundation Trusts. A total of 58 participants were identified for potential inclusion into the study. Following initial contact via telephone, and in several cases an initial visit from the researcher, 20 participants chose not to join the research, citing reasons around not feeling their drooling was severe enough to participate or not having enough time to commit to a research project. A total of 38 participants gave their consent to take part in the study. In an attempt to ensure that drooling did not simply improve by increasing knowledge around its cause and treatment options, once consented participants were randomized into either a control group or an intervention group. The randomization protocol was pre-determined using an online random number generator²⁴. As such, participants were randomized according to their participant number in the study. To avoid having to re-generate the randomisation, if a participant happened to leave the study their group assignment was added to the end of the list.

²³ PIC sites are governed by the National Institute of Health Research (NIHR) and are part of the Clinical Research Network (CRN). They are sites which identify and refer participants to another centre, specifically for research.

²⁴ www.randomizer.org

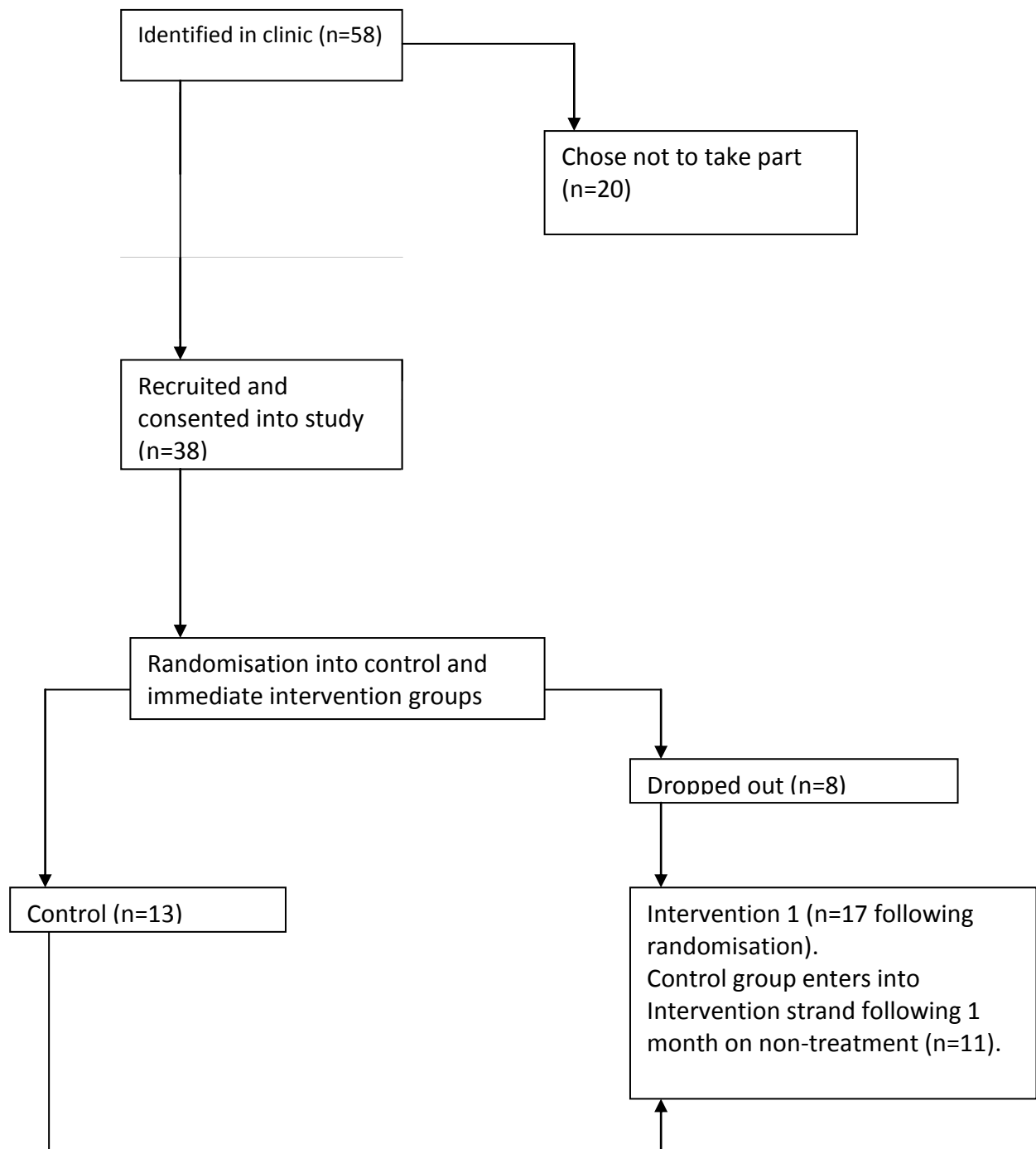


Figure 4: Flow of Participants through the study

All participants were given the opportunity to trial the PDCue device for 1 month. However, the subset of participants (n=13, 5 female), who were randomised into the control group, were delayed in receiving the device for a 1 month period (to represent the time period the treatment group were using the PDCue). These control participants provided pre and post 'no treatment' baseline assessments. Twenty-eight participants overall completed the entire trial of PDCue (10 female, 18 males) with a further 2 providing 'no treatment'

baseline measures only and then choosing not to take part in the study itself (with one participant feeling not well enough to take part and the other feeling unable to give the time commitment). Of the other 8 treatment participants who completely dropped out of the study, 4 stated reasons of ill health, 3 felt that the study was too much for them to manage at the time and 1 did not give a reason. A diagram of the flow of participants through the study can be viewed in figure 4.

4.3.2 Study Methods

This study employed a stepped wedge trial design, which is described by Brown and Lilford (Brown & Lilford, 2006) as being a study design in which an intervention is rolled-out sequentially over a number of time periods, using random allocation to ensure that by the end of the study all individuals or groups have received the intervention being studied. Brown and Lilford (Brown & Lilford, 2006) explain how this study design can be used in projects where, for logistical, practical or financial reasons, it is not possible to provide an intervention simultaneously to all participants. As the PDCue trial only had 5 available devices at any one time, and there was only one researcher (RM) conducting the fieldwork, this study design was deemed appropriate. Every visit with a participant was conducted in their home. A maximum of 12 visits per participant were carried out (2 for baseline assessment of the control group, 2 for baseline assessment pre-treatment, once per week during the 4 week treatment period, 2 for baseline assessment post-treatment and 2 for baseline assessment at follow up; see figure 5 for a visualization of this information). A full discussion of the baseline assessments that were conducted is described in section 4.4.

Participants were assessed for one week prior to conducting the PDCue intervention. In this time they completed the patient rated assessments and filled out a drooling frequency and severity diary for the week (see section 4.4.1 for details). Participants were also assessed using a range of clinician rated assessments (see section 4.4.2 for details). For the control group, participants completed the exact same procedures but then did not move on to complete the intervention phase until one month of no intervention had passed. The

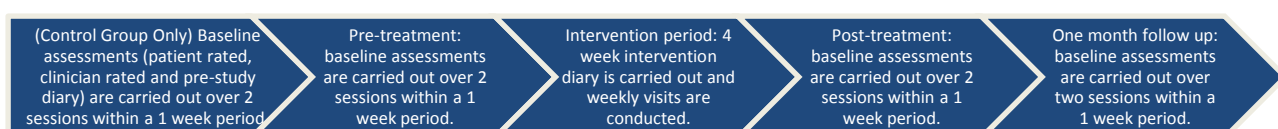


Figure 5: Home visiting schedule

participants who were in the immediate intervention group used the cueing device for 4 weeks, during which time they filled out a daily diary comparing their drooling frequency and severity over the course of one hour when wearing the device and one hour when not wearing it. Following the intervention period the participants were assessed again (in the same manner as the pre-treatment week) and a face to face semi-structured interview (described in section 4.4.3) was conducted in their homes, to gather their experiences of using the technology and initial perception around its effectiveness as a self management option for drooling. One month later, participants were assessed again (using the same protocol) to investigate if any treatment benefits may have been maintained.

4.4 Baseline Assessments

This section provides an overview of the baseline assessments that were carried out and the rationale behind their choice. Several of the assessments conducted were used for screening purposes and information gathering about each participant, in order to profile their symptoms. Participant rated assessments (see appendix 1c) are carried out by the participants themselves, and did not require input from the researcher. With the exception of the diary (see appendix 1e), which was carried out daily, the other self rated assessments were given to participants, in paper format, to complete at their leisure (in the week before, the week immediately after and at one month following the intervention period). This was done to ensure participants were not overburdened during the assessment sessions with the researcher and to allow for focus during these sessions to remain on the clinician rated assessments (see appendix 1d), which required the researcher's presence.

4.4.1 Patient Rated Assessments

The Drooling frequency and severity diary was collected every day for the full 6 weeks of the study (pre week, 4 week intervention and post week) as well as for 1 week at the follow up phase that was carried out 4 weeks following use of the device. The control group completed an additional week of diary entries prior to their month of 'no treatment'. Diaries were generally filled out by the carer so that a covert measure of drooling could be obtained, however, where this was not possible, it was recorded by the participant themselves to monitor how often they felt drooling had happened and how bad they felt it was (7 participants lived alone and 2 participants had spouses who worked during the day). The

person filling out the diary was asked to monitor drooling over the course of an hour of their choice per day. During the intervention period 2 separate hours were monitored per day; one where the person was wearing the device and one where they were not. For the diary, participants were required to fill out the date, the time the observation occurred, indicate the number of separate times they saw drooling occurring, indicate how long they felt drooling was occurring for and place a cross on a 10cm line indicating how severe they felt the drooling was at that time, with 0 being 'no problem' and 10 being 'as bad as can be'. This diary was included as a means for quantifying how frequent and severe drooling was during a brief time frame of a participant's day. It imitates the standardised methods of monitoring using paper diaries currently being used in the medical community (e.g. Edwards et al., 1991; Montgomery & Reynolds, 1990). Compliance levels for filling out the drooling diaries varied. Out of a possible 6,699 diary entries there were a total of 5,069 (76%) entries provided. In order to attempt to alleviate this issue a median score was used for each weekly interval (one week pre treatment, 4 weeks of treatment, 1 week post treatment and 1 week of diary entries at 1 month follow up). It was these median scores, per participant per week, that statistical analysis was carried out on.

All of the following described patient (and clinician rated in section 4.4.2 which comes next) assessments were conducted pre and post intervention, and at the 1 month follow up appointment, as well as the additional baselines collected for the control group prior to their period of no intervention. The Parkinson's Disease Questionnaire (PDQ-39) was developed through in-depth interviews with PwP to produce questions that ask specifically about the influence of Parkinson's on different aspects of life. Questions around aspects such as mobility, activities of daily living, emotional wellbeing, stigma, social support, cognition, communication and bodily discomfort are rated by the patient on a 5 point scale from (0) *never* to (4) *always* (Peto, Jenkinson, Fitzpatrick, & Greenhall, 1995). This test was included as it provides a patient-based measure for the impact of Parkinson's. The items of wellbeing, stigma and communication were observed for change post intervention due to the previously described potential impact that drooling can have on these areas.

In addition, the Radboud Oral Motor Inventory for Parkinson's Disease (ROMP) was conducted. The test is a patient rated assessment of speech, swallowing and saliva control in Parkinson's and aims to measure patient perceived impact of these problems on everyday functioning and social interaction. In accordance with the International Classification of

Functioning, Disability and Health (WHO, 2003), the questionnaire targets symptoms at the levels of functioning and activities, as well as their impact on participation in daily life (Kalf et al., 2011). For the purposes of the study the ROMP-Saliva subset of questions was used. This test was included to give an indication of the impact that drooling had on the person's life.

4.4.2 Clinician Rated Assessments

This section discusses the clinician rated assessments that were carried out. Clinician rated assessments were all carried out by the PhD researcher, who had prior experience of clinical testing²⁵. On the first visit, prior to the conduct of these assessments, the researcher also collected a range of demographic and case history information. This included participants' age, gender and living situation, as well as the number of years since participants had been diagnosed with Parkinson's, their starting perception of their drooling problems (mild, moderate or severe), the number of months that they had been experiencing drooling for, whether or not they had sought prior treatment for drooling and whether or not there was a history of swallowing dysfunction.

The Unified Parkinson's Disease Rating Scale (UPDRS) (Goetz et al., 2008) was used to provide a clinical profile of the individual and their Parkinson's symptoms. This assessment is considered the gold standard test used in the monitoring of Parkinson's and covers structured discussion and subsequent clinician rating around motor and non-motor experiences of daily living, and motor complications, as well as a motor examination performed by the clinician. A series of questions pertaining to the symptoms of Parkinson's are asked within each domain and are rated by the clinician on a structured numerical scale from 0-4. A score of (0) refers to a "normal" rating, i.e. no impairment; (1) refers to "slight", symptoms/signs with sufficiently low frequency or intensity to cause no impact on function; (2) refers to "mild", symptoms/signs of frequency or intensity sufficient to cause a modest impact on function; (3) refers to "moderate", symptoms/signs sufficiently frequent or intense to impact considerably, but not prevent, function; (4) refers to "severe" symptoms/signs that prevent function. Each domain is then given a combined score to allow for comparison across time. If required, specific questions can be pulled out for closer analysis and comparison.

²⁵ The researcher trained clinically as an SLT prior to beginning the PhD.

In addition, the Modified Hoehn and Yahr scale (Hoehn & Yahr, 1967) was included to provide another, clinically recognised, descriptive tool to help profile participants. This scale also assesses the severity of Parkinson's and is graded into 5 stages that refer to the 'extent of disability'. Stage I refers to patients with unilateral involvement only (i.e. with motor symptoms only presenting on one side of the body), usually with minimal or no functional impairment. Stage II refers to patients presenting with symptoms on both sides but without an impairment of balance. Stage III involves patients showing the first signs of impaired 'righting reflexes', shown by unsteadiness as the patient turns, or demonstrated when they are pulled from behind, from standing, with the feet together, also referred to as the 'pull test'. Functionally participants in stage III are seen to be somewhat restricted in their activities but are physically capable of leading independent lives, and their disability is considered to be mild to moderate. Stage IV refers to a fully developed, severely disabling condition, where the patient is still able to walk and stand unassisted but is markedly incapacitated. Finally, Stage V refers to patients who are confined to a bed or wheelchair unless aided. The first two assessments described focused on profiling the participant's Parkinson's in terms of its functional impact on daily living. This was important for providing descriptive information about the participants who took part in the study, as it was a possibility that the stage of their condition could be correlated with the uptake of the technology into their lives. The next set of assessments were concerned with obtaining an indication of the participants' cognitive state, with significant cognitive impairment being an exclusion criteria for the study.

The Mini Mental State Exam (MMSE) (Hoops et al., 2009) is a test of cognitive functioning and a screen for cognitive impairment. A MMSE score of below 24 indicates that the patient has significant cognitive impairment. A score indicating significant cognitive impairment could suggest that the participant would be unable to follow the complex instructions presented in the study protocol pertaining to filling out diary entries and using the PDCue, as well as remembering to swallow when a cue is provided. The Montreal Cognitive Assessment Tool (MoCA) was also included, as it is deemed more sensitive than the MMSE in identifying mild cognitive impairment in a general population. Additionally, findings have shown the MoCA to be more appropriate for assessing cognitive impairment in PwP (Hoops et al., 2009) and it is quickly being included within the assessment protocols of published Parkinson's research (e.g. (Kotagal et al., 2012; Melzer et al., 2011)). A MoCA score

of < 26 indicates that the patient has a cognitive impairment²⁶. Like the MMSE, a score indicating cognitive impairment could signify that the patient may be unable to follow the complex instructions presented in the study protocol. The MMSE was chosen for the inclusion criteria over the MOCA due to its wide recognition across the medical community and widespread use in previous studies. The MOCA was still included as a method of assessment to allow for specific, descriptive information around potential, discreet areas of cognitive issue, which might be otherwise missed from the MMSE ratings. Unlike the MMSE, it assesses executive function, which is commonly impaired in Parkinson's.

The previous sections have described the baseline measures that were carried out throughout the PDCue study. These measures allowed for a profile of both the participant cohort, as a whole, and the individual participants to be developed, as well as providing comparative data points against which change might be observed. The following section describes the final form of data collected during the study, the qualitative interviews conducted upon exit from the study.

4.4.3 Exit Interview

Interviews were conducted with each individual once they had completed one month of using the PDCue to self manage their drooling, to gather qualitative feedback on the participants' experiences. A semi-structured approach was taken to probe; a) participants' experiences of drooling before taking part in the study; b) participants' experiences of drooling after taking part in the study; and c) participant' perceptions around the effectiveness of the PDCue as a way to self manage their drooling problems. Qualitative data collected during the exit interviews were audio recorded and transcribed. Transcriptions were then subjected to an inductive thematic analysis (described fully in chapter 3, section 3.3).

Having explained the study design and the range of baseline measures that were collected, the following section discusses the quantitative and qualitative analysis of the data that were collected during the study.

²⁶ <http://www.mocatest.org/normative-data/>

4.5 Data Processing and Analysis

4.5.1 Quantitative Analysis

All quantitative data were analysed using the SPSS (IBM) statistical software suite and were treated as categorical, or grouped, data given that the analyses were carried out on the control and intervention groups. Within group analysis was conducted to allow for comparison. For each of the groups the pre and post intervention, or in the case of the control group, non-intervention scores, were subjected to within group comparative statistical analysis. This was to test two research questions; 1) that statistically significant change would be observed between the pre intervention and post intervention time points; and 2) that statistically significant change would not be observed between the pre no-intervention and post no-intervention time points. In addition, the post intervention and follow up scores were analysed for the intervention strand, to uncover whether or not the intervention would cause an extended effect beyond the treatment time.

The control group (n=13) were analysed as a discrete data set, to explore whether participants would simply improve due to being orientated to their drooling through focused discussion with the researcher and carrying out the monitoring (diary) process. The intervention group (n=17), i.e. the group of participants who immediately went into using the PDCue, were analysed to explore whether or not the use of the device had an effect on their drooling. In addition, the entire intervention group (n=28), were explored to look at whether or not the results of the study were applicable to the entire group of participants who underwent the intervention, regardless of their initial randomization. This allowed the researcher to investigate if the findings applied to a larger group of test subjects.

Descriptive statistics were used to test each of the data sets individually for normality distribution, to determine the type of statistical testing that would be used. The Shapiro-Wilks test, which is considered the most powerful normality test (Razali & Wah, 2011), was used to test whether or not the population within each data set was normally distributed. If it was found to be normally distributed data then parametric testing (*t-test*, ANOVA) was conducted, to examine whether the results were significant between the different time points (pre intervention (or no intervention), post intervention (or no intervention), follow up). If the data were found to be abnormally distributed then nonparametric testing (Wilcoxon test, Friedman test) was conducted. For the diary entries, drooling severity and

frequency (separate incidents as well as time drooling occurred for) were individually analysed pre and post treatment and at one month follow up.

In addition, a critical element in the data analysis, due to the small sample sizes of the groups, was to look at the profiles of the participant groups to determine whether or not their individual differences might have skewed results due to the randomization process (Suresh, Thomas, & Suresh, 2011). The individual demographic and case history information for each participant in the control (n=13) and intervention (n=17) groups were collated and subjected to between group statistical testing, to examine how evenly matched the groups were. A summary of the research questions that were tested during the data analysis is provided below:

1. Are the demographics and case histories of participants in the intervention and control groups different?
2. Will participants receiving no intervention show an improvement following one month of no treatment, compared to the period of time before beginning no treatment?
3. Will participants receiving the cueing intervention show an improvement after the treatment time, compared to the period of time before treatment?
4. If a treatment effect is observed, will participants receiving the cueing intervention show a maintenance of treatment effect at one month follow up, compared to the period of time before treatment?

This section has focused on the methods that were employed when analysing the quantitative study data. A description of the statistical approach that was applied to the data has been provided, as well as an outline of the research questions that were to be explored. The following section reports on the results of these analyses, relative to each of these research questions.

4.5.2 Quantitative Findings

4.5.2.1 Research Question 1

The first research question was: *are the demographics and case histories of participants in the intervention and control groups different?* There were several pieces of demographic and case history information that were collected during the initial visit with participants.

	Control (n=13)	Intervention (n=17)	p
Demographics			
Mean age in years (min, max, SD)	68 (42-81, 12.35)	71 (50-84, 8.34)	0.62
No. of females (%)	5 (38%)	7 (41%)	0.88
No. of participants living alone (%)	2 (15%)	4 (24%)	0.67
Mean stage of Parkinson's (min, Max, SD)			
- UPDRS score	75 (24-142, 35.94)	67 (28-105, 18.95)	0.29
- Hoehn & Yahr score	3 (2-4, 0.70)	3 (2-4, 0.72)	0.15
Case History			
Mean no. years since Parkinson's diagnosis (min, max SD)	7 (1-23, 6.60)	7 (1-23, 5.10)	0.79
Initial perception of drooling severity, as reported by the participant (no.)	Mild (7)	Mild (7)	0.76
	Moderate (4)	Moderate (6)	
	Severe (2)	Severe (4)	
Mean no. months since drooling first noticed (min, max, SD)	23 (5-108, 29.20)	25 (1-66, 18.74)	0.69
No. of participants with previous drooling treatment (%)	2 (15%)	7 (47%)	0.13
No. of participants with reported swallowing problems (%)	7 (85%)	8 (53%)	0.71

Table 1: Comparison of demographic data and case histories for control and intervention groups

Demographic data related to age, gender living situation and stage of Parkinson's. Case history information was also included. Both the control and intervention groups were compared. Mann Whitney tests were carried out on age, years since Parkinson's diagnosis and number of months experiencing drooling. All other data were subjected to CHI square testing. A summary of findings can be viewed in table 1, where P values are reported.

The analysis showed no statistically significant differences between the control and intervention groups in any of the demographic and case history data collected (where $p < 0.05$). Therefore, the control and intervention groups were well matched and any changes that might be observed in the upcoming analysis of the trial data are likely to be due to an effect of the interventions and not influenced by individual differences in the participant samples. Although not a significant difference, there were a much larger percentage of participants who had received prior treatment for their drooling in the intervention group (47%) compared to the control group (15%). The possible implications for which are discussed in section 4.6.1.

Assessment	Control group (n=13)		Significance of difference (Wilcoxon test)
	Pre	Post	
PDQ-39			
Wellbeing (mean, SD)	28.4 (SD 19.68)	23.9 (SD 13.85)	0.33
Stigma	30.0 (SD 26.89)	21.9 (SD 17.22)	0.52
Communication	35.4 (SD 21.94)	43.4 (SD 24.99)	0.55
ROMP- Saliva			
Overall score	20.2 (SD 4.07)	21.1 (SD 6.52)	0.54
Drooling Diary			
Severity	1.9 (SD 1.81)	2.5 (SD 2.02)	0.42
Frequency (No. minutes drooling occurred in one hour)	3.1 (SD 4.44)	3.5 (SD 4.03)	0.79
Frequency (No. instances in one hour)	2.3 (SD 3.36)	3.4 (SD 3.14)	0.05

Table 2: Assessment and Diary results for control group, pre and post period of no treatment

4.5.2.2 Research Question 2

The second research question was: *will participants receiving no intervention show an improvement following one month of no treatment, compared to the period of time before beginning no treatment?* The control group were given the same assessments (described in section 4.4) as the intervention group. Baseline data were collected at the point that participants were recruited into the study, and repeated one month later after a period of no intervention. A within group statistical analysis was carried out on these baseline data to investigate whether an improvement in baseline scores would be observed between the two data collection points (pre and post no intervention). The results for the control group can be viewed in Table 2. Tests for normality distribution (Shapiro-Wilk) showed the data to be non-normally distributed, thus nonparametric related sample testing (Wilcoxon) was carried out on each of the baseline analyses.

The first assessment to be examined was the PDQ-39 (subtests for wellbeing, stigma and communication). None of these subtests revealed a statistically significant difference between pre and post no intervention scores (when $p < 0.05$). It can therefore be observed that participants did not improve or worsen on the PDQ-39 baseline after a period of no treatment. The profile of the other baseline assessments collected for the control group is similar. The ROMP-saliva assessment also did not show a significantly different change

between pre (mean (M)= 20.2, Standard Deviation (SD) = 4.07) and post (M= 21.2, SD= 6.52) no intervention scores ($p= 0.538$, with $p>0.005$).

The drooling diary entries pre and post no intervention within the categories of drooling severity (pre M= 1.9, SD= 1.81; post M= 2.5, SD= 2.02) and frequency of drooling in minutes (pre M= 3.2, SD= 4.44; post M= 3.5, SD= 4.03) did not reach statistical significance, indicating that control participants did not improve from initial baseline on these measures. The category of drooling frequency relating to the number of instances that drooling occurred in one hour did reach significance ($p= 0.049$, with $p< 0.05$) however, it was the case that drooling frequency increased between the time points of pre (M= 2.3, SD= 3.36) and post (M= 3.4, SD= 3.14) intervention. As such, it can be observed that drooling did not improve within the periods of pre and post no intervention.

4.5.2.3 Research Question 3

The third research question asked: *will participants receiving the cueing intervention show an improvement after the treatment time, compared to the period of time before treatment?*

This next stage of analysis looked at the intervention group who received the PDCue treatment for one month. In this case, the baseline measures were collected immediately prior to beginning intervention (pre), immediately after finishing the intervention (post) and at one month following the end of the intervention period (follow up). The analyses conducted on this data were twofold; firstly an analysis was conducted on the immediate intervention group; secondly an analysis was conducted on the entire group of participants who received the PDCue treatment, including 11 of the original control participants. A summary of the data can be viewed in table 3 for the immediate intervention group and table 4 for the entire intervention group.

Within group differences of pre and post intervention scores were explored first. Again, the data were found to be non-normally distributed, so nonparametric (Wilcoxon) testing was applied to the data. No significant difference was observed in either the immediate or the entire intervention groups in the PDQ-39 subtests, or the ROMP-Saliva. However, there were significant changes when the analyses were conducted on the drooling diaries. Within the category of drooling severity, testing showed a highly statistically significant difference between the time points of pre and post treatment in the immediate intervention (pre M= 4.4, SD= 2.45; post M= 1.2, SD= 1.25; $p= <0.01$) and a significant

Assessment	Intervention group (n=17)		Significance of difference
	Pre	Post	(Wilcoxon test)
PDQ-39			
Wellbeing (mean, SD)	38.5 (SD 28.29)	33.1 (SD 24.25)	0.09
Stigma	29.4 (SD 27.36)	25.0 (SD 22.29)	0.83
Communication	35.4 (SD 19.27)	43.8 (SD 30.62)	0.67
ROMP- Saliva	21.2 (SD 5.54)	22.6 (SD 5.84)	0.07
Drooling Diary			
Severity	4.4 (SD 2.43)	1.2 (SD 1.25)	<0.01
Frequency (No. minutes drooling occurred in one hour)	15.0 (SD 16.48)	12.25 (SD 23.58)	0.11
Frequency (No. instances in one hour)	8.6 (SD 9.71)	3.2 (SD 3.70)	0.01

Table 3: Assessment and Diary results for Intervention group (n=17), pre and post treatment. Please note that lower scores indicate a lowered perceived severity or impact of symptom.

Assessment	Entire group (n=28)		Significance of difference
	Pre	Post	(Wilcoxon test)
PDQ-39			
Wellbeing (mean, SD)	31.6 (SD 23.4)	27.4 (SD 21.94)	0.35
Stigma	26.0 (SD 23.81)	22.2 (SD 19.98)	0.60
Communication	35.6 (SD 24.20)	35.4 (SD 21.94)	0.68
ROMP- Saliva	20.7 (SD 5.85)	20.8 (SD 6.13)	0.74
Drooling Diary			
Severity	3.2 (SD 2.34)	1.3 (SD 1.57)	0.04
Frequency (No. minutes drooling occurred in one hour)	8.1 (SD 11.07)	5.2 (SD 11.91)	<0.01
Frequency (No. instances in one hour)	4.4 (SD 5.73)	1.9 (SD 2.31)	<0.01

Table 4: Assessment and diary results for the entire intervention group (n=28), pre and post treatment. Please note that lower scores indicate a lowered perceived severity or impact of symptom.

difference in the entire group (pre M= 3.2, SD= 2.34; post M= 1.3, SD= 1.57; $p= 0.04$). Similarly, in the drooling frequency category, relating to the number of instances that drooling was observed in one hour, testing showed a statistically significant difference between the time points of pre and post treatment in both the immediate intervention (preM= 8.6, SD= 9.71; postM= 3.2, SD= 3.70; $p= 0.01$) and a highly statistically significant change in the entire group (preM= 4.4, SD= 5.73; postM= 1.9, SD= 2.31; $p= <0.01$). In addition, while the category of frequency of drooling per minute did not reach significance for the immediate intervention group ($p= 0.105$), it was found to be highly significant within the entire intervention group (preM= 8.1, SD= 11.07; postM= 5.2, SD= 11.91; $p= <0.01$). As such, it can be observed that the PDCue intervention showed significant improvements in drooling severity and frequency during the treatment time, when compared to the period of time before treatment.

There are several possible reasons why there were no significant results observed on the standardised PDQ-39 and ROMP-Saliva assessments (which can be viewed in appendix 1c). Firstly, the PDQ-39 subtests were looking at wellbeing, stigma and communication relative to the entirety of the lived experience of Parkinson's and thus may have lacked sensitivity in relation to the specific symptom of drooling. Unless drooling was the major contributing factor, aside from all other symptoms, that was causing a reduction in wellbeing, stigma associations or difficulties in communication, it is unlikely that change would be observed in this type of overarching scale. The ROMP-Saliva on the other hand is specifically related to drooling, so a change in this scale was expected. However, the 9 item scale measured a mixture of physiological (6 questions) and psychological (3 questions) components of drooling and used a 5 point Likert scale approach to capture the different elements of the symptom. It is possible that this scale simply lacked sensitivity in capturing the small improvements that proved impactful on the lives of participants. There was, as has been seen, a noted decrease in (physiological) drooling severity and frequency as captured by the diaries and, as will be seen in the qualitative analysis outlined in section 4.5.3, participants reported significant (psychological) improvements around feelings of confidence and control. This calls into question the reliability of these 'one size fits all' outcome measures and their ability to capture meaningful outcomes relative to people's experiences.

4.5.2.4 Research Question 4

The final research question explored: *If a treatment effect is observed, will participants receiving the cueing intervention show a maintenance of treatment effect at one month follow up, compared to the period of time before treatment?*

Of the 28 participants who completed the intervention, 24 completed follow up assessments. Of the other 4 two participants decided to move on to Botox treatment shortly after the trial, 1 participant experienced a significant health decline and the final participant had moved abroad. As previously discussed (4.4.1), there were compliance issues relating to the diary entries and this was observed even more so during the follow up period. Only 11 participants completed all 3 categories relating to drooling severity and frequency (both number of minutes drooling occurred for and the separate instances that it was observed over one hour). Two participants did not complete any of the categories, while a further 11 only completed the severity rating. Because of this, the data for drooling frequency was discounted, being deemed too incomplete for an appropriate comparative analysis between the time points of post intervention and follow up. The drooling severity score was, however, subjected to analysis on the 22 participants who completed the rating. For the entire intervention group (n=28) there was a very slight decrease in mean severity over the two time points (post M= 1.3, SD= 1.57; fu M=1.1, SD=1.53). As such, it can be viewed that a maintenance in treatment effect for drooling severity was observed at one month follow up, with severity being similarly scored at follow up as they were post intervention. This is also further explored later in the chapter within the qualitative data (section 4.5.4.6).

4.4.2.5 Summary of Quantitative analysis

This section has described the findings from the quantitative analyses that were conducted on the data. The research questions have been examined and, in each case, evidence has been provided that the cueing treatment was an effective intervention for the PwP that took part in the study. These findings will be discussed in more detail in section 4.6. However, while important, the aim of this case study was not only to trial the effectiveness of the cueing intervention but to also understand the ways in which the PDCue might support the daily practices of PwP in the self management of drooling. These were explored in more depth in the qualitative components of the study. The following section will discuss the qualitative analysis methods, before moving on to present the qualitative findings.

4.5.3 Qualitative Analysis

In total, there were 27 end of trial interviews carried out with participants. One participant was unable to complete the final interview due to health issues. Interviews lasted an average of 17:03 minutes (shortest 6:29-longest 36:37). Each interview was audio recorded during the session and then transcribed verbatim for analysis (using the methods outlined in chapter 3, section 3. 3). The following section discusses the findings of the qualitative analysis. It first begins with a contextualisation of the participants; their experiences of drooling prior to the cueing treatment and previous experiences of drooling treatments and their challenges. It then moves on to discuss the effect that the cueing intervention had on participants' lives over the course of the study. Insights into the role of the PDCue technology in supporting self management of drooling—drawn across the entire qualitative and quantitative analysis—and what these insights add to an overall understanding of self management of Parkinson's, are explored in the final 'discussions' section (4.6), through a synthesis and interpretation of the overall findings.

4.5.4 Qualitative Findings

There were a total of 26 codes applied to the data. A total of 312 extracts of transcript were assigned these codes (ranging from 1 to 22 extracts per code). A total of 6 themes were constructed; the impact of drooling on the lives of the participants who took part in the study; challenges around previous experiences of drooling treatment; effect of the PDCue on drooling; emotional benefits which arose as a result of the PDCue intervention; negative effects associated with the intervention; and generalisation and habituation. These are described in detail in the follow sections.

4.5.4.1 Impact of Drooling on the Lives of PwP (Pre-Intervention)

Participants were explicitly asked to give an account of their drooling problem pre-intervention and the impact that it had on their lives. This line of questioning was used to situate the participant within the context of the interview and allow them to reflect on the change, if any, that the intervention might have caused.

By far the most discussed impact of drooling issues pre-treatment was embarrassment (13/27). For some participants it was the honesty of a grandchild that brought their drooling issues to the forefront (CS1P9 and CS1P10). For example, CS1P10

explained: *"You know how little kids are and "Oh Granddad's drooling!" It was embarrassing".* Others found ways around preventing their embarrassment when in public by covering their drooling up with a handkerchief (4/27). CS1P15 and CS1P9 described pretending to blow their nose when around friends: *"I just keep my hand there. They just think I'm blowing my nose or something like that"* (CS1P15), while CS1P13 explained how she would constantly wipe her face 'just in case' she was drooling, even though she recognized that she most likely was not: *"It's embarrassing, in fact I think you're sometimes dabbing around your face and there's probably nothing there. You just feel you want to look your best and be your best"*. However, CS1P9 discussed the fact that it was the appearance of his drooling problem that actually prompted him to tell his friends about his Parkinson's. He felt there was a stigma around Parkinson's and wanted to avoid people discussing him:

"That's when I started telling to lads, you know. And nobody knew that I had it, and I didn't want them to know that I had it (Parkinson's)....it was a stigma then...But with me slaverling (drooling) a lot, which was terrible, well I thought maybe, you know, it goes round the club "have you seen CS1P9?, what's wrong with CS1P9?" so I thought I'd tell people".

For two participants (CS1P22 and CS1P14) the impact that the drooling problem had on their lives was much more severe. CS1P14 discussed the emotional distress he experienced due to embarrassment over his drooling: *"It really dominated my life...it was most distressing, psychologically distressing...it clearly ruled my thinking...in that I was always clasping this grubby handkerchief just in case"*, while CS1P22 explained how her issues caused her to socially withdraw, *"At least once a day it would happen. I was out with company and it made me feel very embarrassed. I tend to withdraw, avoid going out really. Eat on my own. I am pretty strict about manners, and I thought it looked horrible"*.

CS1P22 was not the only participant to discuss eating as a trigger for drooling (6/27) and, hence, embarrassment to occur. CS1P24 and CS1P19 both discussed discomfort around drooling onto their plate or food in public and how this could cause unease in the people around them: *"...if it flows out, for other people to see it, and for it to go onto your plate or tablecloth. So that gives you an uneasy feeling, that you're affecting other people when you shouldn't"* (CS1P24). Putting aside the emotional discomfort around drooling issues, for some participants (4/27) there was a discussion around the physical discomfort that they

experienced—the constant wetness and changing of handkerchiefs—which for CS1P9 caused painful sores around his mouth.

There were several participants who also reported that their drooling was less severe than a spouse found it to be (3/27). The interviews gave several opportunities for spouses to give their opinions of their loved one's drooling problems, and these did not always align with the participants' perceptions. For example, CS1P5's wife explained: *"erm, I think it happens more than you think...you're doing things sometimes that you're not aware of and you think "no that's not a problem", but you haven't realized how often an onlooker sees it more"*. There was also a stage where CS1P1 became upset at her husband's description of her problems when in public, using words like 'annoying' and 'embarrassing' in his account:

"It was a bit annoying the other day, we went out to the shops and went to Boots...you were drooling there and that was difficult because it was going onto the floor which is difficult because you couldn't do much about it. Whether you felt embarrassed about it I don't know?" (CSP1's husband)

4.5.4.2 Challenges Surrounding Previous Experiences of Drooling Treatment

Several of the participants discussed their experiences of having previous treatment for their drooling issues (6/27). Participants discussed previous use of medication to treat their drooling, with little success. For CS1P30 *"they seemed to work alright at first and then they sort of stopped working"* while for CS1P12 *"they weren't working"*.

A couple of participants (3/27) had previous experience of Botox, which is injected into the salivary glands; CS1P12 found the experience unpleasant and did not see a change: *"I think it was a bit drastic, I didn't enjoy having them done...but it didn't do anything"* whereas for P29 *"it was fine but it didn't last a length of time, you know, the days I had between them...I was back to drooling badly"*. For CS1P9, who was receiving regular Botox but had paused his treatment to take part in the study, he felt that the Botox did work: *"when I started getting the Botox it did clear it up a little bit"*. Yet he also felt that that the PDCue was equally successful *"it's a hell of a lot better because I haven't wiped my mouth once since you've been here, you know"*. In fact this participant later said that he would use both options, Botox and the PDCue, in tandem to maximize his results.

For a lot of participants however (8/27), Botox was not an option they would have considered. These participants adamantly did not want to put more medication into their bodies; *“when I saw the consultant they said I could go and have Botulism, an injection. I didn’t want to take any more drugs”* (CS1P22). Botox was associated with words such as *“toxic”* (CS1P25) and *“poison”* (CS1P26) and there was a clear preference for avoiding it, and other additional medication, if possible; *“I think if you can have something that avoids taking drugs I think that’s great”* (CS1P4). These participants, unsurprisingly, preferred the PDCue as a behavioural treatment option; *“I’d rather have the watch”* (CS1P7).

4.5.4.3 Effect of the PDCue on Drooling

Of the 27 interviewed participants, there was a reported positive effect for 22, indicating that the majority of participants successfully engaged with the intervention and found it to be a worthwhile option for supporting the self management of drooling. Many of the participants discussed the direct impact wearing the device had on their swallowing behaviours, noting that it encouraged them to swallow more often: *“when I wore the watch it reminded me to swallow”* (CS1P7). CS1P17 explained: *“I liked the buzzing because it encouraged us to swallow...I never drool much now”*. One participant even associated the cueing intervention to operant conditioning; CS1P10 *“a bit like Pavlov’s dog”*. It was not only the participants themselves who were noticing a difference. CS1P3 explained *“my daughter noticed”* and CS1P23’s husband said *“I think it’s a lot better...I’ve noticed how infrequently she does drool”*. Considering that, as discussed in section 4.5.4.1, there was an observation around a misalignment of participant’s perception of their drooling and the severity of drooling reported by loved ones. There is a question around whether or not some participants were fully aware of their drooling pre-treatment.

There were a couple of participants who provided discussion around specific situations to explain how much better they noticed their drooling to be. For CS1P18, it was a holiday *“I realised I hadn’t been doing it as much on holiday”*, where for CS1P25 it was a New Year’s Eve party, which he spoke about with excitement, *“New Year’s Eve I went to a party and I normally stay until about 9pm, I stayed until 10, half past 10...that’s when I started drooling again”*. While this small amount of added time might not seem like much, CS1P25 had extremely severe drooling and speech issues and felt a great amount of embarrassment and self confidence issues around these; therefore this was seen to be a triumph by him,

which he talked about with enthusiasm. Similarly, other participants discussed specific contexts that their drooling had improved in, and the impact this had on their lives. For some, it was around meal times and their eating, which, as previously discussed, was a significant challenge for some of the participants. CS1P22 discussed how her improved drooling had enhanced her confidence around eating in public: *“Much better, more confident about going out. I have a cup of tea with people and that sort of thing, and a biscuit.”* CS1P10 when asked about whether or not he had felt the device made a difference said: *“Yes, to the extent that I took [wife] out for a meal on Tuesday night, to the restaurant we used to go to. I managed to get through the meal without making too much of a mess”*. He continued: *“I would say there was a definite improvement, I could see an improvement. It wasn’t perfect but it had come down”*.

For these participants, the integration of the PDCue into certain social practices allowed them to carry out activities that they would have otherwise avoided. But it was not only a social impact that was observed, participants also reported emotional benefits from wearing the device, leading to improvements in their self confidence and levels of self esteem, linked to gaining back some control over their lives.

4.5.4.4 Emotional Benefits

Four of the participants explicitly discussed some of the emotional benefits achieved during the study. For CS1P22 and CS1P4 it was gaining back a feeling of ‘control’ through the process of building an understanding of their drooling and how they could self manage it. CS1P22 explained:

“As I became more confident at doing things I got a greater understanding of it [drooling] and myself. How my mouth and saliva were actually working. I became the one in control. Not always, but mostly. That was a lovely feeling” (CS1P22).

CS1P10 discussed a feeling of control that extended beyond the times that he was wearing the device: *“I experienced, over the course of the trial, more control coming and that included the times I wasn’t wearing the watch”*. CS1P22 also talked about the impact that the intervention had on her confidence and self esteem *“it’s helped a lot. My self esteem as well...I avoided going out into crowded places, restaurants and cafes were no-no’s. Now I*

would be nervous at first but I would go out and eat. I'm not going to let it stop me". Equally, CS1P20 stated feeling *"much better, much more confident"*. But it was not only drooling problems that the PDCue had helped. For CS1P20, she experienced an associated improvement in her speech: *"I was slurring a lot more. I don't slur now so much, hardly ever really"*, which was the issue relating to her Parkinson's that she felt most concerned about.

4.5.4.5 Negative Effects Associated with the Intervention

The intervention was not a success for all of the participants. There were 5 participants (CS1P2, CS1P8, CS1P13, CS1P15, CS1P17) who reported no, or minimal, effect from using the PDCue. CS1P2 found no effect at all, although he only reported drooling when in specific contexts or doing certain activities, such as when in his kitchen and working at the sink, washing dishes or peeling potatoes. He reported removing the watch at these times because he was concerned of immersing it in water and breaking it, *"I couldn't put it on on a Sunday morning and that's when I found I was drooling, standing over the sink with the tap running"*. Although he felt that it was the running water that was causing him to drool it is also likely that the combined factor of him being bent over and concentrating on a task was causing his problems. He did report that he felt PDCue would have been useful had it been waterproof, but as it stood, it was of no use to him. CS1P8 explicitly stated that *"I never had much of a problem with drooling"*. Despite the identification of drooling issues being an inclusion criteria he reported using the trial more as an awareness building exercise so that he would know how to manage the problem if and when it worsened. CS1P17 had changed his Parkinson's medication at the beginning of the intervention period (between the control period time) and he associated this, rather than the PDCue, as being the main reason for an improvement in his drooling. Similarly, CS1P13 had undergone some dental work during the trial period and this is what she associated with her improvement. It is possible that for these participants it was, in fact, the PDCue that had made the change. However, for them, they felt that the other elements were more likely to be the cause.

There were also 2 cases where participants reported that the PDCue had made a difference but that they did not feel that they wanted to engage with it further. CS1P1 felt that she would not use the watch in the future because the frequency of cues became *"annoying"*, where CS1P30 just did not engage fully in the initial project—she reported not using the PDCue at times; *"probably just laziness, to be honest with you"*. Below these

participants' individual profiles are unpacked, to explore why there was limited motivation to engage with the technology, despite initially reporting that it had made a positive difference.

CS1P1 reported severe drooling problems pre-intervention, however, it became apparent during interviews that, despite its severity, CS1P1's husband was more affected by CS1P1's drooling than she was herself. When conducting the interview it was CS1P1's husband who responded with rich accounts of *his* experiences of her drooling, and how *he* felt that the drooling impacted on her in terms of embarrassment. It was, at times, difficult to encourage CS1P1 to input her own thoughts and experiences into the interview, despite attempting to engage her by clearly directing questions and clarifications for information at her. In addition, CS1P1 scored a stage IV on the Hoehn & Yahr scale (Hoehn & Yahr, 1967) which, as described in section 4.4.2, ie severe disability relating to Parkinson's. CS1P1 was also experiencing chronic pain due to a trapped sciatic nerve, which she discussed at length during many of the visits the researcher had with her. As such, drooling was not her primary concern, nor did it come close to the top of her health related priorities. In the case of CS1P30, who reported only a mild drooling problem at the initial assessment session, this participant discussed having a 'variable' drooling issue: *"it was good yesterday, for instance, whereas last week it was quite bad. It seems to come and go quite a bit"*. Also, this participant discussed several disruptions around her household, whereby her son had moved into the home she normally lived in alone. As such, these factors led to a disengagement from the study at times, with CS1P30 stating 'laziness' as the main cause (as described above).

4.5.4.6 Generalisation and Habituation

There were several cases of participants reporting a generalization effect, wherein they felt an increase in swallowing frequency was being carried over to times when they were not wearing the PDCue (9/27). CS1P4 said *"Even when I wasn't wearing the [PDCue] every now and again I think, "Oh yes, you haven't swallowed. I need to swallow""*. CS1P3 also noted *"even when I wasn't wearing it I was much more conscious of it"*. Even CS1P30, who we described in the previous section as not particularly engaging in the intervention, reported an increased awareness of her swallowing which was leading her to consciously swallow more *"without necessarily having the watch on, I do try to swallow more, you know?"*.

CS1P19 equally discussed an increased awareness around his drooling behaviour at times when not wearing the PDCue, *“When I took the watch off, I began to be aware, whether I was conscious that I should be swallowing, my drooling decreased when I took the watch off as well”*. Although unexpected, CS1P26 also discussed an improvement to his night time drooling *“I’ve hardly been drooling at all. No, I haven’t. Even during the night I haven’t been”*.

There were a small number of participants (3/27) however who reported becoming habituated to the cues, e.g. CS1P6 *“sometimes I didn’t feel it, but most of the time I caught it”* or CS1P10 *“there were occasions when I had the watch on, I seemed to have got so used to it that I didn’t get any indication”*. This was a concern going into the trial, given that the cues were presented in a temporal (once per minute) manner. However, for most participants this did not seem to be an issue and both CS1P6 and CS1P10 both reported a positive effect from the intervention, despite this habituation.

The findings of both the quantitative and qualitative data collected during the trial have been reported and showed that the majority of participants perceived the cueing intervention to be a success. The following discussion section will synthesise the quantitative and qualitative findings from this study and begin to draw out discussion themes that relate to the overall aim of the thesis around uncovering the role that digital technologies, like the PDCue, might play in supporting the self management of Parkinson’s symptoms. The case study was around cueing for drooling so the focus will remain around this symptom and the temporal cueing method that was employed.

4.6 Discussion

The case study presented in this chapter discussed a clinical trial approach towards evaluating the effectiveness of the PDCue device, as a digital intervention for the self management of drooling, through the provision of regular vibratory cues. The cueing method was temporal (time based) with cues set at once per minute, in accordance with previous understanding from research around swallowing frequency in healthy adults (1.32 swallows per minute) (Afkari, 2007). There is however, as yet, no literature relating to the “normal” swallowing rate of people with Parkinson’s. The research aimed to explore the effect that the PDCue intervention had on supporting the self management of drooling in PwP and the impact that this effect had on their lives. It also aimed to ensure that any effect observed was due to the cueing technology itself, not the provision of information around

drooling and the theories behind increasing swallowing frequency as a mode of management, by also including a control group who had a period of no treatment.

In the following sections several discussion themes will be explored. The discussion begins with an exploration into the effectiveness of the cueing method in supporting the self management of drooling. It then moves on to understanding the group of participants who did *not* observe an effect, to explore whether or not there were any similarities among this subgroup of people which might provide useful insights for researchers wishing to conduct studies of this type of cueing method with PwP in the future. The limitations of the study are presented, in an attempt to inform the design of similar future studies of this kind, before finishing with a discussion of the impact that the research might have in the medical and wider research communities.

4.6.1 Effectiveness of PDCue in Supporting the Self Management of Drooling

A total of 22 participants found a positive effect of the intervention, based on the qualitative data, and a statistically significant effect was observed in quantitative data between the pre and post intervention diary entries of all 28 participants. This section of the discussion synthesises the quantitative and qualitative data in an attempt to understand and interpret these results.

There was a clear reduction in drooling over time, both between the pre and post intervention periods and the post intervention and follow up time frame. Although there was no significant change in the post intervention and follow up time for drooling severity, all other elements of the data collected by the drooling diaries (severity pre and post intervention and frequency of drooling for both timeframes) were found to be significantly different, with mean scores lowering as time progressed throughout the trial. This is certainly a positive result for the project, and shows that the PDCue treatment option can be implemented with positive effects on drooling. Of course, this type of outcome measurement (i.e. self rated diaries) can only ever give a subjective measure of effect, yet diary making activities are heavily used in clinical research as a way to monitor the progress of treatment and log patients' activities over time, without the requirement for a researcher to be present. However, there are reported issues with compliance around diary use in clinical research (e.g. (Stone, Shiffman, Schwartz, Broderick, & Hufford, 2003)), and this was, unsurprisingly, also reflected in the study. These compliance issues highlight a call for

automated monitoring techniques which can eliminate the need for these tedious paper based techniques.

There was a sample of participants, the control group, who did not receive the intervention immediately, instead undergoing a month of no treatment. This sample was studied to ensure that the effect of the intervention was due to the cueing method, and not caused simply by providing participants with information about their drooling and the ways that it can be self managed through increasing swallowing frequency (please note that this was the same information provided within the trial documents to all participants). It was found that participants in the control group did not improve in a 1 month time period of no treatment, which supports the hypothesis that it was the cueing intervention itself that caused the positive effect on drooling. Due to randomisation, which assigned participants into the control and intervention group, it was unknown whether or not there would be an appropriate match of participants who had similar experiences relating to drooling, which may have impacted their motivations towards engaging in the intervention. Upon analysis it was found that, although not reaching statistical significance, the number of participants who had been previously treated for their drooling was higher in the intervention group (7 participants (47%) compared to 2 participants (15%) in the control group). It could be considered that the motivation of participants who had previously sought treatment for their drooling problems might be higher than those who had not. Also, they are more likely to have had more prolonged, and more severe, problems. However, given the nature of the research, and the fact that participants had willingly signed up for inclusion with an identified drooling problem warranting treatment, it could be said that all participants were motivated to change their drooling behaviour.

4.6.2 Understanding Unsuccessful Experiences

For 5 participants the intervention did not appear to be effective. In this section these participants are grouped, to look for recurrent similarities that may provide an indication of why this was the case. The first thing to note was that all participants who did not report a change had reported themselves as having a mild drooling problem at the initial assessment point and had been noticing their problems for an average of 11 months, significantly less than the average 25 months in intervention group. It is a possibility that for these participants, the drooling problem had not yet reached a severe enough point to warrant the

implementation of a self management technique. In fact, CS1P8 shared that he took part in the study more as an exercise around understanding more about his drooling and the possible difficulties he might have in the future, where for CS1P2, drooling was only perceived as a context specific issue for him, occurring most frequently when he was around running water. This is a possible issue with the inclusion criteria of the study, which allowed for any potential participant with a self identified drooling problem to take part. As the case study was exploratory in nature, there was an interest in recruiting a wide variety of participants within the sample. However, future work should consider a more structured screening process.

Another group feature worth noting is the fact that 4/5 of these participants were in the control group prior to entering the intervention stream. Although there were no significant differences in the control groups' drooling pre and post the no intervention period, it is possible that these individuals had more time to consider their drooling in light of the information provided by the researcher about the causes and possible behavioural treatment of drooling. It is also possible that their expectations around what the cueing technology might do, or the effect it might have were increased over the month that they were waiting for therapeutic input. Unfortunately, this was not monitored during the study or probed within the interview so this is an area of investigation that may warrant further exploration in the future.

Finally, whilst not an entire group observation, it is worth noting that both CS1P13 and CS1P17 did in fact report a positive change in drooling over the intervention period. However for these participants they associated the effect with a change in other factors. For CS1P13 it was an improvement to her dentures, whereas for CS1P17 it was a modification of his Parkinson's medication that he felt had made the difference. Parkinson's is a complex condition and requires continuous monitoring and adjustment of medication routines in order to manage the condition. In addition, participants have their own lives outside of the study design, including dental and hospital appointments and changes in their health status outside of their Parkinson's. As such, these individual cases are simply part of working with participants during 'in the wild' fieldwork.

4.6.3 Study Limitations

The first limitation of this study was the sample size. Although 30 participants overall was the sample size intended for this first stage feasibility trial and the results were positive, there is a possibility that the same results would not be observed when conducting a similar trial with a larger population of PwP. There is a need for the conduct of a larger second stage, multi-centred trial in order to prove that the statistical results reported around clinical effectiveness can be applied to the general population of PwP. However, the information collected within this trial has provided important, preliminary data around the effect that the cueing intervention could have. Also, the study has provided insight into the applicability of methods that might be used in a much larger trial, a necessary step prior to obtaining funding for, and running, a study of this kind on a larger scale.

One aspect of the methods that would require revision is the use of the drooling diary. It was found that, of a possible 6,699 diary entries there were only a total of 5,069 (76%) entries provided. This was a particular issue in relation to the follow up data. In regards to the diary entries collected at follow up, only 11 participants completed all 3 categories relating to drooling severity and frequency (both number of minutes drooling occurred for and the separate instances that it was observed over one hour). Two participants did not complete any of the categories, while a further 11 only completed the severity rating. Because of this, the data for drooling frequency was discounted, being deemed too incomplete for an appropriate comparative analysis between the time points of post intervention and follow up. As such, there is a call for a consideration into the ways that data relating to drooling severity and frequency might be collected, in an objective way, without the requirement for participants to fill out paper diaries. One suggestion for this might be around quantifying swallowing frequency using an algorithmic detection of swallowing sounds, using a similar method to that presented in Larson et al (Larson, Lee, Liu, Rosenfeld, & Patel, 2011).

One of the other issues that became apparent during the trial concerned the appropriateness of the MMSE over the MOCA as a cognitive screening tool. There was one participant, CS1P16 (Hoehn and Yahr stage 4), who scored a 25 on the MMSE (inclusion criteria at 24 or above) but only a 15 on the MOCA (a score of 25 or below is indicative of significant cognitive impairment). It was decided that this participant would be included as a case study to investigate if patients with significant cognitive impairment would be able to

use, and engage with, the PDCue. This participant most certainly engaged with the project, and was very supported during the process by his wife. At each visit, he was ready and waiting and reported how much he had been wearing the PDCue. However, it soon became clear that he was not actually using the PDCue as a cueing device. Instead, he was simply wearing the watch and experiencing the vibrations. On observation, he was not responding to cues to swallow, despite prompting from his wife and the researcher. It was deemed appropriate to include this participant as he was within the MMSE inclusion criteria and had a sufficient support system through his wife, who heavily engaged in the project through the diaries and researcher visits. However, this participant's experience further indicates that the MMSE inclusion criteria of 24 and above may allow inclusion of people with significant cognitive impairment. As such, it is suggested that the MOCA would be better as the primary cognitive screen for similar studies of this kind in the future.

4.7 Summary statement

This work has provided evidence that a behavioural cueing method, delivered through the carefully designed PDCue device, can be an effective treatment option for people with Parkinson's experiencing drooling problems. In the context of self care, the participants remained motivated throughout the month long study to self manage their drooling by responding to the presented cues. However, it must be considered that the weekly visits from the researcher played some part in sustaining this motivation and although participants were self managing their drooling with support from the PDCue, it was very much prescribed as a structured treatment. In spite of this, an extended generalisation effect was observed at 1 month follow up. This may be indicative of a learned behaviour change, through increased awareness of drooling and how to manage it. These preliminary findings suggest that this cueing treatment could prove a viable first step for clinicians with patients requiring intervention for drooling, before moving on to additional medication or Botox, which were clearly seen from the participant comments in section 4.5.4.2 as less preferred options.

The next chapter again focuses on the use of cueing to support self management. The cueing method employed in this chapter was temporal, however, the cueing method explored in chapter 5 employs in-situ prompting. This cueing method continuously monitors and automatically analyses data about the PwP, in order to present real-time cues at times

when they are needed in everyday life. The second case study moves away from the symptom of drooling and instead focuses on how the maintenance of speech volume in conversation might be supported.

Chapter 5

LApp on Glass: An application Targeting in-situ Prompting of Increased Volume on Google Glass

The previous chapter examined the design and evaluation the PDCue, a technology employing a temporal cueing system to support the self-management of drooling, through the provision of regular reminders to increase swallowing frequency. In this chapter attention now turns to a different kind of cueing method and a different Parkinson's symptom. Taking speech volume issues as a case study, this chapter explores the potential of in-situ cueing, wherein prompts are provided as and when they are needed within day-to-day conversation, as a way to support the self management of speech for PwP. This cueing option collects and analyses continuous data around the individual's speech volume, providing insight into their symptom as it is experienced. Prompts signal the person using the system to change their speech volume, at a given time, and provide a means by which to reflect upon why, and in which situations, their vocal volume is particularly low.

In order to explore this cueing modality, the Google Glass was selected as the platform which would collect, make sense of and feedback the data to participants in the form of a cue. This platform was chosen due to its head mounted position—an optimal microphone placement when collecting voice samples—its processing capability and its polished design. However, at the time that this case study was conducted Glass was in its infancy, thus there was no understanding around how groups of people, with conditions such as Parkinson's, might value a wearable technology of this kind and its potential to support new forms of self monitoring and self management. Similarly, tests around Glass' robustness and usability were still being carried out, so this research was conducted using what was still very much a high fidelity prototype. In order to address this concern an initial phase of the case study was carried out to determine the level of acceptance that PwP might place in a novel consumer technology such as Glass. The second phase of the study involved the iterative design, development and evaluation of an in-situ cueing application for Glass, to support the self management of vocal loudness and encourage self reflection around *when* their volume was reduced at certain points in their day-to-day conversations.

This chapter first discusses a brief history of head mounted displays and their use within health contexts. It then moves to situate Google Glass within the emerging area of wearable technologies for health. The first and second phases of the study are then discussed before reflecting on the role that digital technologies, such as Glass, might play in supporting self monitoring and management practices of PwP. The discussion ends with a consideration around the in-situ cueing method that was employed and its benefits to PwP.

5.1 The History of Head Mounted Displays in Healthcare

Since the conception of head mounted displays (HMD's) in the 1960's, their potential use within the healthcare domain has been explored. One of the earliest examples was that by Upton in 1968 (Upton, 1968) which employed LEDs, embedded within a set of glasses, to help deaf individuals with lip reading. In Upton's system, LEDs would illuminate depending on a specific phoneme type (e.g. a fricative such as /f/ or /s/, or a stop such as /p/ or /d/). In 1977, Collins presented a tactile imaging system for the blind which converted images collected via a head mounted camera onto a tactile grid worn on the body in the form of a vest (Collins, Scadden, & Alden, 1977). In more recent years, the focus of HMDs in health has turned towards surgical contexts (Bichlmeier, Heining, Rustae, & Navab, 2007; Chen et al., 2015; Figl et al., 2002; Liu, Jenkins, Sanderson, Fabian, & Russell, 2010; Traub et al., 2006). For example, Bichlmeier et al. proposed a stereoscopic, video based HMD with optical tracking system to aid navigation within spinal surgery (Bichlmeier et al., 2007), whereas Liu et al. (Liu et al., 2010) studied a HMD system developed for anaesthesiologists, which provided a continuous view of a patient's vital signs during an operation.

HMDs have also been studied within a range of healthcare applications employing the use of virtual reality (VR). As described by Greenleaf (Greenleaf, 2001), VR has the capability to allow users to experience three-dimensional visual, auditory and tactile environments. Again, many of the examples that Greenleaf suggests are around the surgical domain, namely within the area of surgical training and the use of VR to simulate complex surgical procedures [e.g. (Hon, 1994)]. However, he does bring to light an interesting case of from Weghorst et al (Weghorst, Prothero, Furness, Anson, & Riess, 1994), who studied the use of VR in the management of gait freezing in PwP, wherein a head mounted VR system was used to provide visual cues, moving through the wearer's visual field during walking. Since this time, VR has seen even further advancements in the domain of rehabilitation for

Parkinson's. In a paper by Dockx et al (Dockx et al., 2003), which moves away slightly from HMDs, the authors provide a systematic literature review around VR and motor rehabilitation for PwP. The authors describe the benefits of VR in the provision of augmentative performance feedback via a range of auditory, tactile and visual modes. They discuss the potential for the individualisation of rehabilitation, through examples such as exergaming and virtual environments, which not only support patients in the rehabilitative practice of motor tasks, but also stimulate cognitive processing at the same time.

Despite showing huge promise within the health domain, the use of these types of systems is still in its infancy within clinical practice. The use of HMDs, even within non-clinical populations, are rarely seen being used within a typical person's everyday life, with the majority of sales centring around the defence services and industry (TMR, 2015). However, with the development of Google Glass and Oculus Rift (which is predominantly targeted at gamers) systems, which are positioned as consumer HMD technologies, these types of systems are rising in familiarity amongst the general public. With cheaper, smaller and more accessible units the potential for HMDs in healthcare, and beyond, are becoming a reality.

5.2 Google Glass

The Google Glass (referred to here just as Glass) was debuted in 2012, where it quickly began receiving interest from the media. It was released in its prototypic form, for specialized consumer testing in early 2013 via the 'Glass Explorer' program²⁷—whereby early product users were selected by Google to hack, test, develop and research the prototype to uncover uses, issues and potentials for the system.

Externally, Glass resembles a pair of prescription glasses but holds a processor, a micro-display across the right eye and encases an array of sensors such as an accelerometer, gyroscope, compass, as well as a microphone, a front-facing camera and a rudimentary eye-tracker. The wearer operates Glass through a range of voice commands and via a touch-pad on its frame. In its 'off-the-shelf' form, Glass operates on a version of the Android operating system—and perhaps as a result many of its functions are similar to a smartphone. Users can make phone calls, take and share photos and videos, read and send SMS and emails and get directions via Google Maps. Taking the latter function as an example; a user would either tap

²⁷ <https://www.google.co.uk/intl/en/glass/start/>

the touch pad or say “OK Glass” to activate glass, the OK Glass screen will be visible. They then can navigate the different apps on the system by either swiping downwards on the touchpad to find, or simply saying, “get directions to”, again visible through the eye display. At this point the user can say their destination and Glass will calculate their route. The display will then now show a standard Google maps screen, with the correct route outlined as the user walks through their environment. Steps are verbalised through the bone conducting speaker to discreetly prompt users when they should, for example, take a turn. Frequent automatic updates to the operating system also update the device with new ‘cards’ (applications) that add further functionality. While Glass is still in development²⁸, it does offer great potential in the context of health related monitoring. Its visual display and bone conducting speaker offer opportunities for the presentation of discrete alerts and prompts, while its numerous sensors allow the possibility for capturing data about the wearer. Furthermore, as an envisioned commercial device it offers the potential to be purchased freely by the public and used as an everyday device for health-related self monitoring and management. As a commercial device it might avoid the stigma associated with devices designed specifically for people with a particular health condition²⁹. In this sense, Glass opens a space for exploring the design and development of wearable context-aware systems. However, given the novelty of Glass, the expectations and possible acceptance of such devices were unknown, an issue that will be discussed in section 5.4., later in the chapter.

5.3 Wearable Technologies for Health

With the ability to collect, collate and make sense of a huge range of data pertaining to health, the use of mobile wearable technologies is becoming commonplace within personal healthcare practices. However, many of these technologies are designed for younger populations and, whilst interfaces employ gestural interactions that are intuitive to these groups, these can become a barrier to the uptake of new technologies for an older population (Harada, Sato, Takagi, & Asakawa, 2013)—the majority population of Parkinson’s patients being within this ‘older users’ bracket.

²⁸ Please note that following the Glass explorer program Google halted the supported development of Glass in its current format, but claim that they intend to continue working on future versions of the technology concept (<http://www.bbc.co.uk/news/technology-30831128>).

²⁹ The sense of stigma, and evocation of feelings of disability associated with medical devices was an issue drawn out in the PDQ design work discussed in chapter 4 (section 4.2).

Despite some attempts at understanding the role of digital technology in the monitoring and management of Parkinson's (e.g. (de Barros et al., 2013)), the main focus of prior computing literature on Parkinson's has been on the assessment and diagnosis of the motor aspects of the condition (Arora et al., 2015; Cai et al., 2014; T. Khan et al., 2014; Martens et al., 2013; Westin et al., 2010). Westin et al (Westin et al., 2010) describe the development of a touch screen based computing system to provide in-home motor testing on a range of elements, including traditional finger tapping and spiral drawing tests, as well as self-reported patient information via a diary, where Arora et al (Arora et al., 2015) describe the development and subsequent testing of a smartphone application to assess an even wider range of tests (including voice, posture, gait, finger tapping and response time). Gait freezing, is a symptom of Parkinson's which has been widely explored. Using machine learning techniques, researchers have been able to detect episodes of freezing using accelerometer data, and provide cues that aid PwP to continue their movement (Bächlin et al., 2010; Casamassima et al., 2013; Mazilu et al., 2014)). Mazilu et al (Mazilu et al., 2014) highlight the benefits PwP gain from in-situ cueing over continuous cueing, which can become habituated over time.

Specific to monitoring and management of Parkinson's speech, there is emerging research on the use of digital systems to support the home based practice of vocal loudness. For example, Eglin (Parkinson's UK, 2015b), describes an app with two key functions; a 'feedback-meter' to encourage reflection around how loud the voice is relative to background noise and how loud the user is required to speak in order to be properly heard; and a 'voice training' function to support PwP in their practice of their speech. Similarly, Krause et al (Krause et al., 2013), explored a digital game to support at home practice of volume for PwP by encouraging players to raise their voice enough to meet targets within the game (e.g. breaking a glass when using an opera singer avatar). In this sense the authors again provide visual feedback, albeit in a different way, that volume targets have been met. Although these examples are particularly useful for the practice of speech within a home context, there is little known about how patients react when undertaking real conversations. This prior research does not address the difficulties PwP have in maintaining their volume within external settings. In this sense, the implementation of a technology to support in-situ prompting of volume, at times it is needed in everyday conversation, could prove beneficial.

Most current systems being developed for research and the consumer market for PwP are being designed for use on smartphones, considered as one of the most widely used mobile computing platforms (Ofcom, 2015). There are currently a range of apps on the market, specifically designed for PwP to track their symptoms (mPower³⁰, Lift Pulse³¹, myHealthPal³²), provide information (Parkinson's Central³³, Parkinson's Toolkit³⁴), encourage rehabilitative exercise (Parkinson's Home Exercise³⁵, Delayed Auditory Feedback (DAF) Professional³⁶) and improve smartphone accessibility (Parkinson's EasyCall³⁷). If we look closer at this last example however, it is clear that, despite advances in app development specifically for PwP, there are still physical issues which can impede smartphone accessibility—this will also be discussed later in this chapter (in section 5.4.1.3.1).

Parkinson's EasyCall, developed by Parkinson's UK, takes into account the dexterity issues experienced by PwP, due to hand tremor and impoverished motor control, to provide an easy to use interface that presents regular contacts and speed dial options, removing the need to navigate more complex contact lists. Given these potential barriers, this case study proceeded with the assumption that Google's Glass platform—with its built-in voice commands and simplified touch interaction— could have the potential to remove many of the difficulties PwP experience with making fine motor movements. Also, given the researcher's interest around exploring the concept of in-situ cueing for vocal loudness, Glass' visual display, vibratory capability and conductive headphone provided a range of possible cueing modalities to explore. Whilst Glass was seen to hold potential, there were open questions around the acceptability and value this technology may bring to this group—and more widely to the domain of health monitoring and management. In this chapter a two phase study is described that first explored how PwP perceived Glass, its capabilities and its potential for PwP, before and after an in the wild field trial. The second phase of the study moves to describe the design, development and real world evaluation of LApp, an application developed for Glass to support in the in-situ prompting of vocal loudness.

³⁰ <http://parkinsonmpower.org/>

³¹ https://play.google.com/store/apps/details?id=com.liftlabsdesign.liftpulse&hl=en_GB

³² <http://www.myhealthpal.com/>

³³ <https://play.google.com/store/apps/details?id=com.parktool.aaa&hl=en>

³⁴ <https://play.google.com/store/apps/details?id=com.apps.parkinsons&hl=en>

³⁵ <http://prdassociation.org/publications/8/parkinson-home-exercises-app.html>

³⁶ <https://itunes.apple.com/gb/app/daf-professional/id491299921?mt=8>

³⁷ <http://www.parkinsons.org.uk/content/easycall-free-mobile-app-people-parkinsons>

5.4 The Study

This case study explores how in-situ prompting might be used to support the self management of volume issues for PwP. It aims to uncover whether or not the presentation of these cues, in real time, might encourage on the spot reflection around the times when volume is reduced during conversation, and the level of effort required to sufficiently increase vocal loudness to a target level. Given that Glass was very novel and a highly visible device (in that it is worn on the head), the first phase of this study had 3 initial research questions:

- 1) What issues do PwP currently face with digital technologies?
- 2) How acceptable do people with Parkinson's find the concept and physical form of Glass to be?
- 3) How might a system like Glass support PwP in their day-to-day lives?

The following section describes the process that was taken to explore these questions.

5.4.1 Phase 1: Exploring the Acceptability of Google Glass

5.4.1.1 Methods

In this phase the acceptability of Glass, to PwP, was explored through a qualitative study based on focus group discussions and a week-long field trial of the Glass technology. All participants were recruited through local Parkinson's UK support groups, following a presentation about the research aims. Participants of any age or stage of Parkinson's were

Name	Role	Age	Gender	Years Since Diagnosis	Main issue
CS2P1	PwP	56	M	4	Freezing, on/off fluctuations
CS2P2	PwP	69	M	8	Freezing
CS2P3	PwP	52	M	6	Speech
CS2P4	Carer	49	F	-	-
CS2P5	PwP	70	F	10	Dyskinesia
CS2P6	Carer	70	M	-	-
CS2P7	PwP	46	F	2	Tremor

Table 5: Phase 1 Participant Details

considered for the study and carers were also invited to join. The aim was to recruit as diverse a range of PwP as possible, in order to account for different life experiences and to obtain a range of perspectives around how Glass might be integrated and accepted into individual's lives. Five PwP, representing a diverse range of typical symptoms (gait issues, speech and voice problems, dyskinesia relating to increased movement due to medication, ON/OFF fluctuations), and 2 carers took part in the study. Participants were aged between 46 and 70 and all were supportive of research and interested in the idea of Glass. A description of participants can be viewed in table 5.

The aim of the focus group, which lasted approximately 2 and a half hours, was to gather qualitative insights into the ways in which participants were currently using technology, both socially and in managing their condition, and to gather initial reactions to the Google Glass technology. All 5 of the participants with Parkinson's who took part owned mobile phones and used the internet at home. One participant owned and used a Wii (CS2P3). The focus group began with open discussion about how participants used technology to support daily routines, social activities, and manage their Parkinson's. Following this discussion, a promotional video of Glass was played, highlighting the photo



Figure 6: Boxed Google Glass

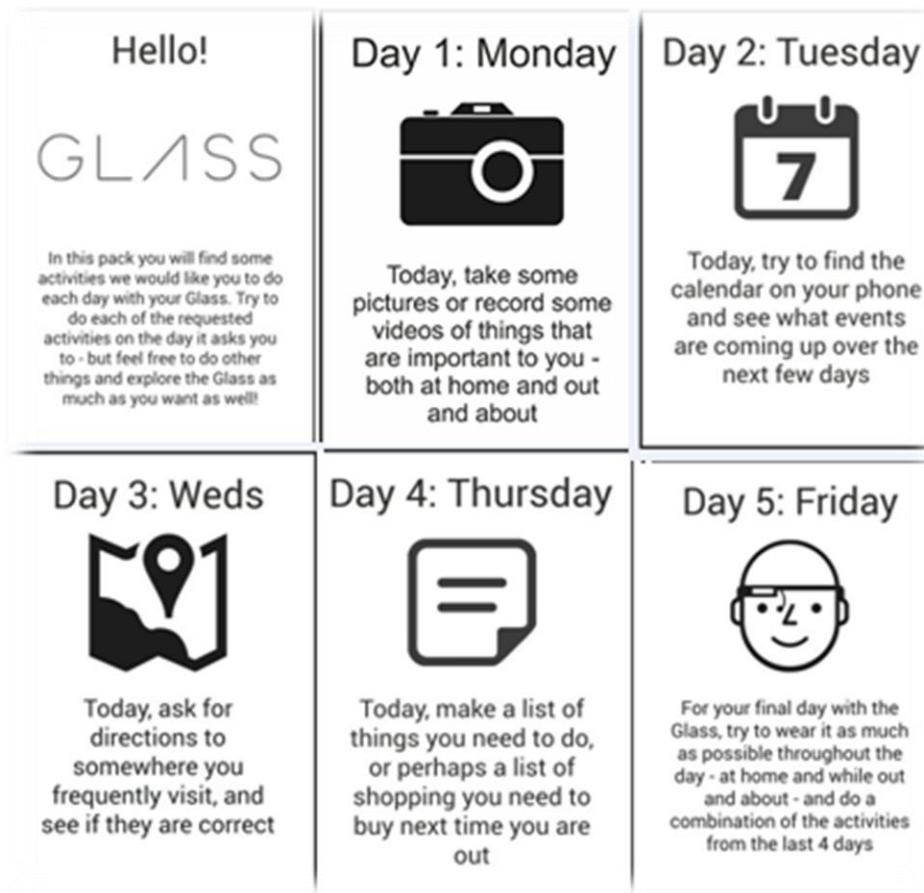


Figure 7: Prompt cards provided to Glass participants

sharing, video calling, social media, street directions, and information searching features of the device. The researcher then gave a demonstration of Glass. Each participant was given the opportunity to wear and use Glass, in pairs, for a short period of time, with support from the researcher and another facilitator. There were two separate systems available for use in the workshop. Group discussions were facilitated throughout, with the purpose of gathering views on what Glass could do 'out of the box' and encouraging participants to express ideas of alternative uses for the device. All discussions throughout the workshop were audio recorded and transcribed, for later analysis in the manner described in chapter 3 (section 3.4).

A short time after the workshop (within one week) participants were contacted by the researcher and an appointment was made to come to their home and deploy the Glass technology. All of the Participants with Parkinson's took part in the field trial except CS2P5, who was on an extended holiday at the time that the field trials were being carried out. CS2P1 and CS2P3 wore a black Glass, while CS2P2 and CS2P7 wore blue. The field trials with each participant lasted 5 days. Participants were provided with a boxed Glass (see figure 6),

including cables for charging (Glass lasted approximately 5 hours with full charge), and a Google Nexus 4 phone to tether it to. Because many of the Glass apps required an internet connection to work, and there was a possibility that participants would take the glass outdoors, it was felt that internet tethering via a pre-paid mobile phone would be the best way to facilitate this. Participants were also provided with a basic instruction booklet (see appendix 2e) on how to operate Glass, and a set of 5 daily prompt cards (see figure 7), which aimed to encourage interactions with the device. These included: requesting and following directions, taking photos, creating videos, checking the calendar, and making to do lists. Due to the fact that Glass was a novel device that none of the participants had interacted with outside of the focus group, brief daily phone calls were made to each individual in order to help them feel supported in the study and to allow for the identification of any significant problems in using the device. At the end of the trial each participant took part in an exit interview. These interviews focused on; when and where they wore the device; what they enjoyed using it for most and least throughout the trial; any areas of the system that they felt could be improved to make it easier for PwP to use; and to identify whether perceptions towards Glass had altered since the workshop. Field trial interviews were audio recorded, transcribed verbatim and anonymised for later analysis. An inductive thematic analysis (Braun & Clarke, 2006b) (see chapter 3, section 3.3) was then conducted on the transcribed data, by coding it at the sentence to paragraph level and drawing out themes across the data set.

This chapter section has discussed the methods that were taken during the phase one trial. It has described a two stage approach involving a focus group and set of 5 field trials. Through the analysis on the transcribed data collected during this study a set of 6 themes emerged, relating to issues and frustrations around technology usage, wearing glass while 'out and about', autonomy, and confidence and safety. These themes are discussed in detail in the following section, which synthesises the discussions from both the focus group and the individual interviews from the field trials.

5.4.2 Phase 1 Findings

5.4.2.1 Research Question 1: Issues and Frustrations Relating to Technology Usage

This research question explored: *what are the issues that PwP currently face with digital technologies?* The focus group began with open discussion about how participants used technology to support daily routines, social activities, and manage their PD. This revealed how many of the participants felt privileged by being able to leave their home and be independent. Participants discussed issues they experienced with existing technologies at length. There were particular problems with smartphones specifically related to Parkinson's. Tremor and a loss of fine motor ability were identified as symptoms causing great difficulty with using touchscreens and a major source of frustration. CS2P7 explained: *"the movements have to be quite precise with a touchscreen and if your hand is rigid and not moving very well it's no good really"*. This linked into discussion around needing to place the phone on a stable surface in order to use it *"I have to put the phone down to use the touchscreen and it's very, very tricky"* (CS2P5). Participants therefore felt that having a voice activation system would be a huge benefit for them—as CS2P5 said: *"definitely some kind of hands free - it's definitely the only option for someone with PD"*. Having this on an easily accessible platform such as Glass was perceived to be immensely advantageous when compared with a typical mobile phone based hands free systems. However, voice command was not without its issues. Many PwP experience severe problems with their speech and voice which can change with ON/OFF periods. CS2P3 in particular had marked difficulty producing intelligible speech, which often caused him to avoid certain situations or social interactions:

"This [his voice] is not right... It's frustrating. You can't get rid of this [...] Now it's really worse, so now I tend to wait for me to be better [...] There's no point in carrying on a conversation if you can't understand me").

This led to concerns from CS2P3 and other participants that the spoken commands would not work unless highly personalised to individuals with Parkinson's voices.

Following the 'trying on the Glass' activity, however, there was a high level of success experienced by the participants using the voice activation, including CS2P3, which incited a sense of encouragement. During the field trials however, all of the participants experienced usability issues with the voice recognition on Glass, causing frustration amongst everyone. CS2P7 said: *"the fact that it wasn't recognising what I wanted was very irritating and very frustrating"*. For CS2P2 and CS2P3, who already had marked difficulties with their speech, this proved deeply disheartening. CS2P3 explained: *"my voice wasn't always working...it came up saying 'try again'"*; CS2P2's wife also commented: *"he had to shout at it a few times because obviously his voice is very quiet"*. It was noted that, for CS2P1, *"the voice application is going to have to be re-engineered and made a bit easier"* in order for it to be usable for someone with Parkinson's. These difficulties contrasted with the relative successes these same participants had when testing Glass in the workshop.

The Glass navigation gestures, namely tapping on the side of the device, were also problematic in everyday use. There was more success when using the swiping gesture to navigate menus. However CS2P1 noted: *"I found that the tapping was quite difficult... your hand just keeps going"*. CS2P2 also found this to be a difficult gesture to master *"scrolling backwards and forwards wasn't too good at times, sometimes you went too far and it was hard to get back"*. However, there were a number of practical successes experienced during the field trials, when using the preinstalled apps on Glass both at home and outdoors. The SatNav system in particular was appreciated by CS2P1: *"it was very good, it was the most interactive one I've had...so accurate it's unbelievable"*. When working correctly participants were struck by the speed at which searches could be performed. CS2P2 praised the internet search, *"the information it gave you was great...it was very quick"*. Participants compared their experiences with the use of a mobile phone and the resulting physical interaction problems they had previously experienced. CS2P1 said: *"I can't do that with a mobile phone but other people can"*; and for CS2P2: *"it's better than a phone. With Parkinson's you can't text because you can't hit the buttons. With the Glass you would just talk, you can see what you're doing, it's just instant"*.

5.4.2.2 Research Question 2: Wearing Glass while 'Out and About'

This research question explored: *How acceptable do people with Parkinson's find the concept and physical form of Glass to be?* During the field trials, all of the participants used Glass

daily at home as well as in outdoor settings, such as the shopping mall (CS2P7), when meeting with friends (all), while out driving (CS2P1 and CS2P7) and during a hospital appointment (CS2P1, CS2P2 and CS2P3), expressing how comfortable participants felt with wearing and experimenting with the device in public. CS2P7 wore Glass to a busy shopping mall and reported receiving a lot of fleeting attention: *“most people would kind of look and then, out of politeness or whatever, would not pursue it”*. She invited conversation from several service staff and was surprised to hear that they had perceived her as having a visual impairment: *“I went into the bank and the coffee shop, the person serving me [...] kept looking. [...] I explained what they were and both of them said ‘oh, I thought you had some kind of visual impairment’”*. This did not however make her feel uncomfortable and she felt the attention was not excessive. CS2P1 took a different approach while shopping. He attempted to provoke a reaction from others but found they *“took no notice”* of him.

CS2P3 however had a very different experience. He discussed removing his Glass while shopping because he: *“felt people were looking at me. They were staring. I found it quite hostile, it was almost like ‘you’re up to something’”*. This contrasted with the experiences of his wife (CS2P4), who had worn Glass while out for lunch with a friend and felt that *“no one noticed”*. CS2P3 stated *“it’s different for you because your hair hides it”* indicating that he did not want Glass to draw undue attention to him. This related to a lack of confidence CS2P3 felt in his daily life due to his poor speech, which saw him often avoiding social interactions with people he did not know. He associated the unwanted attraction with a feeling of disability: *“people peer at you, it’s almost like the blue [disabled] badge on the car - they peer inside to look at you as if to say ‘what’s wrong with you?’ That’s how I felt”*. For CS2P3, the visibility of the device on his head was a source of stigma. CS2P2, who wore a light blue Glass during the trial also relayed concerns about the visibility of his Glass: *“They should be black so people don’t notice it”*.

Several concerns emerged from participants over personal security and the potential that criminals would want to steal the device due to its expense and rarity, CS2P7 explained: *“I think at the moment while they’re still so pricey I’d be worried that someone was going to whip them off me”*. Participants felt the constant visibility of Glass made them vulnerable, in the sense that it must be worn to be used, whereas mobile phones could be hidden and need not be on public display; *“You put the phone in your pocket [...] If you’ve got Glasses on here, they can be running past and have them away”* (CS2P1). However, despite these

concerns there was an overwhelming sense that using the device could provide features that were worth potential security risks. CS2P1 noted: *“it offers so much for you. [...] It’s offering you more safety features than it’s actually giving you a problem with”*.

5.4.2.3 Research Question 3: Confidence, Safety and Autonomy

This final research question explored: *how might a system like Glass support PwP in their day-to-day lives?* All of the participants with Parkinson’s explained how they had lost confidence as a result of the sudden physical changes associated with unpredictable OFF stages, e.g. CS2P2 experienced severe and frequent difficulties with freezing, causing him anxiety in crowds or when out alone. This would lead to situations where they were liable to fall or be unable to get required help from the public. CS2P5 described: *“well, you lose confidence because you can fall...people don’t always understand what you’re saying...your voice gradually wears out”*. Glass was seen as something that could instil confidence for participants by providing a sense of safety. Participants felt they could be independent and go out on their own in the knowledge they could quickly contact someone who could *“see where they are”* and offer instruction and support; *“It would give me confidence back. I would be more independent because I’m not allowed to be independent much at the moment. That would give anyone in that position the confidence back to be able to be on their own.”*(CS2P5). This is in contrast to the concerns over personal security expressed by CS2P1 and CS2P7 in the previous section. Supporting increased confidence and safety was seen to be two-way between patient and carer, with carers also benefiting from knowing their family member could be contacted as and when needed; *“Having that, that person can [...] see that you’re fine and everything”* (CS2P4) and *“the carer would have more confidence in the cared for and the person would have more confidence in themselves to be able to go out and about”* (CS2P5). However, there was also the consideration of burden for the carer, who may not want to be looking over the person at all times *“I wouldn’t want to be watching your every move”* (CS2P6 expressing this sentiment to CS2P5), and apprehension that video linking could be abused by overly concerned relatives, who might think they are helping but are instead using the device as a way to control family members with a medical condition. Participants felt that they would need full control over who was able to call them via video link in order to avoid this issue. CS2P5 said: *“I don’t want my children watching every move I make. There is a potential there for saying, “Mum can’t do this”, or, “Mum shouldn’t do*

that". Concerns were also raised over *'always being available'*, in the sense that relatives would expect Glass to be easily accessible at all times. This was contrasted with a mobile phone where excuses could be made about why it was not answered *"You cannot say, 'Oh, I haven't got my mobile with me'"* (CS2P4).

Although these comments relate to the video calling function of Glass, there are interesting insights into the tensions surrounding the needs and values of PwP, relating to technologies like Glass. On one hand participants have the desire to be autonomous, to have the confidence to be independent. But, there is also a need to feel safe and supported by their loved ones, at times when they need it, which directly impacts on the formation of this autonomous self. However, there is a contrasting issue that comes alongside this familial support, wherein the process of providing support can over become overpowering to the individual and can, in fact, adversely influence their independence. Through this discussion, it became clear that participants required technology, aimed at supporting their daily lives, to be sensitive to these intricacies. In this sense, the concept of self management is a positive construct. By providing participants with the means to self manage their condition, the onus is placed on participants to rely less on carer support and take control of their own symptoms. For example, there was a comment above from CS2P5 which stated; *"well, you lose confidence because you can fall...people don't always understand what you're saying...your voice gradually wears out"* which directly related to a loss of confidence due to falls risk and diminished vocal clarity. Supporting the management of symptoms like these, in-situ, at times when they are most needed can offer a way to increase the confidence and independence of PwP by allowing them to feel supported in the management of these symptoms when they arise.

The following phase of the case study aimed to explore this concept in further detail through the design, development and initial evaluation of an in-situ prompting method for Glass around the symptom of vocal loudness. Speech and voice issues are one of the most commonly experienced problems in PwP, with up to 90% of all PwP experiencing problems at some point in the condition (Ho et al., 1998). Distress, embarrassment and social isolation are described as major impacting factors. (Miller et al., 2011, 2006). Having a way to self-manage the production of a louder, clearer voice at times when it is needed, could be beneficial in supporting confidence and independence for someone with Parkinson's. Glass is fitted with a microphone that could be used to calculate and present back dB loudness to

the wearer discreetly through the visual display. The head is the best possible position for collecting measures of voice in-situ due to the fact that the microphone will always be at a constant distance from the mouth, regardless of the way that the users head is turned. As such, Glass was considered as a useful platform for applying the principles of self monitoring and self management of volume. The next section discusses the study design taken towards the development of LApp; a loudness application for the self monitoring and management of vocal loudness.

5.4.3 Phase 2: Developing the Loudness Application (LApp) on Glass

The second phase of the case study explored a further 3 research questions:

- 4) How are volume issues experienced and managed by PwP in day to day life?
- 5) Through iterative design, can a suitable application for Glass be developed to support the self monitoring and management of volume issues?
- 6) How might a digital system, employing in-situ cueing, be valued by PwP in supporting the self monitoring and management of vocal loudness?

5.4.3.1 Methods

In this phase an application was developed for Glass, to aid in the in-situ prompting of vocal loudness. The application was designed through workshops with 7 PwP (different to those who took part in the phase 1 acceptability study), 6 of whom then used the application in a short field trial. The study was conducted in 3 stages: (i) an exploratory design workshop (see appendices 2c and 2d for workshop protocol and scenarios respectively); (ii) iterative

Name	Years Since Diagnosis	Age	VHI	H&Y
CS2P8	13	79	37- mild	3
CS2P9	20	60	41- moderate	2
CS2P10	6	69	32- mild	1
CS2P11	15	81	78- severe	4
CS2P12	7	73	64- severe	3
CS2P13	5	80	27- mild	3
CS2P14	10	60	33- mild	2

Table 6: LApp Participant details

development of LApp and pilot testing; and (iii) real-world deployment of LApp on Glass (see appendix 2f for instruction manual). Each stage is described in the following sections. All participants were recruited through local Parkinson's UK support groups, following a presentation about the research aims. Participants of any age, stage of Parkinson's were considered for the study, so long as they reported issues with loudness. Four participants had previously engaged in a SLT program to help treat their volume and two were awaiting therapy. Participant details can be viewed in table 6, which shows age, time since diagnosis, Voice Handicap Index (VHI) score (this is a patient rated questionnaire used to gauge the emotional, physical and functional impact of voice problems (Jacobson et al., 1997); and Hoehn and Yahr stage (described in detail in chapter 4, section 4.4.2) to indicate severity of their overall motor status. The first stage involved an exploratory design workshop which was held at Newcastle University and led by the researcher. This workshop lasted 3 hours and had 3 aims; to discuss personal experiences of loudness issues and the impact of this on PwP; to discuss experiences of undergoing SLT and the strategies currently being used by participants to overcome volume issues; and to scope the space for using digital technologies to help prompt loudness in daily life.

Participants were engaged in open discussion around their experiences of living with a volume issue and their previous experiences of Speech and Language Therapy (SLT), if any, and the types of strategies that were currently using to help manage their volume issues. Discussion then moved to the types of features that they would like to see in an application to help manage their loudness, using paper prototyping to visualise any ideas. A scenario based task was then used to engage participants in discussion around imagining use cases of the app and how it might fit into their daily lives. This workshop was audio recorded and transcribed verbatim. Transcriptions were thematically analysed using the same methods described in chapter 3 (section 3.4). Three main themes emerged relating to; speech volume, confidence and socialisation; and monitoring and managing loudness. These are described in detail in the findings (section 5.4.4)

The second stage of the study involved the development³⁸ of the Loudness application (LApp) using the information gained from the workshop. Following an initial design of the application, a small user study was run with 8 participants (5 males, 3 females with ages ranging from 20-40) who did not have Parkinson's or volume difficulties. These

³⁸ By Ivan Poliakov

participants were internally recruited through Culture Lab, Newcastle University and had all previously tried using Glass. This stage was used in order to test initial perceptions and functionality of the app when using it in different settings. Participants were asked, in pairs, to use LApp for approximately 30 minutes while carrying out a series of social interactions of their choosing in a range of settings with varying background noise. They were asked to choose one quiet indoors environment, one noisy indoors environment and one outdoors environment as settings for their interactions. Following this, participants were interviewed individually about their experiences of using LApp, any issues they encountered and any possible improvements they felt would benefit the app. Interviews were audio recorded and thematically analysed using the methods outlined in (Braun & Clarke, 2006a). The results of this study are described in the findings (section 5.4.6).

The final stage of the study was a series of three day deployments of LApp on Glass. These aimed to explore PwP experiences of using LApp in real world contexts, to uncover the types of daily situations participants used the device in, and to promote discussion related to the design of in-situ prompts to monitor and self-cue loudness in speech. The LApp on Glass was deployed with 6 of the 7 participants who took part in the exploratory design workshop (CS2P13 declined to take part in the field trials as he did not feel able to commit to the study at the time of the trial). Participants were visited in their homes and given a demonstration of how to use LApp. The researcher helped them sample a loud voice that was comfortable for them, to be used as the target volume that they would aim for when using the application. LApp was designed to support self-directed management of volume and, in this sense, participants were advised that they could make a specific decision not to raise their voice if the situation required. Participants were provided with an instruction manual for reference and were assured they could contact the researcher at any time for support. They were asked to use the application as much as possible during the period they had the system, within normal, everyday situations. At the end of the trial, each participant was interviewed in their own home for approximately 40 minutes. Each interview was transcribed and thematically analysed in the manner described in chapter 3 (section 3.4).

This chapter section has discussed the methods that were taken during the phase two study. It has described a three stage approach involving an exploratory design workshop, an iterative application development process and set of 6 field trials. Given the very different aims of the three stages of this study, their findings are discussed in detail

separately in the following section, which will discuss how the findings from each proceeding stage fed into the next. Each stage related to a research question, which is detailed below.

5.4.4 Phase 2 Findings

5.4.4.1 Research Question 4

The first research question asked: *How are volume issues experienced and managed by PwP in day to day life?* This was explored through the initial design workshop with 7 PwP. Two main themes were drawn from the discussions within the exploratory design workshop; experiences around speech volume and its impact on confidence and socialisation; and discussions around how participants currently monitor and manage their volume.

5.4.4.1.1 Speech Volume, Confidence and Socialisation

Participants expressed how significant an impact volume issues had on confidence and socialisation. Much frustration and embarrassment came from continuously being asked to speak louder by others: *“I’m constantly being got at by people telling me to speak louder”* (CS2P11), particularly when speaking to strangers: *“I find I have to rephrase things and I get lost and then I get embarrassed, especially if it’s a strange situation”* (CS2P14). CS2P10 described her experience of being dismissed by retail staff in public:

“I find that people don’t think you have the intelligence to understand what they’re talking about, I used to be a financial advisor and recently I was speaking to one and he said I’ll just get your son to talk to me. I mean, I used to do that, I just couldn’t get my words out for him to understand that I understood. That’s the annoying bit, people think you’re sub-level”

Another concern was a feeling of being ignored. CS2P8 explained how: *“coming over in the taxi he didn’t know the way and I tried to tell him but I got no answer, I gave up in the end.”* CS2P11 also described: *“frequently during a conversation with other people I can’t get myself involved, I’m just not speaking loud enough to make an impact”* and for CS2P14, it was a lack of engagement with his family members during conversation that he found most difficult: *“people said they just stopped listening to me, my sister said she found it so hard to hear me that she just stopped listening”*. It was clear that these feelings of dismissal or invisibility had significant impacts on the motivation to interact with others; *“you might go*

but you don't participate because you're spoken to, you don't start the conversation off like you used to" (CS2P12), with reports of participants withdrawing from social situations: *"it's only when I look back that I realise how much I've changed, I shy away more than I used to"* (CS2P14).

There was an overriding sense of 'giving up' expressed by the participants due to an inability to participate in conversation because of their volume issues. CS2P11 discussed how other people's inability to hear him caused him to disengage in the conversation going on around him: *"I turn off if necessary, I find it easier"*. This was echoed by CS2P14, who said, in response to continuously being asked to repeat himself, *"you lose the thread of what you're trying to say, so you just shut up"*. CS2P10 also found this to be a problem in her community activities when speaking in a group context: *"I'm on the committee at my home and we meet in a group. I try to think speak louder, but when you get into your spiel as you say people are constantly saying speak up, so now I don't speak at all, I leave it up to them"*.

5.4.4.1.2 Monitoring and Managing Loudness

Participants discussed their experiences of SLT and the strategies they used to manage loudness issues, for example taking deep breaths prior to speaking, or using stock phrases to *"cue me back in"* (CS2P14) to a louder voice. However, it was clear that these strategies can leave individuals feeling uncomfortable: *"when you're in the pub you raise your voice because there's background noise but in a quiet place I would feel like I was shouting. So sometimes the strategy (to speak loud) works but it often wears off"* (CS2P14).

CS2P9 explained how he would practice his loud voice prior to making a telephone call to ensure that he was understood: *"I rehearse what I'm going to say on the phone and then speak loudly, my voice trails off"*, while CS2P8, who had particularly quiet speech, chose to write things down to ensure she was sufficiently able to communicate her message when discussing a cognitively complex topic, a strategy which was not always successful for her: *"I tried to speak to a financial advisor on the phone about things that were going over my head and I had to write down all the main points I wanted to say otherwise I wouldn't get it out, but I found I get embarrassed when the voice doesn't come out when I want it to"*. This highlights the need for a method of managing vocal loudness continuously, in-situ, to ensure that PwP can communicate effectively in all contexts of their life.

Three of the participants struggled with performing their SLT strategies in the first place. CS2P14 and CS2P9 explained how they would forget their strategies in day-to-day life, while CS2P11 just did not understand the reasons behind carrying out specific exercises. There was discussion around the lack of explanation around SLT exercises from the therapist *“I couldn’t understand the point of the exercises, I didn’t see the point”* (CS2P11) and how this could impact on the home based practice of exercises, which is vital to the generalisation of SLT gains into the real world context; *“it’s human nature, you have to understand something to invest in it”* (CS2P14). CS2P9 also commented on the lack of longevity of SLT gains following discharge from the program: *“it was useful but I quickly forgot”*.

For some, the aspect of simply monitoring their volume to aid understanding of how they are being perceived by others was important, an issue which, as previously described (in chapter 2, section 2.2), can be particularly difficult for PwP. CS2P11 explained: *“I don’t know how to gauge the loudness of my voice, whether it’s too quiet or too loud. I don’t have any standard outside which is the equivalent of the people listening to me”*. For CS2P14, he felt a prompt would be useful for aiding self understanding of how his volume changed over the space of a conversation: *“say I was to speak for 10 minutes, it’s a long time, I start tailing off so I need something to bring me back to realise my volume”*.

5.4.4.2 Design Insights

The exploratory design workshop also provided several design insights to take forward into the development of LApp. In relation to the development of an application to help PwP self-monitor and manage vocal loudness, participants felt that the application was a good idea and would be something they would use, even those who were less familiar with using mobile phone applications day-to-day, as long as they were given training on how to use it (CS2P8 and CS2P13). During the workshops different types of cues were suggested by participants (visual, haptic and auditory). There was some disagreement in relation to what would be preferred, with some suggesting audible cues that only they could hear (i.e. through an earpiece), and others preferring visual or haptic cues they could respond to, finding the thought of auditory reminders annoying. Participants came to an agreement that cue preferences depended on context, but all felt comfortable with the idea of using a ‘traffic light’ style visual cue (i.e. green, amber, red), an idea suggested by CS2P14 as

something that would be “*instantly recognisable to a range of people*”. Participants were all happy to trial the application and to wear Glass and noted that they would share their data with an SLT if required. Participants discussed the importance of practising their speech at home, which was something they said waned over time following discharge from an SLT program, and in this context they felt that having a visual representation of their volume would be helpful when practising.

Following the exploratory design workshop came the development and design iterations of the application. LApp was developed in accordance with the design insights summarised above (described in detail in the following section) and was then trialled with, and redesigned following feedback from, a group of 8 people without Parkinson’s or speech issues (5 male, 3 female). This step was included due to the novelty of Glass and the possible complexities relating to the use of Glass itself for the PwP involved in the study, alongside an added complexity for the participants around using a new application on an unfamiliar platform. As such, testing the application with a group of people without Parkinson’s, but who had used Glass before, allowed for relative feedback around the app itself. Participants in this stage were able to provide useful information surrounding the issues with the app prior to testing with the clinical population and they provided several recommendations for a re-design of the app which led to the final iteration used with the Parkinson’s group. The finding from this stage are discussed in the upcoming section.

5.4.4.3 Research Question 5

This stage of the study saw the reiterative design of LApp and, in order to assess the suitability of the application for PwP, involved some preliminary pilot testing with people who did not have Parkinson’s. This stage explored the question: *through iterative design, can a suitable application for Glass be developed to support the self monitoring and management of volume issues?* The following describes the findings from this pilot test and the iterations of LApp that were taken forward to develop the final version to be tested in the field trials with PwP.

The initial design drew upon the ‘traffic light’ idea presented by participants in the exploratory design workshop. This used a red/amber/green coloured system visualised as an orb on the Glass display which fluctuated accordingly with the speaker’s vocal volume (Figure 8). The orb projected to the limits of a white line representing a conversational speaking volume (60dB (SPL) (American Speech and Hearing Association (ASHA), 2011)). The orb was green when speech was loud enough (60dB and over) and changed to red or amber when volume was too quiet (20-40dB, 40dB being the sound level of a quiet room) or nearing an appropriate level (40-60dB) respectively. A feature was added to allow participants to set their background noise level, which required recording a small sample of background noise, while they remained silent, in order to allow for a background sample to be collected in noisy changing environments. This noise level was then compared to the target speech level (60dB) and the difference was added to the target to compensate for the background noise. The application functioned by continuously monitoring the audio stream coming from the Glass’ microphone and passing it to the cueing monitor. The monitor functioned by waiting for a sequence of audio input volume that remained over the target volume for a certain period of time (set to 2 seconds). When such input was recognised, the application generated the visual cue on the Glass display informing the user that their voice volume was at an appropriate level. Cues disappeared after 2 seconds if the voice was not being maintained at the target level.

Following the first design, a Small user study was conducted with 8 participants

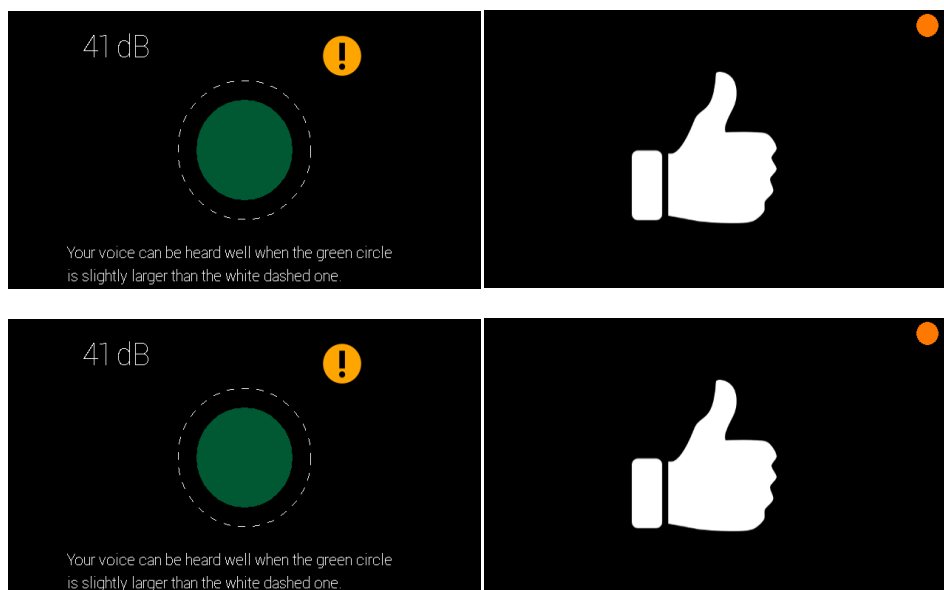


Figure 8: First (left) and second (right) iterations of LApp cue.

without Parkinson's or speech issues. All participants provided very similar feedback about LApp which indicated some required changes. While they found the application easy to access and use, the orb-based feedback mechanisms required too much continuous attention to monitor its size. Instead, participants advocated the use of a cue that could be monitored better within peripheral vision. To this end, the cue was redesigned as a large 'thumbs up' symbol that could be more easily seen peripherally and provide positive reinforcement that appropriate volume levels were being met. When volume reduced the symbol gradually disappeared. Participants additionally had difficulty reaching the 60dB target at times, particularly when in outdoor settings. On reflection, it was realised that it may have been difficult for PwP to reach this target and, given that the aim of the application was to promote increased vocal loudness not reach a standardised dB level, it was felt that having users set their own goals that they felt comfortable with would be more appropriate for maintaining functional gains in day-to-day life. As such, a feature was added that allowed users to set their target volume. Given the issues that have already been discussed in the exploratory design workshop around the lack of perception around vocal loudness that PwP can face, it was decided that this 'target setting' feature would be something used in tandem during the field trials with either the researcher, who would set the target with the participant upon deployment, or a loved one. As such, this activity was set up in two phases; setting the target volume over 10 seconds of continuous speech; and evaluating the target by clarifying if the participant was happy with their loudness, and if their conversation partner found their volume loud enough. If either of these questions were marked with a 'no', the participant would be prompted to record another target sample.

5.4.4.4 Research Question 6

This final research question sought to find out: *how might a digital system, employing in-situ cueing, be valued by PwP in supporting the self monitoring and management of vocal*

Name	Times Accessed	Target dB (TdB)	Above Target (AT)	Below Target (BT)
CS2P8	4	45	8	4
CS2P9	5	45	5	12
CS2P10	3	51	9	11
CS2P11	3	48	13	2
CS2P12	18	55	28	5
CS2P14	11	52	32	6

Table 7: Averages of use data from 3 days of the LApp trial

loudness? In order to explore this question, field trials of LApp were conducted with 6 of the PwP who took part in the exploratory design workshop. Trials were held in their own homes. The researcher visited each participant to deploy the Glass and provide a demonstration of LApp. Trials lasted between 3 and 5 days.

The following sections describe the qualitative data, which was generated into themes from the final interviews with each participant. The interviews gave insight into the ways in which participants used LApp during their deployment phase and the successes and challenges that they had. Four themes emerged from the data; being cued by LApp – conversing and practising, frustrations around feedback, problems with glass, and real life contingencies. These themes are discussed in detail in the following sections.

5.4.4.4.1 Being Cued by LApp – Conversing and Practising

Participants varied in the ways they used LApp. While CS2P9, CS2P10, CS2P12 and CS2P14 took Glass out and about with them to different places, CS2P8 and CS2P11 preferred to use it solely at home. All participants used Glass while talking to friends at some point during the trial. Most of the participants discussed benefits in the feedback the system provided.

CS2P12 immediately found that he was increasing his volume to reach the LApp target: *“it was good for getting your voice up....you had to speak up to get the [icon] on so I found that very good”*. For CS2P12, monitoring his voice was important because, as he said: *“I tend to drift away from this one”*. All participants used LApp for its designed function—as a way to provide in-situ cues related to the loudness of speech. CS2P10 found great comfort in the fact that she was able to confirm her voice was loud enough during a conversation with a hard of hearing friend: *“Going into the conversation, when [friend] said ‘pardon’ twice to me. I had the [thumbs up], so it gave me confidence to know it wasn’t me, it was him [...] every time that someone says pardon to you it knocks your confidence a little bit [...] so it gives you confidence to know that you are not always the one at fault”*.

Some participants felt that the real benefit of LApp however was as a practice aid. For example, CS2P9 discussed his issues when speaking in a group context: *“when there’s a group of us, whenever I do say something everyone says ‘what’ and the longer I leave it to make a contribution to the conversation the quieter the voice gets [...] with certain people it affects me quite a lot”*. He used the LApp more as a home practice aid during the field trial *“reading aloud was good practice I found”* and could see this as a benefit for him in the

future: *“if I was in a situation where I was being told to repeat myself more than I liked I would go away and practice”*. However, he also reported: *“when I’m wearing it I’m conscious of the fact that I have to perform”*. CS2P11 also chose to use LApp in the home environment and when socializing with friends, yet for him it seemed that simply wearing the technology caused a change. This participant had difficulty accessing and using LApp. However, his wife noticed a big change in his vocal loudness during a conversation with friends *“you were speaking quite clearly when you had it on [...] it was lovely to hear you”*.

In relation to wearing Glass, all of the participants said they felt comfortable wearing it, even CS2P10, who had initially said she would not like to wear the blue Glass in public, stated *“I put it on and I forgot about it, it didn’t bother me”*. All of the participants, even those who had a less successful time with LApp, said that they would considering using it again, For example CS2P8 said; *“definitely if I could just conquer it, definitely I would yes”*, and all said that they could see the potential benefit in LApp for helping to monitor and prompt a louder voice.

5.4.4.4.2 Frustrations around Feedback

As noted earlier in the background chapter (Chapter 2, section 2.2.3), perceptions of vocal loudness can be impaired in PwP, leading to difficulties in registering how loud the voice actually is. During the first session, a researcher helped each individual to set a target volume on LApp which was comfortable for them to reach, yet loud enough for the researcher to hear. Despite this, several participants had difficulty reaching and maintaining the target volume once the researcher had left. CS2P14 and CS2P11 found that the LApp *“didn’t work”* or *“just couldn’t pick up my voice”* at points during the trial. During the final interviews (and for CS2P14 during an additional session, where a researcher visited his home following complaints about the application *“just not working”*) LApp functioned as expected: *“when you came round and it was working, 5 minutes later it stopped working and since then I’ve just had a series of disasters, it just doesn’t work”* (CS2P14). On demonstration, it seemed that CS2P14 was in fact trailing off in terms of his loudness, during extended vocalisation, and it was observed that, despite speaking at a sufficient volume, he was speaking in short bursts, producing a disjointed voice: *“in the end I was shouting at the thing...thumbs up!...icon!”*. Considering that LApp was computing average dB over a 2 second time space his overall volume level over the 2 second time period was therefore not

being sustained enough for the app to provide him with a cue. If the quantitative data is revisited for a moment, CS2P14 had the largest average of time when he reached above target, but did not trigger a cue, out of all the participants (average AT value of 33) (see Table 7 for details).

5.4.4.4.3 Problems with Glass

Finally, some of the participants experienced frustrations with Glass, many of which were a result of the Glass platform more generally. While there was an appreciation of the potential of LApp, some found it difficult to set and reset their target volume. The primary issues participants faced related to tremor in their hands and arms which led to difficulties navigating Glass' menus: *"I was touching it, but that's me because I'm a fidgeter with the Parkinson's, but I'd touch it occasionally and set it off on a chain of events"* (CS2P9).

However, a more immediate challenge was that the system lost battery charge very quickly. This caused frustration on occasions when the device was being worn while out and about. Several of the participants found that Glass was not charging effectively and was thus running out of battery before they had the chance to use it as they would have liked *"the batteries gone dead a few times so I've not used it at all or only used it for 10 minutes or so, so it's been hard to do the tasks"* (CS2P14). CS2P9 discussed how even an overnight charge did not help *"I had problems charging the glasses, and in fact I put them on to charge at about 7 last night, so they have about 12 hours to charge and I don't think it will switch on. It switches on but it doesn't stay on"*, whilst CS2P10 expressed frustration around the Glass suddenly losing charge *"I put them on and took them to the garden centre. I felt great, didn't seem like anyone was looking at me, I felt comfortable, I could see my tick, and then all of a sudden it went off"*. While the participants understood that the system was a prototype, there was a level of frustration around the fact that Glass was not functioning optimally as they would have expected.

In terms of the cue presentation, all of the participants felt that the 'thumbs up' icon was appropriate. However, CS2P11 reported difficulties with the screen visibility *"I don't see the screen very easily. I only saw the thumbs up once in the whole time and that was the thing I was looking for"*. In addition, he struggled to hear the voice giving instruction, aptly bringing to light that many older adults have hearing difficulties *"I can't hear that at all. I can hear she's [automated voice] speaking but she speaks so fast. I will not be unrepresentative*

being someone with bad hearing, lots of people my age will have bad hearing". He suggested a slower, more human voice would be more appropriate. CS2P9 also felt automated voice giving instruction was unsuitable and felt a local accent would be more accessible *"the American voice that tells you what's going to happen is important but people would turn and stare when they heard that [...] it just sounds strange"*. There were many difficulties experienced around the sensitivity of the touchpad *"somebody had a bunch of flowers and they went past and that set it off again, the slightest touch"* (CS2P10).

Finally, CS2P10's friend expressed concern that she was becoming distracted by LApp whilst walking around *"she did notice that I was maybe, when I was talking I was noticing the thumbs up, and I was knocking into a couple of things. I wasn't aware of it"*. Although CS2P10 did not feel that it was Glass causing her instability necessarily, considering that her ill health could have been a factor in this, she expressed uncertainty about the cause: *"whether that was my fault, being distracted, or whether she'd never really seen me poorly before with my other thing before, I just don't know. I don't want to blame it [Glass] for something that could well be my problem"*.

5.4.4.4 Real Life Contingencies

There were a few instances of real life contingencies which arose throughout the field trial. A couple of our participants were feeling unwell during the trial, which impacted on their participation: *"I've obviously had my other problem this week so I didn't think that was a fair representation"* (CS2P10) and *"it's just that I'm not 100% well and I just wasn't able to apply myself enough"* (CS2P8). CS2P8 sums up the Parkinson's condition perfectly when she said *"some days I'm better, today and yesterday I've been really bad"*, this highlights the fact that Parkinson's, for many, is variable in the severity of its symptoms, thus we must carefully design future studies to help manage the possibility of unforeseen ill health and day-to-day fluctuations. Other participants reported how their time with Glass had simply been too short: *"I didn't find it long enough, by the end of day 1 the battery was gone so I had to charge it up again and then it was day 2 and day 3"* (CS2P12). Age was considered a factor in the requirement of time to get used to using new technologies: *"old people aren't the best with new technologies [...] you can take a 16 year old girls and say this is how you do it and she'll remember but it takes me quite a few more times"* (CS2P9). CS2P8 echoed this feeling and reflected upon how, for her, learning a new technology was easier when shown to her

by a friend of the same age *“my friend had one [a kindle] when I got it so she was able to show me how to use it”*. She discussed the importance of having *“idiot proof”* instructions to aid use of Glass.

This case study was used to investigate the ways in which PwP might value an in-situ cueing system to support them in the self management of, and reflection on their vocal loudness. While participants found benefit for the cueing method in both increasing their understanding of their vocal loudness and enhancing their practice routines, there were frustrations around the use of the Glass platform as the mode of delivery for these cues. The following discussion section will reflect on the potential of the glass platform as a system to support PwP in the self monitoring and management of Parkinson’s, drawing from both the phase 1 and phase 2 case studies. The discussion will move to consider the in-situ cueing method that was explored, the lessons learned from the LApp study and what this means for future research.

5.5 Discussion of Case Study 2

The following sections discuss how Glass can be situated within the context of self monitoring and management technologies for PwP and contemplates what this might mean for future researchers wishing to explore the potential of novel consumer technology platforms for health in the future, particularly in the context of older user groups with long term degenerative conditions. Within this case study, the work has explored the potential of a completely novel, off the shelf, head worn technology, in the management of Parkinson’s symptoms by probing its acceptability among the Parkinson’s community. This yielded a further piece of work which implemented an application on the Glass platform to enable the in situ self monitoring, and subsequent management, of vocal loudness problems in day-to-day conversation. This case study explored the ways in which Google Glass—framed as a wearable platform for everyday health monitoring and management—may support people with Parkinson’s day to day (acceptability) and more specifically with speech volume issues (LApp).

5.5.1 Glass within the Context of Self Monitoring and Management Technologies for Parkinson's

Participants within the phase 1 study around the acceptability of the Glass platform discussed many issues that they had when interacting with smartphones, both in terms of actual usability and in manipulating a handset when out alone. Glass was thus initially perceived by participants as having positive features, due to its easily accessible position on the head and its modes of interaction through the touchpad and voice. There was value placed around the voice recognition feature, which could alleviate many of the issues that PwP have when interacting with smartphone touchscreens. In the focus groups even those participants with speech impairments had, in their view, surprising success with the voice recognition. In the field trial, however, when using the Glass over longer periods of time, several participants had issues with the glass interaction, finding that the scrolling gesture was too sensitive, as was tapping—where double and often more consecutive taps brought about through hand tremor directed participants into cards (apps) that they did not mean to go into. Voice recognition also caused an issue during the field trial.

There are some possibilities for this juxtaposition of experiences between the focus group and field trials. Firstly, participants were supported in their experience with Glass in the focus group, by the researcher—who was on hand to model ways of interacting with the device and to answer any questions participants had as and when they arose—yet during the field trial they only had an information booklet to refer to. There is a certain level of comfort that comes when in a group setting, where everyone is trying something for the first time and the experience is supported, whereas at home, frustrations arise when feelings are associated with one's own ability. More importantly, it should be considered that participants were using the technology over the course of a week, during which, due to the nature of Parkinson's, they were experiencing fluctuation in their Parkinson's symptoms. As this is a common feature of Parkinson's, these symptoms fluctuations should be carefully considered when designing user interfaces for PwP. Future research should consider a larger study, which would be applicable across a multitude of technologies, which looks at the interaction capabilities of PwP and how this might impact the design of touch gestures and voice recognition.

One suggestion could be around having a voice calibration stage for PwP, which could resolve this issue for main vocal commands like 'ok Glass' and 'take a picture', assigning the

specific voice of the individual to certain commands. Further work should also consider the swipe and tap gestures, and recognising the gestures of someone with Parkinson's. For the loudness application that was developed for phase 2, there were some efforts made to counteract this effect. The LApp was brought to the start of the list upon start-up so participants did not need to scroll through the timeline to access it. Also, LApp remained continuously running in the background which meant participants could instantly re-access the app when they took off and put on the Glass. However, as was seen during the field trial, this cause considerable drain on the battery life. If these types of technologies are to be used to support an individual across their day, more research is require into finding ways to improve interactions with the technology without compromising the battery life of the device.

In phase 1 there was much discussion around a loss of confidence and independence due to Parkinson's, defining a clear need for finding ways to support feelings of autonomy within individuals. This was an issue that was also shared by the carers within the focus group. In a paper by Nunes and Fitzpatrick (Nunes & Fitzpatrick, 2015), which describes the self management of Parkinson's and other chronic conditions as a collaborative experience between both patient and carer, the authors studied the complex and dynamic collaborative experience that occur between the patient carer dyad in the context of self-care. They call for much more interest in the roles of carers within the self monitoring and management of Parkinson's and discuss the need for the development of technologies that involve the role of the carer within its design. These complex roles were certainly uncovered within this case study. In the phase 1 focus group, it was clear that participants greatly valued this role of the carer yet had a desire for independence. When considering use cases for the Glass within their everyday lives, participants, in fact, associated the independence they could gain from using a technology such as Glass with linking them more easily to their carer. However, it was more the easy access of the technology that created the perception of safety, whereby there is already an existing link to the carer with a mobile phone, however, due to difficulties experienced with accessing and using the phone they did not place the same level of trust in its use in an emergency situation. What participants described was a need for support from a carer to help them self manage a Parkinson' symptom, like freezing, at times when they required help, by being able to see where they were and offer instruction and support. In

this sense, the in-situ prompting option can support this need by fulfilling the requirement of the carer, to help the PwP at times of need, whilst maintain their independence.

The aim with this study was to elicit rich initial impressions of Glass based upon the existing, rather limited, selection of apps and functions the device provides. However, there are a range of unexplored potentials for Glass which could be explored in the future. For example, utilising the on-board sensors to detect, and respond to, oncoming OFF periods for someone with Parkinson's. Clinical studies have already shown the potential of using sensors to detect ON/OFF motor fluctuations (Bonato, Sherrill, Standaert, Salles, & Akay, 2004). Context aware medication reminders and information logging capabilities could prove advantageous in the monitoring and management of medication use, providing both clinicians and the individual with Parkinson's an insight into how well their medications are working. Equally, cueing for freezing has been shown to be successful for PwP (Mazilu et al., 2014; Nieuwboer et al., 2007). A person who is seemingly unable to move can be cued into initiation through having a simple visual cue in the form of someone's foot, a laser spot or a walking stick which they are then able to step over. A visual overlay displayed on Glass to provide a cue for people experiencing freezing episodes could prove beneficial for people experiencing this symptom.

This section has considered the possible use cases for Glass based self monitoring and management systems for Parkinson's. It has discussed the successes and challenges of Glass as a platform for the provision of these self monitoring and management systems and has made suggestions for future designers wishing to work alongside PwP with these types of platforms in the future. The following section will move to discuss the LApp specifically and how the participants valued the in-situ cueing method.

5.5.2 Lessons Learned from Phase 2 around in-situ Cueing

Participants discussed a loss of confidence relating to their voice and how this often led to them disengaging in group conversations, and in some cases social interaction altogether (section 5.4.4). These experiences sit within the previous literature around the impact of speech and voice changes in Parkinson's (Miller et al., 2006) and show the motivation of our participant to want a change. Participants reported already using some strategies learned in SLT however others were still awaiting SLT, or had only had minimal input. There was also discussion around the fact that participants were unable to gauge their volume and how

others perceive their voice (CS2P11 and CS2P14). As such, the in-situ promoting provided in LApp was valued as a way to not only improve vocal volume (CS2P11 and CS2P12) but also to gain confidence in ability by confirming that vocal loudness was at an appropriate level (CS2P10). Having a visual representation of speaking volume was thus valued by participants. Although participants had originally suggested the use of a traffic light system—so they could see when they were too quiet, reaching appropriate volume or loud enough—the visibility of this style of cueing was deemed to require too much attention when trialled by the group of non-Parkinson’s users. They felt that having to constantly monitor the changing cue made simultaneous walking and talking a particularly complex task. This was an important insight from the intermediate trial, as there were concerns over participants’ concentration and safety when in public. Also, there was a requirement for the technology, which was aiming to support loudness within daily life conversations, to enhance engagement in natural conversation, not detract from it by having to constantly look at the glass display. The original traffic light idea was particularly selected due to its familiarity, however participants selected the cue presentation because they were interested in knowing more about their volume. By changing the cueing visualisation the use of the app was made simpler, however the amount of information being provided to participants was also reduced, in that they were only seeing when they were loud enough, not when they were reaching an appropriate level, or how low their voice was when speaking too quietly. This is a consideration to be taken forth into future research and something that was explored in the third case study (chapter 6). There was a necessity to further explore how much information about their speech that participants really wanted.

There was also discussion around how SLT exercises, whilst important, were often not generalised into daily life situations, with participants forgetting to use them (CS2P9 and CS2P14). For one participant (CS2P11), he did not even see the point of conducting his SLT exercises because he did not understand the reasoning behind doing them. Many of the exercises prescribed in SLT could be construed as abstract, with individuals often being required to carry out tasks such as sustaining a loud ‘ah’ sound. Although SLT is based on theory and evidence, there was a desire for increasing knowledge and understanding around the reasons why exercises are being carried out, and more generally around understanding their own voice changes. In this sense, LApp provided an indication of when participants were loud enough, in order to facilitate the formation of an understanding around what an

appropriate volume was, and how it needed to be sustained over time. However, what LApp did not do was provide the necessary information around *how* to increase volume. This knowledge was placed on the participants themselves to remember, and know in the first place, how best to increase their volume and by how much. For the participants (CS2P14 and CS2P10) who had undergone Lee Silverman Voice Treatment (LSVT), which is described in chapter 2 (section 2.2.1), which focus on learning the skills required to gain and maintain a loud voice, they had the necessary skills to do this. However, for the others there was perhaps a need to facilitate the practice of ‘being loud better’. The next case study begins to address these points through the development of a supported practice area.

5.6 Summary of Chapter 5

This chapter has described a two phase case study exploring the potential for Glass to support the provision on an in-situ cueing method for the self management of vocal loudness, and to encourage reflection around the times that loudness was reduced in everyday situations. It first described an acceptability study, which examined participants’ pre and post use perceptions of Glass, its usability and its potential as a useful platform for PwP. It then described a second study which saw the design, development and field trial of LApp, an application to aid the self management of vocal loudness. While participants saw the value in LApp in supporting their loudness, there were several insights from this study which highlighted the desire for participants to understand more about their speech and the SLT strategies that they were required to do in order to improve it. While the in-situ cueing method was seen to have value in both a real life and practice context, there was still very much an onus on participants to make sense of and quickly interpret their voice data to support on the spot changes in their vocal loudness. The final case study in the following chapter addresses some of these issues by aiming to support PwP in gaining an understanding of their speech and voice changes and supporting the practice of specified strategies which have been shown to improve aspect of speech impairment.

Chapter 6

Crowdsourcing as a Method for Enhancing Self-Monitoring and Management of Speech and Voice in Parkinson's

The last two chapters have explored the potential for cueing as a self management option for PwP. The first case study (chapter 4) looked at the symptoms of drooling and the ways in which temporal cueing could be used to encourage increased swallowing frequency, thus clearing saliva from the mouth more often and decreasing the risk of drooling from occurring. The second case study (chapter 5) focused on in-situ cueing as a way to prompt PwP experiencing speech volume problems to increase their loudness during everyday conversation, at times when it was needed, and reflect upon the times that their volume was reduced in everyday life. Both case studies have provided useful insights into the value that PwP might place on technologies to help the self monitoring and management of their condition.

However, in the previous case study (chapter 5), there were several needs highlighted by participants that are yet to be explored. Firstly, whilst the in-situ cueing method allowed users an insight into the times *when* they were not speaking loud enough, and allowed them to begin to build an internalised understanding of how much they needed to increase their volume by to reach their 'target loud voice', there was a desire from participants to understand more about *how* to improve their voice at these times. In addition, there was appreciation of the benefits that LApp provided in understanding how others perceived their voice, and as a way to facilitate home practice of voice, which were not the original envisaged use for the device. These insights provided direction for the work presented in the final case study, which explores how technology might be used to support PwP in obtaining feedback around their speech (to encourage reflection around how they are perceived by others) and provide a structured area with which to facilitate the practice of their speech (to support an understanding of how speech can be improved).

This chapter describes the development of Speeching, a simple mobile phone application to support the self monitoring and management of speech parameters in PwP.

The application was designed specifically to account for some of the known challenges with mobile phones that were discussed by participants in the previous chapter. The chapter begins by discussing the crowdsourcing literature pertaining to speech analysis and its application in health areas, before considering the current approaches towards measuring speech intelligibility using digital means. It then moves to describing the case study, which is implemented over two phases. The first phase explores the potential of crowdsourcing for the provision of diagnostically relevant information around speech and voice changes in Parkinson's, by a novice (inexperienced with impaired speech) crowd, and investigates the success of a range of crowdsourcing tasks, which included the use of open and closed rating scales and word selection tasks. The novice crowd were configured in two ways—as a local crowd familiar with the local accent, and as a larger, national crowd, recruited anonymously via a pre-existing crowdsourcing platform. The ratings of the novice crowds are compared against those provided by the experts and experienced SLT groups. The second phase of the case study explores the development and in the wild field testing of *Speeching*, a mobile application that uses crowdsourcing to support the self monitoring and management of speech and voice issues for PwP. The application allows PwP with speech difficulties to complete short voice tasks and record audio, which is then rated and assessed by crowd workers. *Speeching* then feeds these results back to participants, to provide them with examples of how they were perceived by listeners unfamiliar to them (thus not used to their speech patterns). The chapter ends with a discussion of the lessons learned throughout the case study and outlines several directions for future work of this kind. This is reflected on further in the final chapter (chapter 7) which outlines the overall discussion points and conclusions surrounding the thesis.

The following section provides an overview of some of the current examples of crowdsourcing literature within the health domain and then moves to consider the literature surrounding the collection and analysis of speech data.

6.1 Crowdsourcing Health

Crowdsourcing refers to the outsourcing of tasks to a large network of people on the internet (Wichmann et al., 2011). Mini tasks are given to the 'crowd' enabling a larger task to be completed quickly, easily and inexpensively (Wolters et al., 2011). Crowdsourcing involves the outsourcing of tasks to an online community of 'workers', who are not

necessarily experts in the domain of the research, through an open call (Wichmann et al., 2011). There are several large, pre-existing crowdsourcing platforms (e.g. Amazon Mechanical Turk (AMT), Crowdfunder) where crowdsourcing 'jobs' can be posted online, with a description of the necessary task to be completed, for workers to fulfil. Payment is set by the job poster and can often be below minimum wage, which has prompted ongoing ethical questions over the economics and labour of crowd work (Dolmaza, 2011). Job posters can specify certain features from the workforce (e.g. being a native English speaker) and can ensure that the quality of work being supplied by the crowd is sufficient by including control tasks, to which they know the answer (e.g. transcribing a piece of audio). Pay can be withheld if workers do not meet the quality controls set by the job poster and workers can be blocked from completing any further jobs if necessary.

The technique of crowdsourcing was first embraced by computer science researchers as a workaround to solving computationally difficult artificial intelligence problems (von Ahn & Dabbish, 2004). Since those origins, the technique has gained more widespread credibility as an experimental platform, in part due to classic behavioural results in experimental psychology being successfully replicated on the platform (Crump, McDonnell, & Gureckis, 2013). The potential of crowdsourcing has not been lost on the healthcare technology community, which has explored how existing online communities (e.g. Patientslikeme, 2015)) can provide new sources of patient data for research. Much crowdsourcing research in healthcare has focused on the collection of data from people, to understand, for example, whether members of large online health communities can act as representative patients of wider populations and provide a flexible source of data for studies (Bove et al., 2013); to utilize the personal data already being collected by health communities around themselves to gain new understandings into preventative medicine (Swan, Hathaway, Hogg, McCauley, & Vollrath, 2010; Swan, 2012); or simply to understand how online communities function in a supportive role among specific patient groups (Wicks et al., 2012).

Alongside these approaches, others have appropriated crowdsourcing to facilitate the analysis of patient data. In some cases, this involves the outsourcing of data to a crowd of experts. For example CrowdMed (<https://www.crowdmed.com/>) which has been implemented in real world medical communities for the diagnosis of complex medical conditions, as well as work by Xiang et al (Xiang et al., 2014) which explored the crowdsourcing of medical images to aid diagnosis of complex, undefined cases amongst

General Practitioners. There has also been a strand of work focusing on the use of non-expert crowds in the analysis of large scale clinical data, including the use of online games to support the identification of malarial parasites within blood samples (Chunara et al., 2012); the prediction of genomic protein structures (Cooper et al., 2010); and the classification of colonic polyps within radiography scans (Nguyen et al., 2012). Beyond the healthcare context, crowdsourcing has been used as a means for users to gain semi-instant feedback on questions relating to their everyday lives. For example, *VizWiz* (Bigham et al., 2010; Burton et al., 2012) is a smartphone application that provides near real-time feedback on visual information to blind people.

However, as of yet, there has been relatively little work that has examined how non-expert crowd workers might support issues of health self monitoring and management in real world settings. The work presented in this case study builds upon this prior research, by leveraging the crowd to provide real world feedback in the context of self monitoring and management practices surrounding SLT for PwP.

6.2 Crowdsourcing for Speech Data

A number of researchers have explored how crowdsourcing can be applied to speech analysis problems. Crowdsourcing has been used for the collection (McGraw, Gruenstein, & Sutherland, 2009) and transcription (Audhkhasi, Georgiou, & Narayanan, 2011; Marge, Banerjee, & Rudnick, 2010a; Parent & Eskenazi, 2011; Wolters et al., 2011) of speech data, as well as enabling the refinement of speech recognition systems (Goto & Ogata, 2011). Others have examined the use of crowdsourcing techniques to measure the quality of speech samples. Parent & Eskenazi (Parent & Eskenazi, 2010) highlight the value of using measures of intelligibility (or to be exact understandability) in their study, where they invited AMT workers to classify short utterances produced by users of a transport information system. They asked workers to classify utterances as understandable (U)/ non-understandable (NU) and then, if understandable, asked them to identify whether a transcript from automatic speech recognition (ASR) was correct (UC) or incorrect (UI). The second stage saw workers transcribing verbatim utterances that were UI to fix errors produced by the ASR system. This process allowed for a quick 'crowd-patching' of the ASR system, without the need to spend excess time and money asking the crowd to transcribe the entire data set.

Marge (Marge et al., 2010a) looked at the reliability of using AMT for transcribing spoken language. They compared AMT transcriptions with in-house standard manual transcription and found word error rates to be approximately 5% in disagreement with the gold standard, which was created by three trained transcribers (with an initial transcription being produced and then cross checked for error by two other people). The accuracy of transcription was improved by combining multiple transcriptions using the ROVER (Recogniser Output Voting Error Reduction) method developed by Fiscus (Fiscus, 1997) (which is a tool that combines word outputs and then suggests the best possible outcome, yielding a "voting" or rescoring process to reconcile differences) to a disagreement rate of 1.5-2.5%. In addition, they found no effect on accuracy of smaller payment when compared to larger ones. Marge et al. furthered their work by looking at the reliability of using AMT for transcribing spontaneous speech samples (Marge, Banerjee, & Rudnicky, 2010b) and found accuracy to be approaching expert agreement, thereby highlighting how using small segments of speech might yield faster turnaround time and better transcription accuracy. In regards to the rating of perceptual aspects of speech, Evanini and Zechner (Evanini & Zechner, 2011) studied the use of crowdsourcing for annotating prosodic stress and boundary tones in a corpus of spontaneous speech from non-native speakers. They compared expert annotations with naïve annotators and found a high level of agreement, with only 3 naïve annotators being needed to match the agreement of 2 experts. Their workers were given training and information regarding what was meant by the prosodic properties the researchers were looking to annotate.

These studies provide a range of examples of crowdsourcing for speech data, and have highlighted a number of methodological considerations in this domain. Lessons from the literature that were taken forward into the design of the crowdsourcing method employed in this case study included: the use of small segments of speech over larger samples (Marge et al., 2010b); exploring the use of 3 raters to compare to expert ratings (Evanini & Zechner, 2011); and the importance of providing sufficient information to raters around complex perception measures of speech (Evanini & Zechner, 2011). However, whilst the literature provided information around practical methodological considerations, none of the above examples explored the analysis of impaired speech for clinical populations in their work. In this sense, there are specific complexities to take into account around understanding *why* speech is difficult to comprehend (e.g. is it low volume, slurring of words,

fast speaking rate) and how the information derived from the crowd might provide clinically useful feedback. The following section explores some of the technical solutions which have been explored, in an attempt to support intelligibility measurement within clinical populations.

6.3 Measuring Intelligibility: Towards Technical Crowdsourcing Solutions

A detailed description around the speech and voice changes which are commonly seen in people with Parkinson's and the impact that these changes can have on their lives has already been outlined in chapter 2 (section 2.2) as well as the process of assessment that is conducted by a Speech and Language Therapist (SLT) (in section 2.2.1). As such, this section will summarize these points for context but will focus its main attention on the ways that previous research has attempted to provide technical solutions towards the measurement of speech intelligibility.

Common changes in Parkinson's speech can include a reduction in volume, changes to speaking rate (e.g. speaking in short bursts of speech) and reduced variation in pitch (causing a monotonous quality to the speech). In addition, perceptual vocal quality can become impaired, leading to a hoarse, rough, breathy or tremulous speaking voice (Holmes et al., 2000; Skodda & Schlegel, 2008; Skodda, 2011; Tjaden, 2008). For the speaker, these changes can cause loss of confidence and embarrassment, particularly when speaking with strangers and can lead to a tendency to avoid social situations altogether (Miller et al., 2007, 2008, 2006).

To assess speech an SLT typically elicits a range of different speech samples from different contexts (e.g. spontaneous speech, reading, single words, sentences). These are then subjected to a range of analyses designed to uncover underlying impairments and identify targets for intervention. Analyses may involve, for example, phonetic inventories, examination of the distribution of sound errors in words or sentences, acoustic analyses, comparison of speech rate to norm values, and so forth.

In order to assess pure intelligibility, a percentage of words correct score can be derived by asking the speaker to say a list of carefully designed single words (to elicit a full range of sounds in different word positions and contrasts) and recording the number of words that are correctly identified. An analysis of the misheard words can deliver targets

for intervention, in terms of which sounds, or sound contrasts, cause problems with intelligibility in different contexts or word positions. As a further instance, comparing single word and sentence reading samples allows the therapist to judge the person's speech intelligibility without the added context a sentence would provide. For example, - the word 'shop' might be unintelligible when spoken in isolation, however, with the added context of the sentence 'I bought bread at the shop' the message might be understood.

Longer reading samples (sentences and paragraphs) allow the identification of changes in variables such as volume, pitch (variability), rate and voice quality. Identification of impairments here would lead to further assessment to find out why the particular variable is altered. For example, if the PwP does not have the respiratory support to produce a longer speech sample, or they attempt to say the whole utterance on a short single breath, this can cause the words to be produced in short bursts, and at a rate that challenges the changed motor control aspects of the articulators (i.e. any of the vocal organs which aid in speech production, e.g. lips, tongue, larynx). Another type of sample which might be collected is 'spontaneous speech', wherein the person discusses a topic of their choosing. In this case, the structure of reading is removed and the added cognitive load around thinking about what to say might cause difficulties with the individual's speech production when resources are depleted across dual or competing tasks.

One issue with this procedure is the fact that SLTs are highly specialised and experienced in listening to impaired speech. It has been demonstrated in controlled experiments that familiarity with someone's speech, whether this is an SLT or non SLT listener (e.g. a person who might have a loved one, or work with people who have speech issues) leads to better recognition of words in impaired speech (Miller, 2013), and might, therefore not be reflective of how the person is understood by unfamiliar listeners (in a person's real life this could be, for example, someone at the bank they might need to telephone or a family friend who has not seen them for a long time).

In response, there has been recent interest within the clinical domain around the role that digital systems might play in supporting speech intelligibility testing with unfamiliar listeners, conducted remotely via online digital platforms. Ziegler and Zierdt (Ziegler & Zierdt, 2008) proposed the *Munich Intelligibility Profile (MVP) online* system as a

means to remotely provide SLTs with intelligibility judgments on dysarthric³⁹ speech from a group of paid volunteers. The samples that listeners provided judgements on were either single words (by listening to the sample and selecting the word from a set of ‘foils’ or similar choices) or ‘embedded’ sentences which are made up of contextually neutral sentences which do not have any implied meaning that could provide additional context to the target word (e.g. the word X is not easy). While MVP online proved successful (showing a decrease in individual listener deviation from the mean with increased numbers of listeners), the system still required a level of external control—speech samples that were submitted for analysis were collected in a clinical setting and reviewed by a SLT. In addition, moderators assigned speech samples to listeners and collated and reviewed listeners’ responses. As of yet, the concept of conducting unsupervised data collection and analysis for the purpose of speech and voice intelligibility testing is yet to be explored.

Within the context of speech intelligibility testing, the availability of large, affordable and spontaneous workforces through crowdsourcing platforms allows for the inclusion of a huge number and variety of non-expert listeners. While no previous work has yet examined the potential for crowd workers to provide speech analysis that can feed into a programme of speech therapy, the use of pre-existing crowdsourcing platforms in providing diagnostic speech ratings is emerging. Byun et al. (Byun, Halpin, & Szeredi, 2015) asked untrained listeners, opportunistically recruited on AMT, to classify speech samples from children with /r/ misarticulation as either correct or incorrect, and compared those judgments to those of experienced listeners. They found that the agreement between those two groups of listeners was extremely high ($r=0.98$) and highlighted the potential for crowdsourcing to play a greater role in SLT practice. However, while this binary approach holds promise, there is currently little understanding of how more intricate measures of intelligibility can be elicited through crowdsourcing practices.

The rest of this chapter describes the design, development and evaluation of Speeching and attempts to address these gaps in the literature by: (1) exploring novel methods towards both eliciting and collecting real world speech samples; and (2) exploring the potential for crowdsourcing in the analysis of samples to be presented directly back to the individuals who submitted them. The case study was conducted in two phases. The first

³⁹ Dysarthria is a motor speech disorder characterized by unclear articulation of words. PwP experience hypokinetic dysarthria characterized by reduced volume, abnormal speaking rates and harsh or breathy vocal quality (Darley, Aronson, & Brown, 1969b).

phase aimed to demonstrate the feasibility of using anonymous online crowd workers to rate impaired speech (this phase 1 study is described in the following section). The second phase involved a real world deployment of the Speeching system - the collection of samples from, and provision of feedback to, PwP, unsupervised, in their home environment.

6.4 Phase 1: Exploring the Potential of Crowdsourcing for SLT in Parkinson's

In this first phase of the study, the main aim was to explore the development of a set of crowdsourcing tasks which might elicit expert level ratings around Parkinson's speech. Building on the model presented by Ziegler and Zierdt (Ziegler & Zierdt, 2008) it moved a step further by probing how well designed crowdsourcing tasks could elicit effective, yet unsupervised, ratings of Parkinson's speech intelligibility. In this phase, the speech ratings of experts (the gold standard) were compared with different groups of listeners, in order to explore which configuration of the crowd might be most suitable for the study. As it was still unclear how a digital system might be used to support the crowdsourced rating of complex speech parameters (such as vocal loudness, pitch variance and rate) by inexperienced listeners (i.e. without SLT training) there were three crowd types explored: SLTs (with experience), novice listeners local to the area (without experience but with a familiarity with the local accent) and novice listeners recruited via AMT (without experience and supposed unfamiliarity with the local accent).

The following discussion of this phase 1 study first discusses the development of an online crowdsourcing platform for the analysis of Parkinson's speech samples. It defines the specific set of crowdsourcing tasks that were designed to extract expert level ratings of speech and voice in Parkinson's. It then provides a comparative analysis of the obtained data, and discusses the wider implications of this work for the development of future systems incorporating crowdsourcing for the analysis of disordered speech. This study then moves to reflect upon the type of information that was successfully drawn from the novice crowds and how this could be employed within the extended domain of SLT for the self monitoring of speech changes in Parkinson's. There were 2 research questions being explored within this phase of the study:

1. Which crowd formation provides the highest correlation with the experts when rating Parkinson's speech?

2. Which types of task provide the highest correlations with the experts?

6.4.1 Phase 1 Methods

6.4.1.1 Selecting the Speech Samples

In order to cover the main elements of impairment within Parkinson's speech, as identified in the literature (see chapter 2, section 2.2), the issues of rate variation, pitch variability and volume reduction were selected to investigate. To ensure the standardisation of speaker data for the study, excerpts from a pre-existing data set of speech, collected from 125 PwP under controlled conditions, was used to serve as stimuli for the work. This data set was originally collected for a study by Miller et al (Miller et al., 2007) which explored the prevalence of speech intelligibility impairment in PwP and how these changes were perceived by listeners who were unfamiliar with Parkinson's speech. All speakers were recruited from the North East of England, and had a diagnosis of idiopathic Parkinson's. The researcher⁴⁰ navigated the 125 samples and informally coded each sample for overall perceptual severity (mild, moderate, severe). She also rated the extent to which the parameters of volume, rate and pitch affected the intelligibility of the speaker (by rating them in the same manner with a mild, moderate or severe effect), which was required for the selection of mid-range exemplars for these parameters (the relevance of which will be discussed in section 6.4.1.2). In order to avoid bias, another member of the research team then used this coding system to select a sample of 12 speakers from the entire dataset. Speakers made up equal categories of mild, moderate and severe intelligibility problems, with 2 male and 2 female speakers in each category. Each speaker provided 10 single words which had been read out individually from a pre-defined list designed to elicit a range of different sound contrasts (unconnected speech) and 9 sentences (connected speech) taken from a reading sample, the 'Grandfather Passage' (Darley, Aronson, & Brown, 1975).

⁴⁰ The researcher is trained as an SLT and has experience in both clinical SLT testing (both formal and informal) and Parkinson's speech.

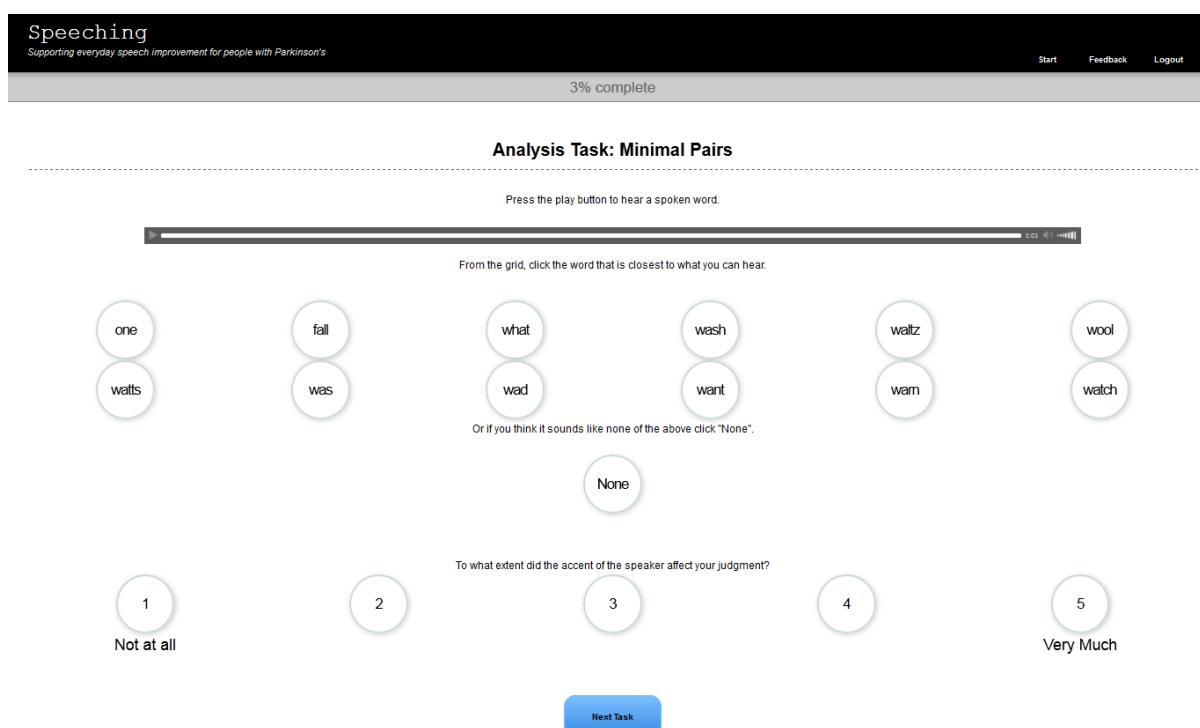


Figure 9: Phase 1 screen capture of the word recognition task

6.4.1.2 Designing the Crowdsourcing Tasks

This stage of the process involved working alongside an expert in Parkinson’s speech to design the Speeching analysis tasks. The tasks were designed in a manner similar to standard SLT assessment (described above in section 6.3). The first category of speech sample chosen to study was unconnected speech, or single words, providing a measure of intelligibility in isolation, without any additional context that might add to a listener’s ability to make sense of the message being expressed by the speaker. Crowd members were asked to select the target word from a set of 12 similar words (e.g. what, waltz, watch, want) in a ‘word recognition test’ (see figure 9). There were a total of 10 carefully selected single words (eliciting a variety of different sounds contrasts) within each assessment that was carried out with the speakers. Each individual word and its associated foils were presented to the crowd, who listened to the audio and selected the word that they thought had been spoken (see example in figure 9). The responses from the crowd were then given a correct/incorrect code and the results were then aggregated across the total 10 word assessment, giving an overall percentage of words correct for the speaker.

The second set of speech samples were sentences (connected speech). For these, two types of rating measures were applied to each sample. The first was an Ease of Listening

(EOL) rating (see figure 10), to provide a subjective measure of how much effort it took to understand the speaker. This five-point scale has been used successfully in the past with novice listeners unfamiliar with dysarthric speech and was found to have a strong correlation to intelligibility scores (Landa et al., 2014; Miller et al., 2007). The second set of ratings, addressing perceptual measures of rate, pitch variability and volume, involved more complex judgments.

When rating speech quality, Likert scales lack sensitivity (Côté, 2011; Miller, 2013) but the use of continuous scaling systems can mitigate some of this difficulty (Côté, 2011). One method which has been previously used for perceptual intelligibility measures is Direct Magnitude Estimation (DME), whereby an anchor, or midrange exemplar, of impaired speech is played to the listener, who then estimates how far this deviates from the anchor (e.g. 50% more intelligible; 10% less), to allow for an estimation of the magnitude of difference (Weismer & Laures, 2002). As the non-SLT crowd workers were not experienced in disordered speech, this concept of providing a mid range exemplar was drawn upon, to provide workers with an example of impaired speech to base their ratings on (see figure 11). This was included to account for the possibility the crowd might exhibit a wide variability in

Speeching
Supporting everyday speech improvement for people with Parkinson's

Start Feedback Logout

1% complete

Analysis Task: Ease of Listening

Press the play button below to listen to a sentence being spoken, and answer the questions that follow...

Please rate how easy it was to understand the speech in this audio clip

1 2 3 4 5

No Problem Totally Unrecognisable

To what extent did the accent of the speaker affect your judgment?

1 2 3 4 5

Not at all Very Much

Next Task

Figure 10: Phase 1 screen capture of Ease of Listening Task

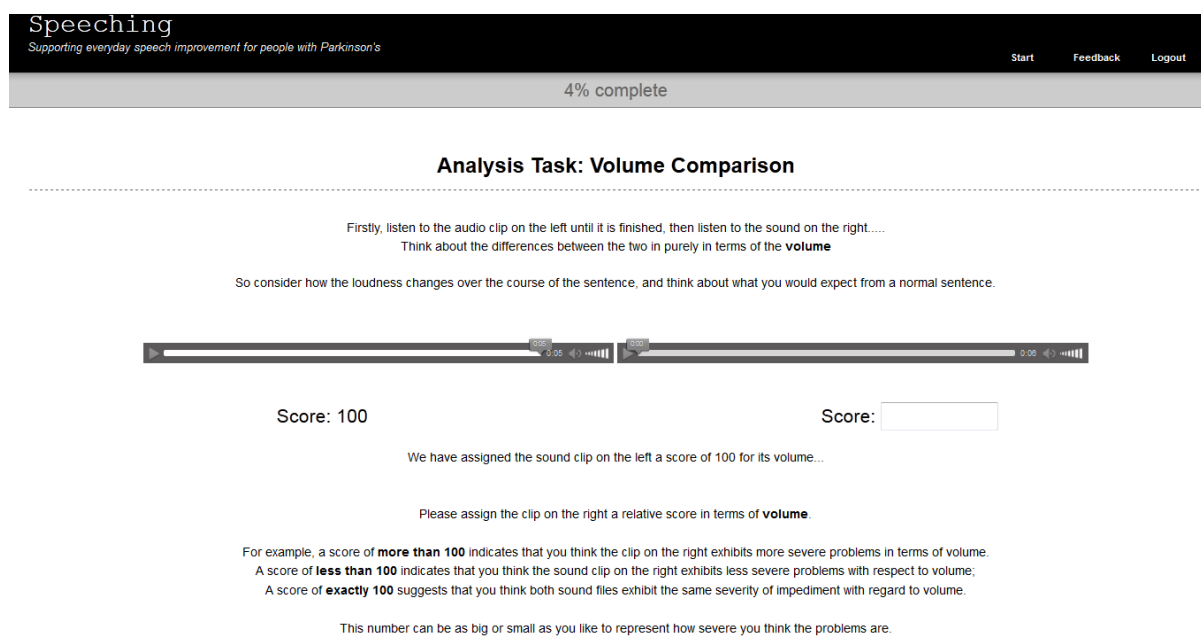


Figure 11: Phase 1 screen capture of Volume Analysis task

their judgments of volume, pitch variability and rate, (with each worker having a variable internal understanding of impairment).

In order to select the mid-range exemplar sample, one male and one female speaker representing a moderate impairment in each measure (pitch variability, rate and volume) were selected from the original data set of 125 speakers that had been analysed by the researcher (described above at the end of section 6.4.1.1). These mid-range exemplars were not from speakers who had been included in the subsample of 12 speakers for crowdsourced analysis that were being tested. Mid-range exemplar samples were gender matched to the participant samples that were used in the final dataset, to account for any natural pitch difference that might be heard in the male vs. female voice which might skew results by becoming the focus of difference. Raters were asked to listen to the mid-range sample and then a sample from another one of the speakers and were asked to provide a comparative rating. The mid-range samples were given a score of 100, to allow for the crowd to score above or below the mid-range sample, with a score of less than 100 indicating that the second sample was less impaired (in the parameter being studied) than the mid-range and a score of more than 100 indicating that the second sample was more impaired than the mid-range.

Finally, given that the speakers were all from the North East of England, a rating scale to determine the effect that accent might have had on the intelligibility of their speech was also included (as seen in figures 9 and 10), to explore whether or not there was an accent effect experienced by the anonymous AMT group, who were not familiar with the local accent. A 5 point Likert scale asked workers to indicate to what extent the accent of the speaker affected their judgement—with 1 being ‘not at all’ and 5 being ‘very much’.

6.4.2 Participants

A total of 82 crowd workers were recruited to take part in the study and were sectioned into four distinct categories:

- 1) Two highly experienced experts in Parkinson’s speech to act as a ‘gold standard’.
- 2) Twenty-two practising SLTs, who were recruited online via email and social media.
- 3) Twenty-five local (to the North East of England) listeners, with no experience in SLT or Parkinson’s but who were familiar with the accent of the speakers. They were students and staff of Newcastle University.
- 4) Thirty-three native English speakers opportunistically recruited from AMT (who were from the UK)

The expert, SLT and local groups volunteered their time and were not paid; the AMT group were paid at the USA minimum wage (please note that AMT is a USA based platform) at a rate of \$7.25 per hour (£4.78).

6.4.3 Distribution of Tasks via the Speeching Platform

There were a total of 228 crowdsourcing tasks presented for completion (each of the 12 speakers provided 10 single words in the word selection task and 9 sentences, from the Grandfather Passage, which were subjected to EOL and DME analysis). It took approximately 120 minutes to complete the entire task set (228 tasks).

In order to obtain a set of expert ratings for the study, to act as the ‘gold standard’ for comparison, experts were asked to complete the entire dataset. All other groups were asked to do as much or as little of the tasks as they desired. However a suggestion was made to complete at least 25% of the set. This figure was decided upon following internal pilot testing of the crowdsourcing method on 5 people from Newcastle University. They were

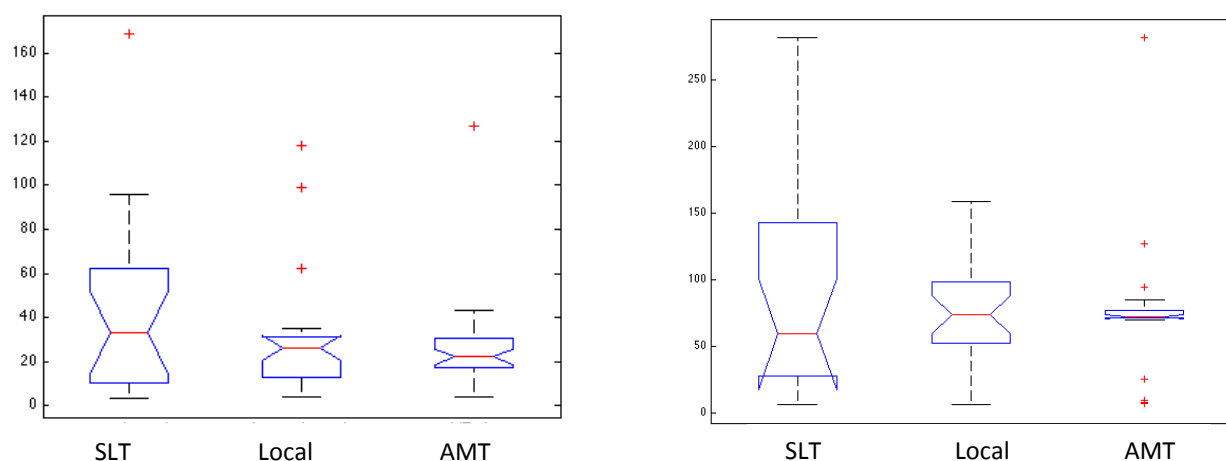


Figure 12: left) the distribution of minutes spent per participant on the crowdsourcing tasks overall according to their experiment group; (right) the distribution of the number of tasks completed by participants according to their experiment group.

openly asked to complete as much of the dataset as they could. All pilot testers stopped their involvement between 20 and 45 minutes, no one completed the full dataset.

For all of the participants, tasks were presented via the Speeching platform (a website)⁴¹. Listeners were asked to register their details by providing an email address, age range, gender, native language, and indicating whether or not they were a practising SLT. Once registered, listeners could log in and out of the system at any time. In order to encourage the completion of more tasks by each individual listener, they were informed that they were not required to complete all tasks in one go.

Crowd members were assigned a crowdsourcing task in a random order. The functionality of the system aimed for a minimum of three ratings per individual speech sample per group, tasks were therefore assigned to allow for this, whilst ensuring that the same listener did not rate a sample twice. Because there was variation in the number of tasks that listeners completed, samples which had been completed (received 3 different ratings) were indexed and the task assignment was re-randomised until the entire dataset was complete. Listeners were provided with a progress bar so that they could see how far into the dataset they were.

⁴¹ Developed by Paul Dunphy.

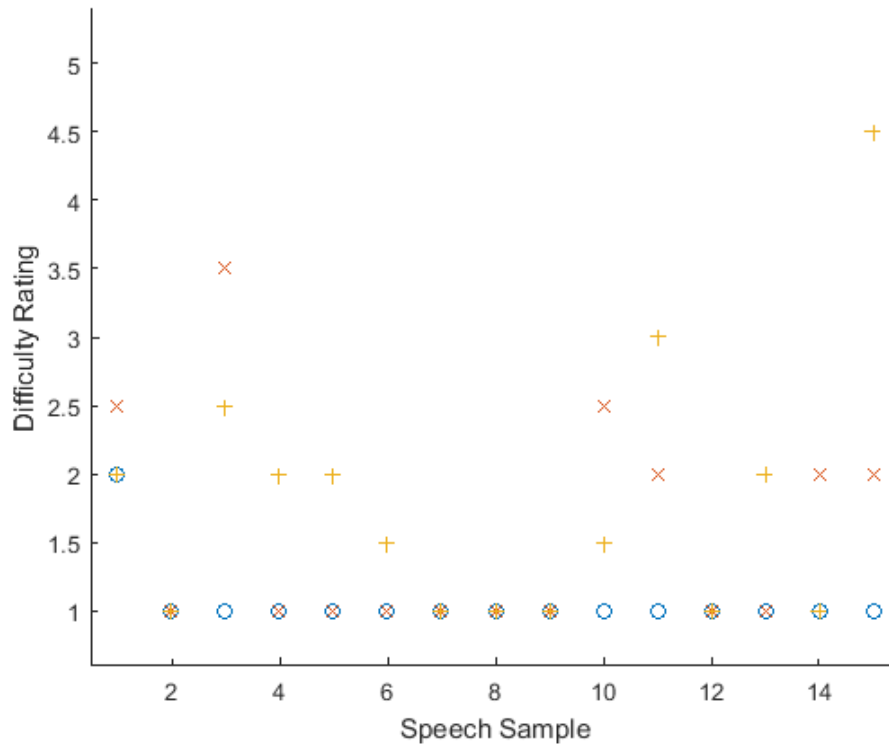


Figure 13: Distribution of EOL scores across all 15 connected speech samples, with O representing SLTs, X representing Locals and + representing AMTs

6.4.4 Phase 1 Findings

The following sections present the findings of the phase 1 study. Between group analyses was conducted to discover the correlation of the groups' ratings to those of the experts. These findings are then discussed, and the lessons learned from this study are explored, in order to inform the design of the phase 2 study, which involved the provision of direct feedback PwP.

6.4.4.1 Overall Task Engagement

Boxplots depicting task engagement can be viewed in figure 12. Measures were first taken to gain insight into the engagement of the crowd with the dataset. First considered was the time that participants spent, overall, completing their tasks, including time spent across multiple visits to the site. Participants in the SLT group spent a median of 29 minutes on task (IQR= 58.75; 25th percentile 10.25, 75th percentile 71), compared to 26 minutes (IQR= 18.75; 12.75, 31.5) for the local group and 22 minutes (IQR= 14; 17, 31) for those on AMT. *T-Tests* conducted between each group showed no significant difference between any of the groups, although the comparison closest to reaching significance was that between the SLT and AMT

group ($p=0.08$). On the surface, it was the SLT group which exhibited the greatest diversity in the length of time that they spent on task (see figure 12).

When considering the number of tasks (absolute total= 228) that participants were able to complete, those in the SLT group completed a median of 59 (IQR= 115; 27.5, 142.5) tasks compared to 73(IQR=45; 52.5, 97.5) tasks in the local group, and 72 (IQR= 5.5; 70, 75.5) tasks in the AMT group. Again, *T-Tests* showed no statistically significant differences between any of the groups in terms of number of tasks completed, although it should be noted that AMT participants were provided with the suggestion of completing a minimum of 70 tasks, 25% of the total, in order to receive payment, which can be used to explain a clustering of data points around the median of 72 tasks completed.

6.4.4.2 Crowdsourced Task Ratings

The correlation between experts and the individual groups (SLT, local, AMT) were calculated on each measure (single word recognition, EOL, volume, pitch variability, rate). For the single word recognition task, which provided 10 single words, a Spearman's Rank Coefficient was used to determine the relationship between the success rates (i.e. percentage of words being correctly identified. Successful recognition of the target was given a binary correct/incorrect score which was then aggregated into a total) across each of the sound files for each crowd group with the selections provided by the experts. A strong correlation (see for example (J. Evans, 1996) for correlation strength guidelines) was noted between the scores of the experts and those of the SLT group ($r=0.71$, $p<0.01$), the experts and the local crowd ($r=0.74$, $p<0.01$) and finally between the experts and the AMT group ($r=0.70$, $p<0.01$), indicating that all configurations of the crowd provided similar levels of success rate to the experts during the word recognition task.

Self-reported impact of accent was also collected from crowd members to uncover whether workers perceived accent to impede on their judgement of the speech sample. The interest here was not to explore the correlation with the expert, rather it was to attempt to investigate whether individual crowd grouping may have perceived an effect of the local accent on their ability to judge the speech sample. A graph depicting the scores for each of the individual groups (SLT, local and AMT) for each connected speech sample ($n=15$) can be viewed in figure 13. Scores were provided on a 5 point Likert scale with 1 being accent affected the judgement 'not at all' and 5 being accent affected the judgement 'very much'.

The median rating for the impact of accent was 1 (IQR= 0; 1,1) for the SLT group, 1 (IQR= 1; 1,2) for the local group and 1.5 (IQR= 1; 1,2) for the AMT group. A *T-Test* was conducted between each of the groups too look for a statistically significant difference between the scores. All tests proved significantly different; between the AMT and local crowds ($t= -2.31$; $p= 0.003$); the local and SLT crowds ($t=2.31$; $p=0.01$); and the SLT and AMT crowds ($t=-2.81$; $p<0.01$), indicating that an accent effect was present.

For the ease of listening analysis, the interest moved back towards considering correlation with the experts as this self rated assessment, indicating how understandable the speech sample was generally, has been shown in previous studies to be a good indicator of impaired intelligibility (Landa et al., 2014). As such, a linearly weighted Cohen's Kappa test was conducted to measure the correlation between the different crowds (SLT, local and AMT) and the experts, on the sound files containing connected speech. This statistical test was chosen due to the fact that EOL used a categorical rating system (1-5). Analysis found a substantial agreement (Landis & Koch, 1977) between both the experts and the SLTs and the experts and the local group; with a moderate agreement being observed between the experts and the AMT group (Kappa = 0.48 ($p =0.07$), 95% CI (-0.06, 1)).

Spearman's Rank Correlation was conducted on the measures of pitch, rate and

Measure									
	Volume			Pitch			Rate		
	Median + IQR	Range of scores	Spearman's rank correlation with the expert (p)	Median + IQR	Range of scores	Spearman's rank correlation with the expert (p)	Median + IQR	Range of scores	Spearman's rank correlation with the expert (p)
Expert	98 (IQR=23; 90, 113)	60-120	Intra- expert agreement 0.03, ($p=0.91$)	100 (IQR=10; 90, 100)	50-115	Intra- expert agreement 0.52, ($p=0.05$)	75 (IQR=40; 60, 100)	40-205	Intra- expert agreement 0.581, ($p=0.023$)
SLT	100 (IQR=30; 85, 115)	50-150	-0.15 ($p=0.59$)	100 (IQR=35; 75, 110)	50-130	0.54 ($p=0.04$)	89 (IQR=60; 50, 110)	30-150	0.83 ($p<0.01$)
Local	100 (IQR=38; 75, 113)	50-150	-0.52 ($p=0.05$)	100 (IQR=22.5; 77.5, 100)	35-120	0.66 ($p=0.01$)	100 (IQR=25; 95, 120)	55-200	0.17 ($p=0.55$)
AMT	100 (IQR=35; 85, 120)	50-123	0.16 ($p=0.57$)	100 (IQR=20; 80, 100)	20-140	0.81 ($p<0.01$)	85 (IQR=50; 50, 100)	20-180	0.71 ($p<0.01$)

Table 8: Summary of results for phase 1 study on the measures of volume, pitch variability and rate

volume to look at the comparison of the individual groups and the experts on each of the measures (see table 8 for a summary of the data and results. Please note that the range of scores is provided simply for descriptive purposes). This statistical test was chosen due to the independent nature of the data being studied; each sample was rated by a different set of raters and the ratings themselves were conducted on continuous scales. For each sample being rated, the median score was computed (across all 3 raters, or 2 raters in the case of the experts) and it was these median scores that were used for the correlation analysis. The SLT and AMT groups had the best overall correlation across all measures with the expert's in fact, the AMT group had a strong, or approaching strong, correlation with the experts on all measures except volume. Volume provided only a weak correlation with the experts for the AMT group and a negative correlation for the local and SLT group. The possible reasons for this are discussed further in section 6.4.5.2). Overall, these scores indicate that the anonymously recruited AMT group provided similar ratings to the experts in the measurement of speech changes in a subsample of PwP. They also provide evidence to support the feasibility of the developed crowdsourcing method. The following section will explore these findings further and will explore the lessons that were learned—which can be brought forward into the second phase of the study.

6.4.5 Discussion of Lessons Learned in Phase 1

6.4.5.1 Research Question 1: Selecting the Crowd

The first research question that was explored in this phase of the case study was: *which crowd formation provides the highest correlation with the experts when rating Parkinson's speech?* There were several elements to consider when thinking about how to select the crowd for this case study; 1) level of experience and ability required to provide appropriate ratings of speech, 2) ease of recruitment and 3) the engagement of the crowd in the completion of tasks. This final requirement was important for the phase 2 study given that the crowd were going to need to provide a fast turnaround of ratings for the users of the self-monitoring application with Parkinson's.

The SLT group were experienced in speech and language problems and the local group had accent familiarity. Both provided their time for free but required extensive recruitment and prompting from the researcher. In total it took around 6 weeks to sign up and collect the data from these groups. On the other hand the AMT group were extremely

easy to recruit, completed all of the work within a matter of days and required no prompts or reminders to take part, but they were paid for their time. Each group had specific desirable qualities but the AMT group were, by far, the easiest to manage and required the least effort from the research team. Unsurprisingly, the paid AMT group were consistent in the amount of work they completed, with all workers completing the minimum amount of requested tasks (70, or 25% of all 228 tasks). On the other hand, the busy SLT group, who were providing their time altruistically, had a huge variation in the amount of tasks that they completed. The local group had some variability in the amount of tasks that they completed for the study but their lower range was much closer to the target, at around 50 tasks. This is possibly due to the fact that they were members of a research lab and were used to the demands and requests of research projects, therefore were more likely to complete a greater amount of tasks.

In short, there are considerations which should be made for future researchers wishing to use crowdsourcing in the future, in regards to the selection of their crowd. If expertise is necessary then an agreement should be reached relating to how much work is expected. In this study we left it completely open ended with a suggestion for 25% across all groups, in order to better explore the behaviours of each group. However, as was shown through the findings, the involvement of experienced and specialist crowd members is not always required, with the novice AMT crowd providing highly correlated ratings to the experts in many tasks. In this case, and moving into phase 2, the use of a pre-established crowdsourcing platform, will be advocated for fast and reliable results.

6.4.5.2 Research Question 2: Selecting appropriate tasks

The second research question was: *which types of tasks provide the highest correlations with the experts?* In order to investigate this, the individual task types are explored in isolation. For the single word recognition task, there was a very high between group correlation on minimal pairs testing across all groups. This indicates that this type of selection task is particularly well represented within a crowdsourcing platform. All of the groups were also strongly correlated with the expert. This is unsurprising given that this type of task was simply a digitized version of the pen and paper format of the tasks which would be provided within an SLT research context, which has been proven to be successfully rated by non experts (Landa et al., 2014). This task was also successful in the fact that it was quick and

required minimal expertise to complete, being that it was simply a selection of a word from a list.

The discussion now moves to consider the perceptual measures of speech that were included: pitch, rate, loudness. Both the SLT and AMT groups had high, or approaching high, levels of agreement with the expert on pitch and rate but not volume. Volume ratings gave particularly poor agreement levels with the experts across all groups. One reason for this could be the fact that, as described in a seminal paper by Fletcher and Munson (Fletcher & Munson, 1933), loudness is a relative concept, dependent on not only the quality of the recorded sounds, but also on the intensity of the sound, and indeed the listening environment of the rater. The fact that listening environment was not constant across raters is certainly a limitation to the study, however is a realistic representation of crowdsourcing platforms, wherein workers conduct jobs in their home environments and are unsupervised in their efforts. Given that the purpose of this work was to scope crowdsourcing as a taskforce for the rating of speech, imposing restrictions on listening environment was not deemed to be appropriate. Instead, moving into the second stage of the study, the researcher focused on improving the consistency of the data being collected from the speaker. The fact that the crowd were rating the speaker's volume in comparison to another speaker (the mid-range exemplar) could mean that there were other factors in the voice (such as increased stress on certain words, additional pitch variance throughout the sentence) which made volume in isolation difficult to attend to. In addition, the quality of the recordings, although collected in a systematic way with the same audio recorder and in the same room, could not account for possible variances in the physical positioning of speakers (stooping of the head, slouching, exact distance from the microphone). In this sense, the variance seen between the experts and the crowd workers could be related to experience, with the experts having the ability to filter external factors and attend to solely the volume of the speaker's voice, and having a more solid internal baseline for what a loud vs. quiet voice is. If this thinking is extended into the phase 2 study, a direct comparison of the speaker's own voice, collected in the same way each time, could alleviate some of these issues, by providing a consistent baseline for novice listeners to compare against. It is also worth noting that the range of scores provided by the expert (60-120) and crowd workers (50-123) were similar, and there was a smaller range of scores for volume than the other measures. This question asked raters to think about the differences between the midrange

sample and the sample being scored purely in terms of volume. It stated *a score of more than 100 indicates that you think the clip on the right (the sample being scored) exhibits more severe problems in terms of volume* (than the midrange), with the reverse being stated for *less than 100* (less severe). We were considering that a low volume indicated impairment, however this was not explicitly stated to raters. As such, it is possible that they were rating on the lower end of the scale to indicate any difference in volume, where the experts may have had an internalized perception of impaired volume and how this might affect the speaker. There were several instances where the crowd rated the samples in the 60-85 category (less severe problem), where experts were rating 100-120 (more severe problem). It is possible that crowd workers were rating lower for lower volumes, while the experts were rating severity. In light of this, it was decided that the questions would be revised for phase 2, to ensure full transparency of what was being asked.

In short, this phase 1 study has shown potential for the role of crowdsourcing, using non-experts, in the identification of speech and voice issues in Parkinson's, when compared to ratings provided by experts. The next phase will explore how the crowdsourcing method can be applied in a real world context, with PwP, as a means to support the self monitoring of speech. The next phase involves the development of a mobile phone application to facilitate the collection of speech samples, to be passed for analysis to the crowd, and then to provide this feedback from the crowd back to the user.

6.5 Phase 2: Using Crowdsourcing within a Self Monitoring and Management Context

In phase 1 the aim was to explore whether or not a crowdsourcing methods could support the identification of speech and voice changes in Parkinson's. This next phase applied these results to the self monitoring and management domain by exploring the ways in which PwP might use feedback, generated via crowdsourcing, to support them in understanding more about their speech and subsequently directing their SLT practice. In order to do this a mobile phone application was developed to collect real time speech data from a cohort of PwP and see how a fast paced turnaround of analysis could aid them in monitoring their own speech and voice. There was also an interest in supporting this feedback by giving participants a way to practice improving elements of their speech through a cohesive system.

The study was split into two stages. The first involved developing the Speeching system (a mobile app and online crowdsourcing area). The second stage involved an ‘in the wild’ deployment of Speeching, with a group of PwP, to gather their views on the usefulness and feasibility of a system such as this. There were a further 3 research questions being explored in this phase of the study:

- 3) Can crowdsourcing be used to derive feedback on the speech of PwP collected ‘in the wild’?
- 4) How might Speeching be used as a tool for supporting the self monitoring and management of speech for PwP?
- 5) To what extent do PwP value crowdsourced feedback on their speech?

6.5.1 Stage 1: Implementation of Speeching

The Speeching system was made up of several components. The individual, who was using the system to self monitor their speech issues, accessed an application⁴² on their mobile phone. The app was used to collect a variety of speech samples through an assessment task. This task was then uploaded to the Speeching service⁴³, which packaged the separate recordings into a ‘job’ for the crowd (see appendix 3f for screenshots of the jobs which were defined as a page of work that the rater was required to complete for payment) and uploaded it to Crowdfunder (chosen over AMT due to imposed financial restrictions in the UK). Five crowd members were requested to complete the job—the method was slightly modified from phase 1 to include 5 rather than 3 minimum raters to ensure that participants using the system were provided with as high quality ratings as possible. Ziegler and Zierdt (Ziegler & Zierdt, 2008) discuss less deviation from the mean when the number of raters is increased.

Workers were asked to listen to and analyze two types of speech samples. When analyzing single words (10 in total) the crowd worker was asked to select the word they had heard from a choice of 10 similar sounding words. When analyzing sentences (3 in total) the crowd worker was asked to transcribe the sentence and to provide an overall rating of understandability (EOL). They also provided ratings on the volume, rate and pitch of the sample. The individual analyses were sent back to the Speeching service, aggregated and

⁴² Developed by Dan Richardson

⁴³ Developed by Mohammad Othman

then the median score (median was chosen over mean to account for possible outliers in the data) of the ratings was sent back to the participant, through the app, as feedback on their speech performance. The participant could then use this feedback to inform the areas of their speech that required practice, and use the app to conduct targeted exercises on their speech to improve their intelligibility.

6.5.2 The Speeching App

6.5.2.1 Assessment Area

The assessment tasks prompted several types of speech sample (see figure 14 for the types of task presented to the participant). The first of these was unconnected speech, or single words (derived from a task originally developed for a study by Miller et al. (Miller et al., 2007), which asked participants to read a word as it was presented on the screen. Participants were asked to read 10 single words as they appeared on the screen, recording each one individually by pressing a start/stop button. The second type of sample was connected, or sentence level, speech. This task required participants to either read a sentence as it appeared on the screen; or describe a picture, or answer an open question in order to elicit free speech. In order to provide structure to this task, on-screen prompts were presented as scenarios, such as ordering a pizza or taking a bus ride. Subsequently, there was a combination of reading and free speech collected as participants made their way through the scenario. Each scenario asked for two reading samples and one free speech sample. Again, each separate sentence was recorded individually using the start/stop button on the app.

Participants were prompted each time they made a recording to hold the phone “one hand’s distance away” from their mouth before speaking, to ensure a consistency of recording quality for each individual participant. Following the completion of the assessment, the 13 separate samples were packaged together into a ‘job’ and sent for analysis. Jobs were completed in full by 5 crowd workers.

6.5.2.2 Practice Area

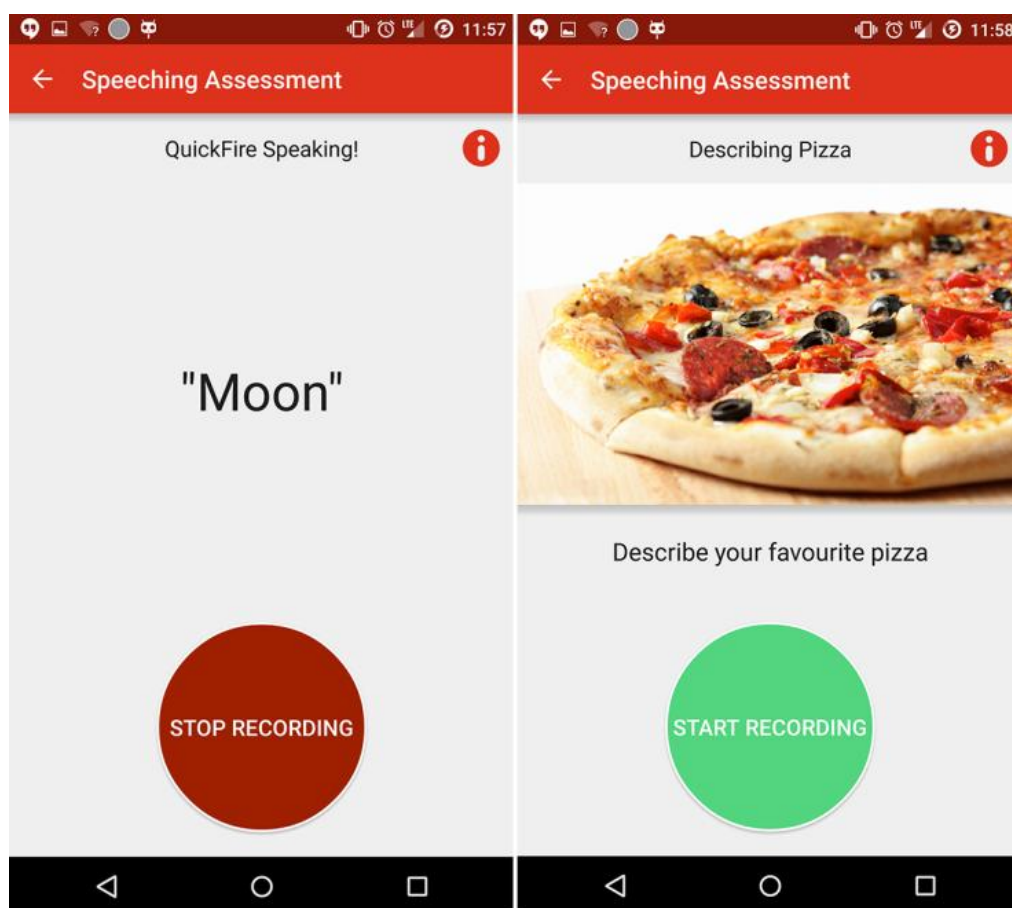


Figure 14: Speeching assessment screens: Single word elicitation (left), sentence level free speech elicitation (right)

In a separate tab was the *practice area* where participants could access a reading sample, which was pulled daily from the Wikipedia home page to allow for a variety of subject areas across the deployment period. These tasks were added for practice only and, due to their length (advice from Marge et al (Marge et al., 2010b) suggests the use of small segments of speech), samples captured could not be uploaded to the crowd for analysis—although participants did have the option to listen back to their sessions. Focus was placed on two types of practice tasks, improving loudness and improving rate, which along with pitch variability issues are the most common issues in Parkinson’s speech. In addition, previous research has noted the benefits of improving loudness for other areas of speech and voice, such as intonation, which is associated with pitch variability (C. Fox et al., 2002). For both practice exercises, a video tutorial from an expert in SLT and Parkinson’s was created explaining why the exercise was being carried out and how it should be completed. This was

a design insight taken from case study 2 wherein participants expressed a desire to understand more about how to practice SLT exercises.

In order to target improved volume, participants were asked to set an appropriate target, i.e. by counting to 10 in their loudest speaking voice (another design insight taken from the LApp system in case study 2), and attempt to maintain their volume level to an equivalent or higher volume while reading a segment of text on-screen. A numeric visualization of their decibel level, and their set target, was provided on the screen and a green/red system was used to indicate when the participant is above or below their target level, respectively. The second practice task focused on slowing rate of speech. In the first stage of the task participants were presented with an auditory metronome and prompted to speak a syllable per beat, to begin getting used to slowing their speech down (e.g. WHAT-TIME-WILL-THE-TRAIN-BE-COME-ING). The metronome could be made faster or slower depending on the participant's personal preference and skill level. Once this skill had been mastered, this task progressed towards using the metronome in a more naturalistic way, using natural intonation and stress patterns that would be seen in everyday speech. In this case the important words were spoken on the beat to add a natural stress pattern (what TIME will the TRAIN be COMING).

6.5.3 Integration with Crowdsourcing Services

The Speeching app was linked with Crowdfunder, an online crowdsourcing service. A Speeching API was created in Microsoft C# consisting of a web service (ASP.NET Web API) that linked the app and crowdsourcing platform together. All data was stored on a secured Microsoft Azure server. Once an assessment was uploaded by the participant it was posted to the Crowdfunder site with a unique identifier code. Each job was assigned to a minimum of 5 crowd workers for analysis (if a task was incomplete due, the crowd member was not paid for their work and the task was passed to another rater for completion, until 5 full ratings of the task were collected). Ratings from the crowd are aggregated and the median score (to account for outliers) is delivered back to the participant.

6.5.3.1 Micro-Task Design

Tasks were carried over from phase 1 with minimal changes. Single word samples were subjected to a selection task, with crowd workers being asked to select the target word from

a set of 10 similar words. For the sentence level data, the ease of listening (EOL) rating from phase 1 was carried out again and the measures of pitch, rate and volume were adapted from phase 1 by providing a comparative element for the crowd workers to use in their ratings. Rather than using a mid-range example, the participant's own speech was used as a comparative sample. In this case, when participants upload their first assessment for analysis, crowd members were asked to rate speech, out of 100, for volume, rate and pitch variance. However, in subsequent ratings the crowd workers were provided with the participant's previous speech sample to listen to, and the median rating that this sample was given for each measure by the last group of crowd workers who rated it. This allowed for quality control within the analysis, since crowd workers were given an exemplar of what a speech sample, for example rated with a score of 60, sounded like. This design aimed to both promote comparable scoring among crowd workers and ensure participants obtain scores that are relative to their previous submission. In addition, in an attempt to alleviate some of the possible issues which were identified with the wording of the volume task that was presented to the raters (see section 6.4.5.2), the format of the question related to the task was edited to add clarity around what we were looking for in regards to volume impairment; to read "please enter a number from 0-100 indicating how loud you felt the first sentence was, where 0 is 'so quiet I could barely hear them' and 100 is 'very loud'.

6.5.3.1.1 Providing Feedback to Participants

Within the Speaking app, participants were provided with a graph of their EOL score over time, the EOL score of the sample they had just submitted, along with its volume, rate and pitch scores (Figure 15). In order to allow participants to make sense of the median data being presented back to them via the app, 'goals' were assigned to the measures to give them something to aim for and improve upon. Participants were advised that their scores should fall within 50 and 80. These scores were chosen by the research team and expert to explore the impact that providing suggested goals might have on the participants of the phase 2 study on the practice. If participants scored below or above the threshold values, a prompt was added to their feedback to suggest how they should modify their speech.

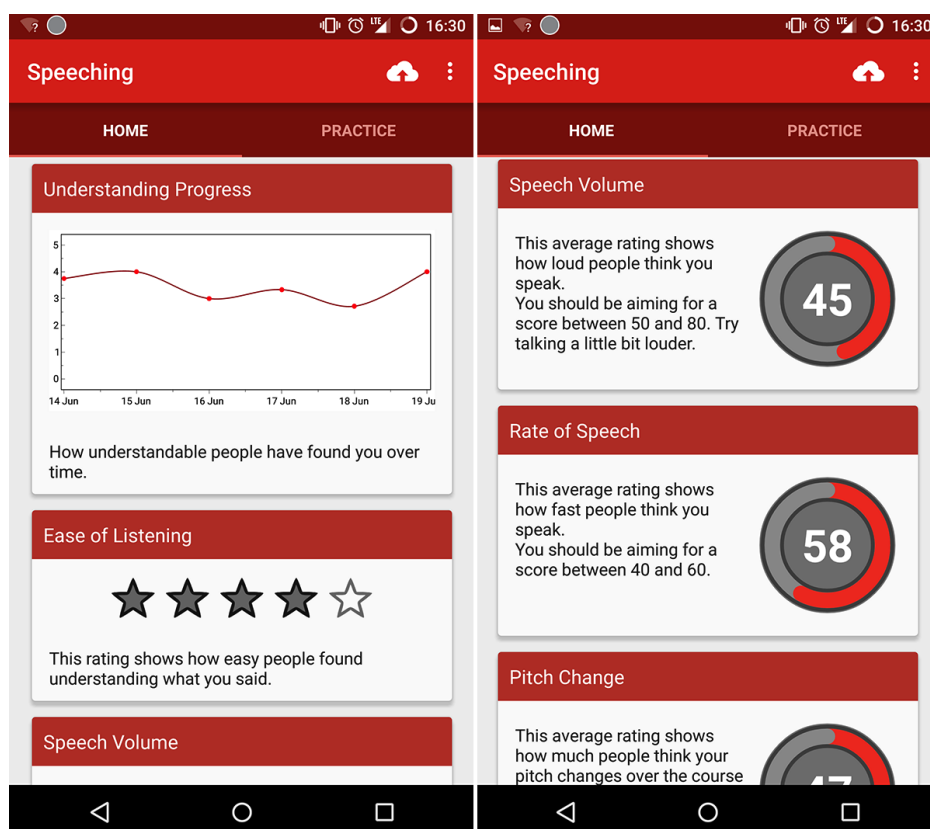


Figure 15: Ratings presented back to participant; EOL score over time (top left); EOL score from last sample (bottom left); volume, rate and pitch scores from last sample (right)

6.6 Real World Deployment with PwP

The Speeching app was trialled in a real world context with PwP. The purpose of this was to test the crowdsourcing approach with a group of PwP, who could receive and react to feedback being generated by the crowd, to explore how a system such as Speeching might support the self monitoring and management of speech.

6.6.1. Participants

Six PwP were recruited to take part in the study, 4 of whom had taken part in the case 2 LApp trial. All participants were recruited through local Parkinson's support groups following a presentation about the research aims. Participants of any age or stage of Parkinson's were considered for the study, so long as they reported issues with their speech. A profile of the individual participants and their main reported speech issues can be found in Table 9 (which is presented alongside the results section in section 6.6.3).

6.6.2 Methods

Participants were visited by a member of the research team in their own home and given a smartphone with the Speeching app pre-installed on it. The researcher demonstrated how to use Speeching and participants were given an instruction manual (see appendix 3e) bringing them through each step of the process for both the assessment and practice areas. They were asked to complete an assessment task during the initial visit so that any issues with the app could be discussed with the researcher and a baseline measure of their speech could be collected. Following this, they were instructed that they should receive feedback within 1 hour of completing a task. The researcher then helped them to navigate to the practice area and showed them the types of practice tasks that they could complete. Participants were asked to trial Speeching for one week, during which time they could use the app as little or often as they wished, though it was requested that on at least one day they used the practice area and completed one other assessment before the end of the deployment. They were advised that they could upload their speech for analysis at any point during the deployment phase, to gain a direct comparison of their speech before and after practice. Participants were additionally contacted via telephone at the midway point of the deployment to discuss any issues they might be having.

Following the deployment each participant took part in a semi-structured interview. Interviews lasted between 19 and 45 minutes (average 30 minutes). Interview topics included their experiences of using the app over the week (frequency and ease of use, features they liked and disliked) and their opinions on the feedback from the crowd (if they found it useful, whether or not it motivated change, how they felt about being anonymously rated). Interviews were audio recorded and were transcribed verbatim for later analysis. Inductive thematic analysis on this qualitative data using methods outlined by Braun and Clarke (Braun & Clarke, 2006b) (see chapter 3, section 3.3), by coding data at the sentence to paragraph level and drawing out themes across the data set.

Quantitative data collected during the study included the number of tasks uploaded for analysis to the crowd each day of deployment, and the ratings that were provided by each crowd worker for each of the rated measures. Participants uploaded 13 samples for analysis each time they completed an assessment session. These groups of samples were packaged into job sets for rating by the crowd. The crowd provided ratings for the parameters of volume, rate, pitch variability, EOL and single word recognition. As this phase

study did not perform a between group analysis, the quantitative data was analysed in a different manner for phase 2. In this phase, the interest was around exploring how each group of 5 raters performed in relation to one another, and the feedback that was therefore being presented back to the participants.

In any crowdsourcing project, there is a possibility that system 'gamers' could provide inappropriate ratings within the data, defined as workers who seemingly complete the crowd tasks, without actually providing appropriate data (Parent & Eskenazi, 2011). This might involve providing random ratings to samples, without any meaning (e.g. rating everything with a score of 50). In part, there was an attempt to manage rater consistency through the design of the perceptual measures task (for volume, rate and pitch), which showed the previous sample uploaded by the speaker and the crowd score it had been given as a 'guide' for comparison. However additional care had to be taken to ensure that the subjective ratings were being provided by raters who were engaging fully in the tasks. Due to the exploratory nature of the study, and the fact that it was impaired speech being analysed, it was decided that automatic data filtering should be avoided. As such, the final dataset was reviewed manually by the research, in the manner described below.

A transcription task was added to each connected speech sample, asking raters to transcribe verbatim the sample being played to them. The transcriptions of each worker were reviewed individually to search for patterns in their work which might indicate poor quality. Any crowd worker who provided consistently imprecise transcriptions for each sample (e.g. one worker simply wrote 'black' for each sample) or provided similar scores across all samples analyzed (e.g. 50 for every rating) were removed from the data. Crowd workers who consistently did not provide a transcription or provided nonsense strings within the transcription box, were marked for review, in the consideration that the sample they had rated may have, in fact, been unintelligible. Their work was then studied in the context of the other raters for each sample. If it was clear that audible speech was present, as indicated by other worker's transcriptions, then the worker was removed from the dataset. In total 11 workers met these criteria and were discounted from the dataset, leaving a total of 84 workers and 1,228 ratings for analysis. For the rest of the data, the mean result for each individual task was taken (i.e. mean rater scores for volume, rate, pitch and EOL) and then the overall mean across all of the sample in each parameter, for each individual participant, was observed, along with the mean range of scores. This was felt to be the best analysis due

to the variability in participant uploads and the focus on scores being provided to each individual participant. The main concern with this phase surrounded the provision of high quality, similarly rated scores from the crowd to provide an appropriate measure of how PwP are understood by strangers.

For the unconnected speech samples (word recognition test), it was decided that the potential for this task to provide directed insight into the specific types of sound contrasts that were causing intelligibility issues, and thus provide future insight into therapeutic direction, would be further explored. As such, the individual word errors were calculated for each participant, to explore if there were any particular patterns that could provide understanding of their specific intelligibility issues. The following section provides an analysis of the phase 2 quantitative findings. It first begins with the word recognition test data before moving on to discuss the analyses conducted on the connected speech samples and the parameters which were rated.

6.6.3 Phase 2 Quantitative Findings

There were 119 jobs in total uploaded to the crowd for analysis during the course of the study, with 5 raters completing a job each time. Overall, participants were varied in the amount that they used the app, with uploads to the crowdsourcing platform ranging from 2-39 uploads over the 7 days of deployment. A full breakdown of their individual engagement can be viewed in Table 9 (in section 6.6.3.2). A total of 6,180 ratings were completed by the crowd, with 5 workers completing each assessment uploaded to the system.

6.6.3.1 Unconnected Speech

For unconnected speech samples (please note that the three word lists that were presented at random to participants can be viewed in appendix 3g), a confusion matrix was constructed for each participant, to visualize the error rate in the single word recognition task by the crowd (see figure 16 for comparative matrices for CS3P18 and CS3P20). These matrices showed how more severe intelligibility issues (CS3P20) were identified by the crowd when compared to participants with milder speech impairment (CS3P18). This exercise was expressive enough to capture a variety of participant performances and provides useful direction for future work aimed at using tasks such as this to provide specified therapeutic direction for speech self-management.

For example, CS3P20's confusion matrix, shows many more instances of crowd workers identifying words that are different to the target. In the case of CS3P18, the bulk of errors stemmed from the misinterpretation of vowel contrasts (e.g. cop heard as cup 15 times, see 4 down 6 across in the figure). However CS3P20, who had much more severe intelligibility issues, had a similar profile of errors, but was also experiencing word initial sound contrast difficulties (e.g. cape to heap 4 times (1 down, 7 across), or sheep to heap 8 times (9 down, 7 across)). This indicates a more severe intelligibility difficulty which is indicative of CS3P20's issues. He spoke at a fast pace, and often ran out of breath, making it difficult to project his voice and position his articulators (e.g. tongue, palate, lips) into the correct position at times, which caused a slurred, imprecise quality to his speech. This suggests an opportunity for future functionality in the form of automatic provision of materials that target the repeated practice of these word initial sounds, with a view to improving his intelligibility (without the need for therapist input).

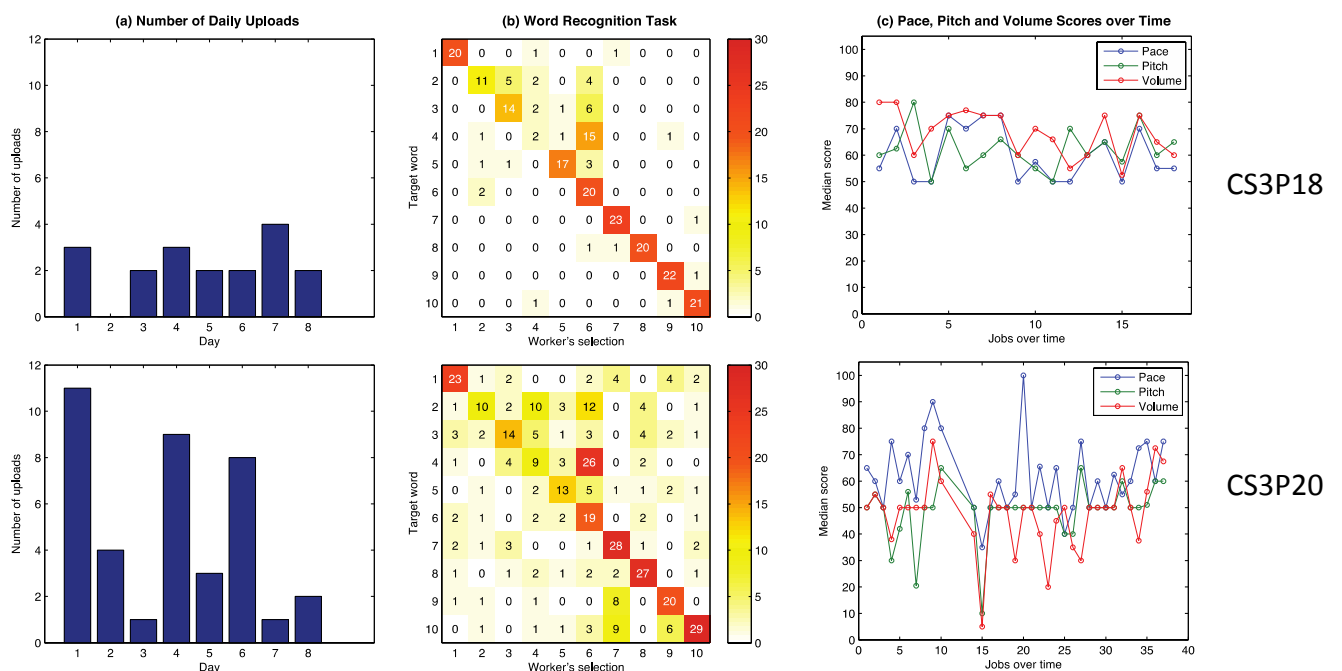


Figure 14: this figure provides comparative descriptive results for CS3P18 (top) and CS3P20 (bottom); a) presents the number of daily uploads each participant provided over the course of the deployment; b) shows confusion matrices detailing the number of times that single words were recognised as either the correct target, or another word entirely (from 1-10 the words were, cape, carp, coop, cop, cub, cup, heap, keep, sheep, hub); c) shows the median scores for rate, pitch and volume presented to the participants following each upload in the deployment

6.6.3.2 Connected speech

For connected speech samples, mean range and standard deviation (SD) for each set of 5 raters was taken for each analyzed speech sample (see table 9). This method was chosen due to the fact that each speech sample had the potential to be rated by 5 completely different raters at each point of submission and to account for the fact that participants uploaded different numbers of speech samples across the deployment. The range of scores across all 5 raters for each speech parameter (volume, rate and pitch) was taken for each speech sample that was uploaded by participants, to represent variability amongst scores. The mean of these ranges was then calculated across all samples that were uploaded for each participant during the course of the deployment. The highest range of scores were observed within the measures that participant had perceived to be their biggest problem (see table 9). For example, CS3P15 had a higher range in his volume and rate scores, where CS3P19 had the highest range in his volume scores (the possible reasons for this will be further explored in section 6.7.1). There was also a large mean range of EOL scores for each

Name	Age	Years Since Diagnosis	Participant perception of speech severity	Main issues as reported by participant	No. Uploads	Mean pitch range (SD)	Mean rate range (SD)	Mean volume range (SD)	Mean EOL with 1 being most severe (SD)
CS3P15	69	10	Moderate	Rate and volume	5	43.4 (18.8)	55.8 (23.8)	50.8 (21.3)	3.0 (1.3)
CS3P16	52	9	Severe	Slurring, rate and volume	24	27.8 (13.4)	40.7 (20.4)	35.4 (17.4)	2.5 (1.2)
CS3P17 *	61	21	Moderate	Breathy quality and volume	2	36.3(17.0)	40.3 (19.0)	37.5 (17.4)	2.0 (1.0)
CS3P18 *	70	5	Mild	Slurring and volume	18	37.0 (16.4)	37.7(16.8)	39.7 (17.7)	2.4 (1.1)
CS3P19 *	61	11	Moderate	Volume	31	43.4 (18.8)	44.5 (19.0)	50.6 (21.6)	2.8 (1.3)
CS3P20 *	74	8	Severe	Slurring, volume, rate and pitch	39	41.6 (20.8)	51.1 (25.8)	44.7 (21.4)	2.2 (1.0)

Table 9: Speeching participant information and quantitative results. Please note that participants who also took part in the case study 2 LApp study are denoted with a (*)

participant (2-3 points). Given that this was only a 5-point scale this indicates a large range in the perceived ease with which each participant was understood, it is also worth noting here that this measure was only moderately correlated with the expert ratings in the phase 1 study. Again, this will be explored in detail in section 6.7.1.

It had already been established through the initial feasibility study that crowd workers could provide equivalent ratings to experts in Parkinson's speech in the measure of pitch, rate and EOL. However, the phase 1 study showed that the crowd did not score similarly to the experts on the measure of volume. It was speculated in section 6.4.5.2 that using a direct comparison of the speaker's voice (over different time uploads), as opposed to a mid-range exemplar, volume scores might be improved. As such, an expert was asked to rate volume on a small subsample of the entire data set, equalling 28 speech samples. The expert ratings were then compared with the median crowd ratings to look for a correlation in the data. A Spearman's Rank Correlation Coefficient was conducted ($r = 0.57$; $p = 0.01$) and indicated a moderate, almost high, positive correlation between the volume scores of the expert and the crowd, indicating an improvement from the phase 1 study.

6.6.3.4 Engagement and Cost Analysis

A total of 84 crowd raters were included in the study, with an average of 8.9 jobs per rater. On average, it took 59 minutes to complete each job package for each set of 5 workers, from submission of the tasks by the participant to the provision of feedback. Crowd workers were paid an average of £0.28 per packaged job. With 5 workers per job this meant a total of £1.38 per job was paid for each assessment uploaded for analysis, equalling a total of £168.38 spent on the 119 jobs submitted to the study. As a means of comparison, a (mid-pay point) specialist SLT in the UK is paid at approximately £15.27 per hour, which is the approximate amount of time taken to complete an assessment session with one client (not accounting for travel time for a home visit).

The previous sections have briefly explored the quantitative findings from the phase 2 study. The following sections will analyse the qualitative findings before the chapter ends with a discussion of the overall findings.

6.6.4 Analysis of Phase 2 Qualitative Findings

Three major themes were identified from the qualitative data: appreciation of the anonymous crowd; feedback and self-understanding; and problems with practising and tasks. These are discussed in detail below.

6.6.4.1 Appreciation of the Anonymous Crowd

Participants responded well to the concept of crowdsourcing as a method of obtaining feedback about their speech. There was discussion around how people within their social networks are often not good markers of their ability. CS3P16 compared the crowdsourced feedback to that he would normally receive from friends and neighbours: *“It was interesting to see how people rate you, because people don't usually tell you what they think”*. The app was valued in its capability to provide a sense of how speech was being perceived by others, without necessarily having to ask the question to friends and family. CS3P19 echoed this sentiment: *“sometimes I just talk to people and they just look at me”*. He discussed the fact that gaining feedback about his speech from others can cause embarrassment and drew comfort from the anonymity of the crowdsourcing method:

“if you're face to face with a person, it can be embarrassing, if they're saying that your speech needs to be improved, it's like, “Yes, okay.” If it's a machine that you know is via a person, I think that's quite nice. There's some kind of validation to it. And it's the machine I'm talking to, but I know some human is marking the progress.”

CS3P19 found the ratings from the crowd a motivator to improve his speech *“it's quite a boost to you in terms of how they understand you, and trying to achieve a better rating.”*

6.6.4.2 Feedback and Self-Understanding

Most of the participants found the feedback features helpful as a means of understanding their speech and targeting improvements. CS3P19 used the feedback from the crowd as a way to challenge himself to improve: *“I kept wanting to get to 5 [in EOL]. And then speech volume, I wanted to increase that one, as well.”* He also enjoyed the speed that he received his feedback *“getting it within, say, half an hour, an hour, is good...being so instantaneous”*. CS3P16 echoed the positive view that he saw the feedback as a *“challenge”*. His wife

described the process CS3P16 went through to improve his scores if the crowd rated him lower than his previous attempt: *"When he did one and he got the assessment and it was low he would do it straight again to see if he could up it"*. Due to having only limited Internet connectivity during the trial, CS3P15 only used the app minimally during his deployment. However, despite only using the app at a couple of different time points, he did find that the feedback gave him insight on his speech rate *"I was a bit surprised at the scores of speed...I think that is reflective on my speech at the moment because I speak very quickly"* and that overall the app provided him with a way to monitor improvement *"this tells me that I can improve if I'm willing to change and improve. Being reflective is enough for me"*.

While the feedback from the crowd was, for the most part, found helpful, three participants (CS3P17, CS3P18 and CS3P20) frequently used the listen back function within the practice area as a way to self-monitor their speech. For CS3P18, who was the most avid participant of the function, she found it most useful for practising and making changes to her speech *"it does help you to realize that you're not speaking properly, and for certain words there's no clarity in them, for other people, you know?"* CS3P18 practiced particular elements of her speech which she felt were unclear, helping her to focus specifically on words or phrases that were affecting her clarity. For CS3P17, the listen back function gave him a tool for realizing and accepting how he sounded to other people *"I thought I was disturbing the house by shouting, I played my voice back and it sounds like I'm whispering all the time."* Impaired volume perception is a common issue in Parkinson's speech (Ho et al., 1998), so supporting an increased understanding of how the voice actually sounds is particularly positive.

6.6.4.3 Problems with Practising and Tasks

The two practice tasks, metronomic pacing and volume monitoring, were discussed at length by participants. Several issues were identified with these, particularly with the pacing exercise: *"He was going faster. It would do about three beeps and he's halfway. He's way ahead of what the beeps were."* (CS3P16's wife). CS3P19 and CS3P17 similarly had difficulties: *"I didn't like the pacing... I understand it theoretically, but I can't do it practically"* (CS3P 19). CS3P19 also discussed the fact that he struggled to monitor his volume during the

task due to the placement of the db level monitor at the bottom of the screen *“The text is here, and the green light's there. So you've got to try and concentrate.”*

There was also discussion around how modifying the materials to be used within the practice exercises could increase motivation and improve engagement with the app. CS3P15 wished to use his own material to read, while CS3P16 noted the scenarios were not relevant to him: *“I wouldn't get on the bus”*. For CS3P20, the scenarios were just too simple: *“it asks you stupid questions”*. CS3P19 and CS3P18 however liked the scenarios due to their everyday nature *“they're all interactions you use every day, don't you? Like I go to the paper shop every day, I say, “Good morning, how are you?” So it's a set routine”* (CS3P19), although both reported that more variability in their content would be appreciated.

6.7 Discussion of phase 2: Supporting Self Monitoring of Speech using a Crowdsourcing Method

6.7.1 Research Question 3: Crowdsourcing the Analysis of Impaired Speech

The third research question being explored within this case study asked: *Can crowdsourcing be used to derive feedback on the speech of PwP collected ‘in the wild’?* This aimed to build upon the findings from the more controlled phase 1 feasibility study to explore how the crowdsourcing method might be implemented on data that was submitted by participants. The phase 1 feasibility study demonstrated that anonymous crowd workers, recruited opportunistically via an online crowdsourcing platform could provide ratings on measures of speech that were equivalent to that of an expert. The second phase additionally supported a consistent way of collecting speech data in the wild, which, alongside the use of the speakers own voice as the comparative element during the volume task (i.e. in that workers were asked to rate the speaker's voice in relation to a previous speech samples from the same speaker), could account for the improvements in volume scores observed during the second phase. The findings also indicated that the Speeching system could prove useful within the area of speech diagnostics in the future. The variability expressed within the crowd's scores around volume, rate and pitch provided insight around the severity of speech impairment experienced by participants..

In addition, the single word recognition task provided useful insight into the specific issues that might be causing intelligibility issues and, as such, useful indication for therapeutic input. Future work of this kind might serve to leverage this diagnostic potential of the crowd through the careful restructuring of crowd tasks with SLTs, providing a cheap and abundant task force to aid in the diagnosis of speech and voice issues. In addition, further training of the crowd, and the implementation of binary selection tasks such as that used by Byun (Byun et al., 2015) could quickly and easily highlight areas of issue from voice collected in the wild. Although unrelated to crowdsourcing, relevant work conducted by Arora et al (Arora et al., 2014) has additionally studied the diagnostic potential of using automatic voice analysis on speech collected, over the phone, in the identification of undiagnosed Parkinson's. Supporting automatic diagnostic tools with therapeutic input provided by the crowd could greatly enhance the access to SLT level input, without the need for SLT resources. Considering that SLT uptake for PwP is thought to be less than 40%, despite 90% of all individuals experiencing speech and voice problems (Ho et al., 1998; Miller et al., 2007), digital technology could serve to fill a much needed therapeutic gap.

The analysis showed that crowd workers displayed a high range of scores within measures that participants perceived to be their main problems with their speech. This is possibly due to the fact that the untrained listeners had more difficulty quantifying more severe problems with the speech. This is a problem which has been documented in previous studies such as Landa et al (Landa et al., 2014), who found that listeners can struggle to agree on speech ratings with increasing severity. Future research is required in order to scope this question further and draw out the best possible ways to train listeners to rate increasingly impaired speech. One possible solution worth exploring might be to draw much more attention to the measure being explored in isolation. For example, presenting the listener with a speech sample and asking them to focus only the volume in relation to a standardised tone (beep sounding at 60dB) which they increase or decrease to equal to volume in the speech sample equally; or asking a listener to draw a line to represent the speech sample, with increases and decreases in pitch being represented as peaks and troughs. Similarly, EOL was also found to have a high range of scores from the crowd workers. One reason for this might be that this task is based on a discrete ordinal scale yet the ratings are subjective. As such, there is likely to be an experience driven effect, which would see the experts using a different internal rating mechanism towards understandability

to that of completely novice listeners (Miller, 2013). However, in an attempt to better standardize and structure ratings, the addition of a more detailed account of *why* one would select a score of, e.g. 1 over 2, would make this process more precise.

6.7.2 Research Question 4: Speeching as a Tool to Support Self Monitoring and Management of Speech

The fourth research questions sought to explore: *How might Speeching be used as a tool for supporting the self monitoring and management of speech for PwP?* This study has explored how PwP might be supported in the self monitoring of their speech through the crowdsourcing method. Through the provision of crowd ratings participants were subsequently able to consider how they might best self manage their speech issues in an attempt to increase their crowd ratings. The practice area supported this to a degree, however, there were many issues surrounding the content of the practice tasks, which, having been pulled daily from Wikipedia, was often deemed too complex and jargon filled for participants to be able to concentrate on. The complexity of the reading stimuli was seen to ‘impede the flow’ of the participants’ voice when conducting the practice tasks and made it difficult to concentrate on improving their speech. However, CS3P18 found a workaround to this issue by using her own content as practice material. Using the features of the app she was able to still practice her skills without placing too much cognitive demand on the stimuli that she was reading. This also meant that she was working with content that was meaningful and interesting to her, something that was discussed by all of the other participants as an element that would increase their motivation to continue practising with the app, and indeed practice their speech more generally.

Considering the personal differences and interests that people have (e.g. for CS3P19 it was cooking, for CS3P17 football, for CS3P15 poetry, where for CS3P16 it was music) care would need to be taken to ensure that any pre-programmed content in an app of this kind spanned a huge range of personal interests. Perhaps, taking CS3P18’s lead, a better option would be to simply provide the features allowing for the practice of speech (e.g. for maintaining loudness it was a volume monitor, for moderating speed it was a metronome) and leave the space for participants to decide which content they would like to use as their practice materials. These might be sentences provided by a therapist or simply reading from a newspaper or book of their choice. This would also facilitate the integration of a system

such as Speeching in daily life, allowing it to be utilised as part of the daily practices already put in place by the individual.

One feature of the application which was surprisingly well received was the 'listen back' option added to the practice tasks. This option allowed participants to listen back and reflect upon their own voice during their practice session. This facilitation of self-reflection is particularly important in the case of Parkinson's due to the fact that self-perception of their speech is often impaired, particularly in the case of volume (Ho et al., 1998). There was surprise from some of the participants who used this listen back function over the quality of their speech (CS3P18 and CS3P17) and they used the tool as a reflective method of understanding their issues and practising until an improvement was seen. In this sense, particularly for CS3P18, the crowdsourced ratings were used to simply confirm that her own perceptions around how her speech had improved through practice were being observed by others. However, even without the crowd ratings this feature of the app was used as an effective tool to support self-management. Future, similar technologies might try to support this even further by providing the audio captured before practice and after practice to allow for participants to have a direct comparison of their speech.

6.7.3 Research Question 5: Trust and Appreciation of the Crowd

The final research question asked: *To what extent do PwP value human feedback on their speech?* There was much appreciation for the fact that the crowdsourcing method employed real people to conduct the ratings. Participants used the crowdsourced ratings to gain insight into the ways that they were being understood by others and to achieve a baseline for themselves upon which to improve their speech upon. This, in itself, is a huge benefit for the Speeching system. Through the process of self monitoring their speech, participants were able to engage more holistically in self management practices. They used the crowdsourced feedback to gain insight into their issues and, through practice, brought about a change in their speech in an attempt to improve their scores. Without conducting a larger scale trial, it is unclear whether this method would be a motivator for a second group of participants, and indeed, what their reactions would be if their results increasingly worsened. This is a direction for future work and should certainly be considered given that degeneration in ability is an almost inevitable concern for PwP. However, for those

participants who are motivated in their rehabilitation efforts, using a method such as this could prove beneficial.

There was also a level of appreciation surrounding the anonymity of the crowd, which could absolve feelings of embarrassment surrounding speech and what others might think of it. Similarly, participants expressed how they felt this anonymity led to a more truthful measure of their speech, which could not be obtained from friends and family (who remain polite) or professionals (who are trained in listening to Parkinson's speech). This last point was a reason why a non-expert crowd was chosen in the first place, as the 'familiarity effect' has been widely researched in the past (Landa et al., 2014; Miller, 2013; Ziegler & Zierdt, 2008). CS3P15 however had another option on this matter, feeling that his friends and family would be better objective raters of his speech as they would be "hard" on him. Although his ideas contrast with the other participant's views his opinion sits within a line of thinking (R. Putnam, 2001) around leveraging a person's social capital to help support sustainable systems within healthcare.

6.7.4 Envisioning Future Crowd Formations

One concern for ongoing sustainability is the expense associated with the crowd—while this is small compared to expert SLTs, there are still resource implications for paying crowd workers (and indeed ongoing ethical questions over the economics and labour of crowd work (Dolmaya, 2011)). While we might imagine ways of exploring how such work might be financially and ethically resourced, an alternative might be to envision new crowd formations, made up of distributed networks of people interested in working for a purpose to make the lives of others better. One reconfiguration would be to shift from making use of the anonymous crowd to one that is formed by connected individuals, within national charities and support groups, leveraging individual and collective capital. Strong social capital often comes with benefits for personal health: it can reduce barriers to healthcare (Perry, Williams, Wallerstein, & Waitzkin, 2008), facilitate trust around health personal health practice (Ahern & Hendryx, 2003) and increase self-rated perceptions of health (Kawachi, Kennedy, & Glass, 1999). While evidence suggests that people with Parkinson's may experience losses in social capital, it is acknowledged that this is offset by participation in support groups such as those from which we recruited our participants. In the Parkinson's community self-care is not an individual but a collaborative activity (Nunes & Fitzpatrick,

2015), and within these communities there is an already present altruistic component relating to the donations of money and time that could potentially be harnessed within a crowdsourcing context. The anonymity enjoyed by participants could be extended within this context by connecting with unknown members of the wider community through motivated engagement in causes that are meaningful to the contributors.

6.8 Summary Statement

This chapter has described a two phase case study exploring the potential for crowdsourcing to be used as a method for supporting the self monitoring practices surround speech changes in Parkinson's. It first described an exploration into the concept of self monitoring speech changes for PwP using a structured approach to the appropriateness testing of the crowdsourcing method. The ratings of non-experts and experienced SLTs were compared to those of two highly experienced experts in Parkinson's speech to examine whether or not a non-expert crowd could provide equivalent ratings to that of an expert. Experts are extremely difficult to find and recruit into research projects, thus this process was important to explore if another source of insight could be derived. The first phase study showed that, indeed, a non-expert crowd could provide high quality ratings on Parkinson's speech. Following this, a second study was conducted around appropriating the crowd sourcing method within a real life context. Six PwP trialled the Speeching system, which supported the collection, outsourcing for human analysis and provision of feedback on speech via a mobile phone application. Users of the app highlighted a desire to understand their condition, shared by participants in Case studies 1 (chapter 4) and 2 (chapter 5), and showed appreciation for the crowdsourcing approach which showed them semi-instant feedback from a group of real people. The app was also seen to motivate the practice of speech by providing participants a method of which to meter their progress. In short this study has seen benefit for PwP in their self monitoring, and subsequent self management practices and has addressed several of the needs and desires expressed by PwP throughout the course of the thesis research around gaining an understanding of their condition.

The following chapter will approach the three case studies explored in this thesis as a whole and will synthesise the findings across the research period to inform insights into the role that digital technology might play in the self monitoring and management of Parkinson's symptoms. Guidelines for future researchers wishing to work within the self monitoring and

management domain with participants experiencing neurodegenerative conditions will be outlined through a reflection on the approaches and methods employed within the PhD.

Chapter 7

Discussion

This thesis has explored the role that digital technology might have in facilitating self monitoring and management practices in people with Parkinson's, within a speech and language therapy context. Several aspects were considered: the benefits that digital technology might have for allowing PwP to understand and manage their own condition (through self monitoring and management practices) and, in doing so, enable independence; and the benefits that technology might bring in enabling certain types of self management or therapeutic practices, beyond therapy sessions, in real life settings. The thesis began with a discussion of the previous literature surrounding Parkinson's, as a complex condition, and the specific symptoms of drooling and speech changes that were the focus of the PhD research. The literature review then moved to discuss self monitoring and management technologies currently being explored within the context of chronic health conditions. This provided insight into how the technologies designed within the scope of the thesis might be positioned within current understanding. The methods that were employed within the PhD research were then discussed, to situate the reasoning behind the selection of the specific methods used.

Three cases studies were then described in detail. These cases employed the use of UCD methodologies, to gain an understanding of PwP and their very specific needs and values. This was then applied to the development of technical solutions to aid in the self monitoring and management of SLT issues; specifically the symptoms of drooling, decreased volume and additional speech issues common to Parkinson's. They aimed to provide insight into how PwP can be supported within self-directed models of care, whilst exploring the underlying sensitivities of engaging the Parkinson's community in the design and evaluation of digital self monitoring and management technologies. The first case study, presented in chapter 4, described an evaluation of the PDCue, a device to support the self management of drooling through the use of a temporal cueing method to increase swallowing frequency. This study aimed to explore the effect that using the device over a one month period might have on improving drooling and whether or not this effect could be attributed to the device

itself, by comparing the results with a control group. The study proved successful and showed evidence that drooling can be behaviourally self-managed through cueing. However, the cueing method employed a relatively passive mode of encouraging self management; with participants being provided a cue per minute and increasing their swallowing frequency in response. While this worked in the context of the drooling symptom, it opened questions around how PwP may react to more active methods of engaging with their condition, to increase understanding of their symptoms and to modify their self management behaviours in response. To this end, the concept of cueing was re-explored in the second case study (chapter 5); however in this case study, an in-situ cueing approach was applied. The LApp system provided real time visual prompts to alert participants to times when their volume was reduced, to support them in increasing their volume back to a sufficient level. While participants saw the value in LApp in supporting their loudness, this case study highlighted a desire from PwP to understand more about their speech to gain insight into how others perceived them. It also highlighted a need for supporting the home practice of speech, as seen by the re-appropriation of LApp within a practice context. In response, the final case study, Speeching (chapter 6), employed a crowdsourcing method to obtain feedback about PwP speech and provided a way for participants to engage in supported, home based speech practice through an app. This study yielded many positive responses from participants, who valued the feedback on their speech and used it as a motivation to make a change to their practice routines in order to improve. This is of course very different to the cueing methods seen in Chapters 4 and 5, as this was the only system designed to support in-home assessment and practice of speech. However, it provided insight into the value PwP placed upon semi-instant, human feedback for supporting their practice.

In the remainder of this chapter, the overall research questions raised in the thesis will be revisited and the findings across the three case studies will be synthesised. The chapter will explore the lessons learned across the cases and the opportunities for future research that were identified. The chapter will then reflect upon the implications of the work for clinical practice and research through some final conclusions of the PhD work.

7.1 Research Question 1

How is the monitoring and management of Parkinson's symptoms, using digital means, understood within the HCI and wider medical communities?

A review of the literature surrounding Parkinson's and its treatment highlighted a complex condition requiring multidisciplinary clinical input. Examples included medical teams finding the right combination of medications to help manage the symptoms of Parkinson's, and therapeutic clinicians providing skills and strategies to manage symptoms as they appear and/or progress (e.g. physiotherapy, SLT). The importance of self monitoring and management within Parkinson's was clear, particularly in relation to the often transient and unpredictable alterations in symptom severity (ON/OFF periods) that can arise. However, the literature highlighted challenges surrounding the maintenance of therapeutic gains following discharge from therapy programs (Green et al., 2002; Nijkrake et al., 2007; Wight & Miller, 2015) and a need to find new ways to support individuals in their self care practices. Technologies – and particularly commonplace wearable and held technologies (e.g. smartphones) – have the potential to support PwP in taking control in self monitoring activities and managing their condition, by offering simple ways to track and make sense of their symptoms. However, care needs to be taken to ensure that the information being provided to individuals supports an increase in understanding of their condition without becoming a source of anxiety, or drawing attention to ill health (Lupton, 2013); particularly when considering the transient symptoms and decline (inevitable for many) that characterise Parkinson's. There is also a requirement to ensure that these technologies do not become a source of burden for the individual using them (Riggare, 2015).

Although digital self monitoring and management is relatively well researched within the self care domain generally (Choe et al., 2014; Estrin, 2014; Lupton, 2013; Rooksby et al., 2014), the literature review highlighted a need to uncover the specific complexities relating to Parkinson's that may impact on the uptake or use of self monitoring and management support systems. In general, the corpus of literature in the HCI field on Parkinson's is arguably small, with most current work focusing on the clinical monitoring of Parkinson's symptoms (Arora et al., 2015; Cai et al., 2014; A. M. Khan & Lee, 2013; Martens et al., 2013; Westin et al., 2010), and gait assessment and management (Bächlin et al., 2010; Casamassima et al., 2013; Mazilu et al., 2014; Nieuwboer et al., 2007). There are only a few

accounts in this corpus concerning the design of self monitoring and management systems (de Barros et al., 2013; Krause et al., 2013; Mazilu et al., 2014), and these studies have focussed mainly on usability and meeting clinical goals. As such, there are still huge gaps in this literature that relates to developing understanding of how PwP might use, need and value data provided by self monitoring and management technologies to make sense of their condition. Equally there has been, at the time of writing, no research in the HCI field around investigating the impact that self monitoring and management technologies might have on the daily lives of PwP.

The following research questions attempt to explore these gaps in the literature more thoroughly, by drawing lessons learned throughout the case studies conducted during the scope of the PhD. Research question 2 aims to address the gap in understanding about supporting PwP in their self care practices at home, by scoping the types of feedback that PwP require in order to take control of their symptoms and make a change to their practices. Research question 3 addresses the gap in understanding how self monitoring and management technologies may be integrated, used and valued in the daily lives of PwP. Finally, Research question 4 explores the issue surrounding the distinct lack of design work in HCI engaging PwP in the design process, by reflecting upon the design experiences obtained throughout the PhD research and drawing out some guidelines for future designers contemplating working with this complex user group in the future.

7.2 Research Question 2

What types of feedback are required to provide PwP with a sense of agency when using self monitoring and management technologies, in terms of increasing their understanding of their condition and facilitating them in making a positive change that will help manage their symptoms?

As was seen in the literature review, Parkinson's and its symptoms can have huge social and emotional impacts on the person experiencing them. With a reduction in physical ability often comes a reliance on others, which can greatly impair feelings of agency and control within the person (e.g. (Bramley & Eatough, 2005; Lindgren, 1996)). In addition, associated feelings of fear, embarrassment, stigma and loss of confidence can become so severe that the person will avoid leaving home or socialising. These were feelings that arose within the participant samples in the PhD research. The design activities conducted in the case studies

enabled understanding to develop around people's lived experiences of Parkinson's and the specific feelings that are associated with loss of functional ability or specific symptoms and its impact on the person and indeed their family members. Within the preliminary acceptability trial for Google Glass (described in chapter 5, section 5.4.2.3), there was much discussion around how the symptoms of Parkinson's led to anxiety when alone (around a fear of falling or not being understood if help was required) and how this caused them to lean on the support of carer. There was an overwhelming desire to have access to a system which would build self confidence and support independence. Participants within the LApp design stages (section 5.4.4.1.1) also reported feelings of being 'ignored' or 'dismissed' due to their quiet speaking voices and discussed loss of confidence in their speaking ability, even withdrawing from social situations with friends at times. Finally, in the final interviews for the PDCue study (4.5.4.1), participants reported not wanting to leave the house or go out to eat due to embarrassment and feeling of stigma surrounding their drooling.

In response to these feelings expressed by participants, and to consider how a sense of control over their symptoms might be given back to them, it was important to consider how different feedback types (e.g. cue, visual display, scores) may promote, or become a barrier to, achieving a sense of agency. In order to do this, the types of feedback are framed with the concepts of responsiveness (the speed of reaction required for a given stimuli or feedback provided by the device) and agency (the level of independent control that the participant has in the behaviour completed in response to the stimuli provided by the device) required by the PwP when engaging with the three devices that were developed. Figure 17 visualises these concepts within a quadrant. The Y axis of the quadrant considers the temporal responsiveness of the person in relation to the information or data that is presented to them and the X axis represents the agency that is placed in the individual surrounding the decision they need to make in regards to changing their behaviour in response. Below, the feedback types are discussed individually alongside some theoretical perspectives around why each type may have worked.

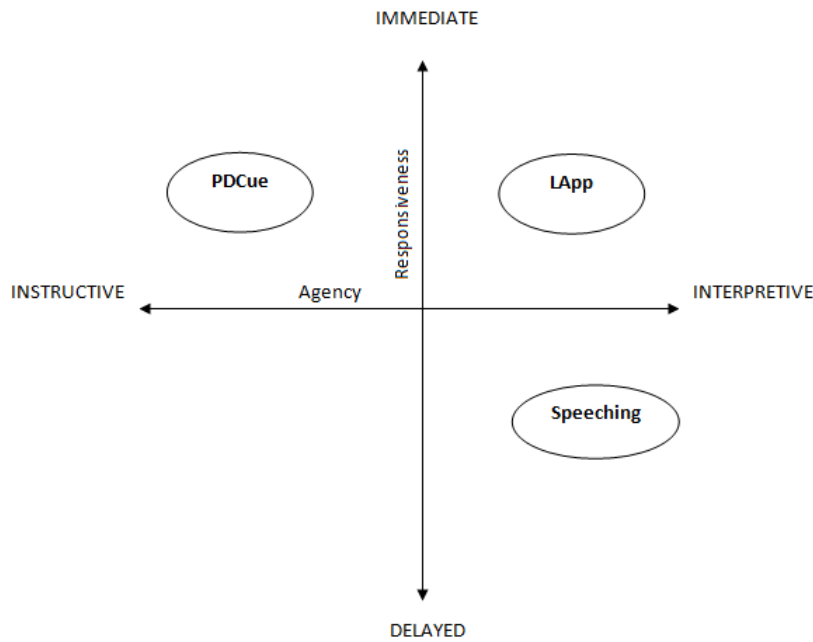


Figure 15: Quadrant considering agency and responsiveness in relation to the case study devices

7.2.1 Immediate, Instructive Feedback

The PDCue device helped investigate temporal cueing as a feedback mechanism, offering an immediate, instructive intervention. The user received immediate information (the cue) that they were not required to interpret, instead they simply followed the instruction to swallow which had been predetermined by the researcher. In short, the vibratory prompt stimulated a change in behaviour (increased swallowing frequency). This concept of cueing could be likened to, for example a medication reminder, which prompts an immediate response to take medication. Other researchers have also explored this method with success in the domain of gait training for Parkinson's (Nieuwboer et al., 2007) which is built upon observations that the training of a metronomic cue brings about the execution of a new motor plan, which facilitates walking and suppresses the impaired motor plan currently inhibiting the intended movement (Bötzel & Schulze, 1996; Georgiou et al., 1993; Sarma et al., 2012). There is a level of automaticity in the complex movements of both walking and swallowing of saliva that link these two symptoms together and allow for cross comparison of motor theory. Both are triggered, patterned responses involving automated neural processes that generally do not require conscious thinking for carrying out the activity. However, in the case of Parkinson's, these automatic movements can become impeded

when difficulties with motor initiation arise. In terms of neurophysiology, cueing is believed to suppress pathological basal ganglia activity through activation of corticostriatal pathways (Sarma et al., 2012). That is to say, the cue causes the initiation of an alternative pathway in the brain, also linked to motor activity, which brings about the initiation of movement that has been halted. This method of temporal cueing provided a simple way for participants to improve their drooling and, post trial, led to increased feelings of control, confidence and self-esteem. As such, it could be said that a sense of control was derived from the positive outcome of the use of the cue. In this sense, the 'prescribed' model of self management, which is so common in traditional transactional models of healthcare (with the patient being given something by the therapist and left to use it), has proved successful. However, whilst the alleviation of the drooling symptom was very much appreciated by participants, this feedback method did not allow for participants to add any understanding around drooling; why or when it was happening how it might be improved in different contexts.

7.2.2 Immediate, Interpretative Feedback

The LApp device, discussed in Chapter 5, was also associated with an immediate response due to the nature of the cueing intervention that was provided. However, the app afforded an extended level of agency to users in that there was an interpretive element to the data that was being viewed. LApp showed a continuous stream of data in the form of the cueing system that reinforced positive behaviours (i.e. obtaining target volume). The app was designed in this way so as to not distract participants during conversation; rather than cueing people when they were too low, the app gave them a signal when they were at an appropriate level. It was felt that cueing participants when they were *not* speaking loud enough may distract them during the flow of conversation. Instead, this approach took on more of an active, or interpretive, role to encourage participants to monitor their speech and react as and when needed. From a theoretical perspective, this approach could be viewed within the same line of thinking as errorless learning, which has been widely explored within the rehabilitation of cognitive impairment (e.g (Clare et al., 2010; Kessels & Haan, 2010; B. A. Wilson, Baddeley, Evans, & Shiel, 2010)). In this technique, there is a focus on reinforcement over punishment, in terms of encouraging an increase in behaviour (improving loudness) rather than a decrease in a behaviour (speaking too quietly). As this PhD research surrounded supporting the person in their self care practices, it was felt that

supporting a positive view of their progress as opposed to reminding them of their failures, which as described by Lupton (Lupton, 2013) can become a source of anxiety, would be an appropriate method to choose.

One way to define the type of feedback provided by the in situ cueing method is to look at behavioural theory surrounding motor learning, the principles of which have been shown to map well onto motor learning theory in the treatment of motor speech disorders (Maas et al., 2008). In a paper by Wulf, Hob and Prinz (G Wulf, Höß, & Prinz, 1998) the authors studied the differential effects of internal (attention on one's body) and external (the effect of the action on an external factor) focus of attention during motor skill learning. The authors found that the provision of instructions relating to the effect of the participants' actions on the external, experimental apparatus (in this case it would be the LApp system displaying when their volume is loud enough), is more effective for the motor learning of new skills than instructions directing participants to attend to their own body (e.g. simply instructing someone to speak louder). As described by Salmoni, Schmidt and Walter (Salmoni, Schmidt, & Walter, 1984) there are several types of feedback mechanism that can support motor learning. Knowledge of response (KR) is a feedback method that provides a response outcome in relation to the environmental goal. This allows the learner insight into whether they are correct or incorrect but does not provide additional insight into the error (i.e. how they were right or wrong) and is the feedback mechanism employed by the LApp. On the other hand, knowledge of performance (KP) provides specific feedback about the person's performance (this feedback mechanism was employed in the Speeching study which is described in section 7.2.3). Although speech is not a new skill for the participants to learn, it has already been discussed that the motor speech patterns controlling volume are degraded, as such there is a certain level of re-calibration required to help the PwP to begin to learn what a loud speaking voice is. In this sense the provision of KR feedback around their speaking volume in situ can allow participants to retrain their awareness of the force required to produce a loud speaking voice in different conversational settings. Schmidt (Schmidt, 1975) discusses the importance of continuous KR within motor skill learning. If KR is not present then the internalised representation of what the movement should be is gradually weakened. In this regard, vocal force could be weakened if feedback around speech is removed, causing the person's internal representation of how their voice should sound to resume back to impaired levels. There are several specific environmental feedback

mechanisms used by participants to maintain their KR/ internal perception of their voice, for example, a spouse or family member continually asking them to speak up. However, there is a well documented familiarity effect which can occur surrounding loved ones' perceptions of intelligibility (rating them more intelligible the more familiar they are) (e.g. (Landa et al., 2014). Systems like LApp offer a method of providing this continuous KR, without risking a familiarity effect occurring.

7.2.3 Delayed, Interpretive Feedback

In the final case study, Speeching (Chapter 6), the intervention that was presented elicited a delayed, interpretive response. The users of the system were required to wait, albeit not very long, for feedback on their speech and then interpreted the scores provided to them as a means to facilitate their practice sessions to improve their speech. This method of feedback provision, which allowed a sense of agency in the decision making process surrounding when to receive feedback and on which speech samples, as well as choosing how to interpret and use that feedback to guide practice, corresponds with a piece of work by Wulf (Gabriele Wulf, 2007) around self-controlled practice for enhancing motor learning in physiotherapy. Wulf advocates a move from prescribed to self directed training protocols, found to enhance motivation, encourage active involvement in self care and correspond more to specific needs. The author describes how allowing individuals to choose when and how they receive feedback schedules, use assistive devices (such as walkers) and receive demonstrations of a movement, can enhance not only the retention of motor skill, but also the transfer of skills to other areas and contexts.

This may now be considered in terms of the participant's behaviour throughout the study, and how they used the feedback from the crowd to facilitate their speech practice. Although there were practice tasks to encourage and shape their practice, it was clear that participants only carried out the tasks that they felt would improve their own speech difficulties. For example CS3P18, who went beyond the practice tasks that were available and used the app in her own way to improve her speech clarity, practising specific words and variances in her pitch levels that she felt were causing problems with her clarity, or CS3P19 who used the crowd feedback to challenge himself to achieve an optimal score. In addition, the finding that participants used the listen-back function as a tool for reflecting on their speech and understanding why the crowd was rating them in certain ways, demonstrates

how a self-controlled approach can allow for users to develop their own practices outside of prescribed notions.

A further example of a delayed, interpretive intervention would be in the domain of dietetics. Individuals who receive information on weight, cholesterol levels, vitamin deficiencies etc., will be given a list of foods and drinks to add or avoid within their diet, yet it is ultimately them who must make the decisions about how to implement the advice in a way that is achievable within their lives. Another example is the common commercial fitness monitors (e.g. Fitbit, Polar, Garmin), which monitor heart rate and calorie burn during fitness activities. Users can view the accumulative effort of their workout and use the information to decide if they need to do any more activity, or modify their diet accordingly within the day. Similarly, giving up smoking following a lung function test, the overall aim is to stop smoking altogether, however how the person chooses to do this—by cutting down the number of cigarettes they have daily, using an e-cigarette, using nicotine replacement therapy—still very much lies with the person. If these are considered within the model presented in figure 17; the data being presented is there to be interpreted by the users, thus encouraging them to make better choices, however, the agency of the behaviours that will be modified still very much lies with the individual. These types of behaviour change can be positioned in the transtheoretical, or stages of change, model developed by Prochaska in the 1980's (Prochaska & DiClemente, 1982), which discussed five stages of behaviour change: pre-contemplation, contemplation, preparation, action and maintenance. In this sense it could be speculated that Speeching supports individuals in the action stage who have already taken the steps to begin their change (improving their speech) by seeking SLT intervention (or, if this were a commercially available system, taken the step of downloading the app) and are motivated to continue with their speech improvement through monitoring their progress and practising to promote improvement.

7.2.4 Delayed, Instructive Feedback

Finally, a delayed instructive intervention was left unexplored during the thesis but would fit into the final quadrant. This intervention would be akin to the majority of prescribed rehabilitative programmes, whereby the provision of information surrounding long term changes to behaviour is coupled with clear instruction around how to make the change over time. See for example LSVT (Ramig et al., 2001), which several of the

participants had undergone, which is an intensive four week programme aimed at improving vocal loudness and provides much structure in terms of both the sessions with the therapist and the home practice sessions. In this case there is a requirement for professional input, to guide individuals in changing their behaviour and there is less of an onus on the person themselves to make the change. Whilst this type of supported intervention provides individuals with the knowledge and skills necessary to change their behaviour, research has shown that the maintenance of gains obtained within clinical contexts can be difficult to support once therapeutic input has been removed (Green et al., 2002; Wight & Miller, 2015).

7.2.5 Summary and areas for future work

There are several positives and negatives surrounding each of the feedback mechanisms described. The immediate instructive response provides an on-the-spot cue to conduct an action, meaning it can quickly bring about a change in an instantly gratifying way. However, the PDCue device did not provide any KR and as such, the opportunities for learning (i.e. about how much the use of the device has helped the drooling problem, or how much saliva has been cleared from the mouth) cannot be reinforced. Future work could build upon this concept of immediate instructive feedback provision by incorporating a level of KR into the feedback system. This is particularly difficult for the symptom of drooling, unless there could be some level of an automated swallowing monitor built into the system to tell participants that they had performed an appropriate swallow. However, for self management systems looking to prompt, for example physical rehabilitation movements, such as reaching out of the upper limb or synchronous movements of the arms and legs, there would be a potential for providing KR around the quality of a movement following a cue.

The immediate interpretive cue provided by the LApp, equally provided an instantly gratifying feedback mechanism, in that it showed participants when they were loud enough. This system also supplied opportunities for learning through KR for participants, as they could reflect on the level of force required to produce the loud speaking voice in different settings. Yet, aside from switching the device on and off, there were no opportunities for participants to self control the feedback they were being provided. Future related work could look at incorporating different levels of feedback to be customised based on an individual's needs, for example: providing the option for users to see a visualisation of their volume (either in numeric dB or in an abstract visual form) to allow for reflection around

how close to the target they are; or displaying an overview of their performance (KP) to allow for reflection on their volume over the course of a conversation.

Finally, the delayed interpretive feedback method allowed for self-controlled learning to occur by providing participants of the Speeching system with detailed information about what was making their speech unintelligible. This method could be applied to a range of symptoms for which quality of performance is required (e.g. physical rehabilitation, range of movement, facial expression). However, while the participants of the study responded well to the feedback they were provided, there is a potential with this system to draw attention to a decrease in ability, which may cause frustration for other individuals (Lupton, 2013). The focus of this study was around understanding how this type of feedback could be used to support home practice of speech, however, it did not uncover the impact that negative (or positive) feedback might have on participants over time. Further work is needed to uncover this question, trialling systems like Speeching over longer time periods and with larger numbers of participants. A more immediate direction for future work would be uncovering PwP opinions around the best ways to present detailed feedback around their symptoms.

7.3 Research Question 3

What are the current challenges for the integration of self monitoring and management technologies into the daily lives of PwP?

It was clear to see from the literature review surrounding Parkinson's and its multitude of symptoms that it is a complicated condition, with a plethora of physical, cognitive, social and emotional complexities that interplay to impact of the day to day life of the individual who is experiencing it. The complexities of the condition alone highlight several areas of consideration within the context of self monitoring and management and the possible challenges which might arise when trying to integrate technical support systems into daily life. As discussed by Riggare (Riggare, 2015), the process of tracking Parkinson's can have both positive and negative implications. Self monitoring can play a vital role in taking ownership of the condition; in understanding the individual daily symptom fluctuations, optimising medication routines and indeed ensuring that the condition is being managed outside of the infrequent contacts with medical staff. However, it can also become a burdensome task, requiring time and effort in daily life that can impact enjoyment in life. As such, it is vital that technologies designed to support these practices do so in a way that fits

into the daily lives of the person. In this sense, the use of automated monitoring techniques, or easy modes of self management that do not require much time to interact with are optimal. When attempting to understand the daily lives of PwP however, the condition and its impacts are not the only factors to consider. Each individual has their own lives, with appointment filled days, hobbies, families and friends and indeed other medical conditions outside of their Parkinson's to deal with. This was very clear throughout the course of the PhD research, where each separate case study saw participants who, for one reason or another, were unable to fully engage with the technologies being deployed due to factors in their individual lives. For example, in the LApp study CSP10 was experiencing problems with an existing eye condition during the study which she felt inhibited her use of Glass, and in the Speeching study CS3P15 went on holiday to visit his daughter in an area with low mobile internet connectivity meaning he was unable to use the system as much as he would have liked.

The case studies investigated several different contexts of daily life (at home practice of the Speeching system, in situ use of LApp during conversation and continuous use of PDCue during everyday activities) and the technologies differed in their ease of integration. The PDCue device could be worn continuously in any setting due to its discreet design; it could be switched on when required and needed minimal concentration from participants to use it. In addition, its battery lasted for up to 2 weeks without charge. Arguably, for these reasons, the PDCue device was the easiest to integrate into daily life. LApp on the other hand, which ran on Glass, could again be worn continuously (if desired) for up to four hours, although the study found that this estimated battery life did was not always correct and forward planning to charge the glass for a specific situation was often needed. In addition, several participants in the preliminary acceptability study around Glass discussed feeling uncomfortable with the visibility of the device (see Chapter 5, section 5.4.2.2). The LApp could be and switched on when required, yet it required concentration for the participants to monitor and make sense of the cues being provided. Speeching supported at home practice and could thus be used as desired on a standard mobile handset. However, there was a level of motivation required from participants to use the system and, although self-controlled feedback mechanisms have proven successful in the learning of skills (Gabriele Wulf, 2007), it is unclear without further research whether the system would support long term home practice of speech.

As mentioned above, there were several challenges relating to the technologies themselves which made integrating the systems into daily life difficult. Most of the current research (this PhD research included) aiming to support self monitoring and management in Parkinson's, and in fact healthcare more generally, is conducted using generic consumer technology platforms, and for very good reasons (Arora et al., 2015; de Barros et al., 2013; Dickerson, Gorlin, & Stankovic, 2011; M. Lan et al., 2012; Mazilu et al., 2014; Sha et al., 2008; Watanabe, Kawarasaki, Sato, & Yoshida, 2013; Zimmerman & Chang, 2008). Consumer platforms like mobile phones and consumer wearable devices are readily available, relatively inexpensive to buy (when compared to medical technologies) and are often already owned by, and familiar to, the health communities being explored (although, as described later on, this is not always the case with older people and people experiencing physical conditions that may impact on their ability to use certain technologies). In this sense the rise of mobile phone applications for health has overtaken the development of bespoke medical systems due to their ease of distribution, relative inexpensiveness and their ability to utilise already available sensors which are present on the mobile platforms.

Another benefit of developing systems for consumer technologies is the desire to design systems that will not become a source of stigma for the user, which, as discussed in Chapter 4 (section 4.2) can be a feeling placed on to current medical technologies such as falls alarms. However, there are tensions that can arise with the use of these consumer technologies in Parkinson's research relating to challenges around physical accessibility, as highlighted in the discussions around mobile phone usage in Chapter 5 (section 5.4.2.1). Of course, there is the option to develop more accessible systems, designed with PwP or with PwP in mind. However, there are several complexities surrounding application updates which should be addressed. Updates to operating systems and applications based on mobile phones can cause changes to the ways that systems are interacted with and add features that have previously been unseen by users. This new wave of development, which sees designers releasing applications and fixing bugs as they go along, through over the air updates, is now common practice. However, it is causing the release of what is, to all intents and purposes, fundamentally flawed pieces of software. Whilst familiar users can readily adapt to software changes as they occur, this can cause several issues for those who might be unfamiliar with current 'update' methods of software improvement. The main issue that arises when working with users who might benefit from the applications being released, but

who do not necessarily have extended familiarity with the ways that apps are developed, like older users for example, is that these practices can cause distrust and frustration with the technology if it is seen not to be working, causing disengagement from its use. Indeed, this was observed in case study 2 (chapter 5, section 5.4.6.2) where CS2P14 became increasingly frustrated with LApp due to its inability to pick up his speech and associated this with a distrust in the technology rather than his own ability. However, this participant also took part in the Speeching study (as CS3P19), wherein he greatly valued the feedback of Speeching because it was a 'human' at the other end who was conducting the analysis on his speech. This calls for a need to further explore the different levels of trust that PwP are willing to place in technologies that are being employed to support self monitoring and management, particularly due to the sensitivities that surround the finding of a potential to track decline of ability over the course of the condition.

7.3.1 Summary and areas for future work

In answering this research question and analysing the different qualities of the case study devices, several points arose for considering how these qualities might help or hinder integration. Firstly, the implementation of self monitoring and management tools on discreet, robust platforms is key so that individuals can have bring systems into any situation in which it might be required. In this sense the PDCue was an optimal example, however, for novel consumer platforms such as Glass, which have not yet been brought to the market, there were several participants who felt uncomfortable wearing the system in different public settings. One option for the future would be to implement a system like LApp on a more recognisable platform, such as a smartphone. This would also improve the issues experienced with Glass relating to battery life, which was a huge source of contention for the Glass users. Future work could consider the LApp on a mobile handset, however there would need to be some consideration into the type of cueing mechanism that the LApp would then employ. In daily conversation it is likely that a visual cue on a mobile would detract from the social context of the conversation, if one speaker were to be continuously looking at their phone. One way to resolve this could be through the use of auditory cueing through an earpiece linked to the mobile, or a vibration through the phone. However, receiving positive cues using these methods might be difficult, for example continuous

beeping could become irritating to participants. As such, it would be necessary to cue participants when their voice is too quiet instead.

7.4 Research Question 4

How might PwP be engaged in the design of feasible technical solutions to facilitate self monitoring and management practices for PwP?

As of yet, there are no published guidelines surrounding the best methods of engaging PwP in the design of technologies. In fact, there is only one example that could be found, from de Barros et al. (de Barros et al., 2013)⁴⁴, which actively engaged PwP in the design process outside of simple requirement gathering. As such, the process of conducting design work with participants throughout the PhD was a novel experience.

Several experience-centred reflections around the practicalities of designing with PwP were drawn out. There are a myriad of intricate sensitivities that were taken into account when planning and undertaking the process that have not yet been reported within the literature. Lindsay et al (Lindsay, Jackson, et al., 2012) outline clear guidelines for conducting participatory design with older users. These were drawn upon throughout the PhD work. However, it became clear that several Parkinson's specific issues were inadequately addressed by these guidelines. Firstly, speech problems are extremely common in PwP (whether conducting research around impaired speech or not) and can thus be a barrier to both the involvement of participants and the quality of data that can be collected. The design work undertaken in the LApp study was a discussion based approach, which led to its own difficulties relating to facilitating a discussion with a group of PwP experiencing impaired speech. As described by Massimi (Massimi et al., 2007) in his paper around designing with older adults, it is the researcher's job to ensure all participants are being heard within the design process. This was difficult at times, particularly when considering the fact that there are always participants who are more dominant than others in discussion. The researcher had to carefully observe the participants and look for indications that they were attempting to engage in the discussion. The research also had to ensure that the conversation was equally spread across participants by calling for participation from specific individuals, using clarification techniques to ensure the message

⁴⁴ Please note that de Barros et al. frame their work on the methods outlined in the researcher's 2011 paper 'Cueing swallowing in Parkinson's' (McNaney et al., 2011b).

was understood by the rest of the group. Another aspect that facilitated the participation of all members in the discussion was that they had been recruited from the Parkinson's UK support groups and, as such, many of the participants knew one another. A level of support and a respect for each other's opinion within the workshops allowed even those participants with particularly poor vocal loudness to have their say. This echoes findings from Lindsay et al (Lindsay, Brittain, et al., 2012) in their study of designing with people with dementia, in which they describe how the recruitment of existing groups and caregivers can facilitate the sharing of personal narratives in a comfortable and sympathetic space. On reflection, the group sizes of seven may have been too large to facilitate the participation of all members. This echoes a finding of Massimi et al (Massimi et al., 2007) who advocated the use of smaller groups when working with older adults in design to overcome deficits and enhance participation. Also, in a study by Galliers et al (Galliers et al., 2012), which worked with people experience moderate to severe aphasia, the groups sizes were selected to be even smaller, with 2 to 3 participants and 3 facilitators to support them. Smaller groups sizes allow for greater time and attention to be placed on encouraging people with communication difficulties to express themselves effectively and could prove a beneficial consideration for future designers wishing to work with people with communication difficulties. Speech issues also caused difficulty for several participants when conducting the final face-to-face interviews. The researcher used a clarification technique at these times that speech was particularly unintelligible, either repeating back what they had said or reframing the message for longer utterances, to ensure that both their message was understood by the researcher and to improve the quality of the recordings for later transcription.

Another consideration for the researcher within the group discussion setting was general mobility. Specific motor symptoms, such as freezing of gait, can make tasks such as going to the bathroom, entering a lift independently or getting in and out of a chair difficult. The researcher was required to be mindful of this when setting up the workshop venue, ensuring that the room was equipped with chairs which had arms to make the transfer of sitting to standing easier, and always having at least one other researcher in each design session so that the discussion was not disrupted if a participant required assistance. Other practicalities relating to the workshop related to medication schedules. Medication timing is key for PwP, particularly those who suffer from ON/OFF symptom fluctuations, so ensuring

that clear schedules were set out for each session, and strictly adhered to, was important to ensure participants knew when to expect breaks.

Aside from the practical issues, there were several challenges around engaging PwP in discussions around technology and the design of self monitoring and management systems for different platforms. Several of the participants within the LApp design work (and the PDCue design work) did not own or use a mobile phone, nor were they aware of how applications for smart devices functioned. This was predicted by the researcher and, as such, there was time planned into the session to uncover people's existing experiences with technology and to demonstrate, and allow the opportunity for practice on multiple mobile handsets, made available to participants during the session. Without this, it would have been difficult to progress understanding around how the application might function. Overall, however, these insights show that with effective facilitation and careful planning, PwP can be supported to take part in technology design and we should, as suggested by Newell et al (A. Newell et al., 2011), be not only expecting, but actively seeking diversity within our participants.

7.4.1 Summary and areas for future work

On reflection of the design methods employed during the PhD research there are several points for summary that are arguably useful to future researchers wishing to engage PwP in their research. Discussion based methods were used successfully during the process, despite working with participants experiencing speech issues. The development of a relaxed speaking environment and careful facilitation from the researcher was key to ensuring that all participants could share their thoughts and opinions. In addition, attending the workshop with no preconceptions about how technology savvy the participants will be is important. There were also several practicalities relating to the workshop set-up that ensured a comfortable environment for participation. Given that there is very little work surrounding engaging PwP in design work these basic guidelines provide a starting point for thinking about the community's closer involvement within the design of digital health systems.

This discussion chapter has provided insights into the ways that future designers might encourage users of self monitoring and management systems to reflect upon, and subsequently respond to, data surrounding Parkinson's symptoms in different ways, whilst

promoting a sense of agency within the individual to make a change. The thesis will end with some final conclusions for the research.

7.5 Conclusions of the Thesis

The work presented in this thesis has provided a useful starting point for discussion around the types of technologies, interventions and feedback mechanisms that may support self monitoring and management practices around issues managed by SLT in PwP. Through a synthesis of diverse literature, drawing from multiple domains of medicine, HCI and speech and language sciences, it has offered new knowledge around the ways in which Parkinson's and digital self monitoring and management are represented within the HCI community and has highlighted several gaps in the literature which provide insight into opportunities for future research. Through three distinct cases, the research has offered insights into the ways in which technologies can be designed to aid self monitoring and management of Parkinson's symptoms, as well as how these technologies are then experienced and valued by PwP.

The PDCue trial provided evidence that a behavioural cueing method, delivered through the carefully designed PDCue device, could be an effective treatment option for PwP experiencing drooling problems. The findings of this study indicated that the self management option might be best suited to participants who have an internal motivation to improve their drooling (i.e. those who feel their drooling has reached a level of severity that warrants self management), with participants experiencing milder drooling problems showing less success with the device (described in detail in Chapter 4, section 4.6.2). Clinical recommendations relating to the prescription of this type of self management option should take these factors into account, ensuring that participants are fully motivated to change their drooling behaviours prior to advising the intervention.

The LApp trial showed how participants used in-situ prompting to support the self monitoring and management of vocal loudness issues. The study provided several insights surrounding a desire from participants to understand more about their volume and the ways in which technologies may support the home practice of loudness. This countered the primary envisioned use-case of LApp, which focused on the 'in-situ' provision of support, in day to day conversation. In this sense, the features of LApp facilitated new ways of understanding participants' speech, appropriated in an unexpected manner by PwP. As such,

this highlights that tools to support the development of home based voice self management programs (such as (Krause et al., 2013)) should not be entirely dismissed in favour of tools for in-situ, real time, feedback. However, the study also showed how being reliant on a system such as Glass can lead to considerable frustration if things go wrong (i.e. in the case of the negative feedback provided to CS2P14). This echoes the perspective of Lupton (Lupton, 2013), who described how digital health technologies have the potential to become reminders of illness or impairment rather than tools for empowerment. Given the noted issues of personal distress and embarrassment associated with Parkinson's (Miller et al., 2006), this emphasises the importance of well-tested applications and a non-trivial level of technical support (e.g. an accessible troubleshooting guide or access to a person). There were several considerations drawn from the study relating to the Glass platform itself, which could be further applied to other novel consumer technologies employing similar features. For systems like Glass to be more usable for PwP, the sensitivity of touch gestures should be investigated more. The provision of longer timeframes for accessing features, as well as ability to lock down the technology to a single application could aid functionality in this sense. Participants also had issues with battery life when using Glass, so future applications should consider such issues, particularly for systems aiming to provide continuous in-situ prompting. In general, there is a level of caution that should be applied to novel commercial wearable and mobile technologies, used as platforms for research studies in real-world settings. It is worth noting here that Google, in fact, stopped supporting Glass as a product after only two years of development. In this sense the expectations and reaches of hope extended to the platform by the Parkinson's community were lost, as the prospect of seeing Glass develop into a product diminished. Overall, wariness should be fostered around novel commercial platforms used in research; by and large these are inflexible to researchers to the extent that there is not enough known about them to be able to maximise accessibility for specified groups. In such a research context, one must ensure that the physical and computational forms of devices are in tune with one another, and avoid situations in which sophisticated visual aesthetics may cover up underlying flaws in the software.

The final case study, Speeching, explored the potential for using crowdsourcing as a method to obtain human feedback on PwP speech in order to increase understanding around speech issues and provide direction for practice. This method was shown to provide a level of trust from the study participants as a means to elicit honest feedback on their

speech. It also met its aim by motivating participants to practice elements of their speech at home in order to improve their vocal clarity. Participants valued the level of understanding that came along with receiving feedback around their speech, and seeing how their practice had made a change. Of the three study approaches taken, this method could be viewed as the most successful for supporting reflection around self monitoring and management practices. Future work is needed to look at the types of human feedback that PwP, themselves, might value for supporting self monitoring and management practices long term.

Finally, whilst not a theme that arose during the case studies, it is worth considering in future related work how the systems that were developed could lead to the potential tracking of decline. The Speeching and LApp systems provided data to participants about their speech and without a longer study it is unclear how they would manage seeing their speech decline further. This was an area of discussion in another piece of work conducted outside of the PhD around the design of rehabilitative exergaming systems for PwP (McNaney et al., 2015). Participants in this study expressed how they would not want to see negative feedback surrounding their movement as it could lead to feelings of worthlessness, rather than willing them to practice. Although not explored in the PhD research, future studies could investigate the longer term benefits of these types of systems. Designers should arguably consider new ways of presenting data so that it is mindful of the daily fluctuations and inevitable long term decline associated with Parkinson's.

This thesis has offered a deepened understanding of the relationship, and distinctions between, both the clinical and personal needs that must be encompassed within digital self monitoring and management systems for health and the complexities that arise through the heterogeneous nature of Parkinson's as a condition which is expected to degenerate over time. Whilst the research has offered a much needed starting point to begin thinking about digital self monitoring and management for Parkinson's, and how we might engage the community in technology based research, there is still much to learn. The Parkinson's community who engaged in this research had a wealth of life experience, both in terms of their Parkinson's and beyond, and an admirable devotion to supporting one another. There are opportunities for learning about this community that go beyond the scope of personal health and into the realm of socially supported health networks. For instance, there are possibilities for expanding systems such as Speeching to involve the

community themselves as raters, or in developing health networks that support self monitoring and management practices through friendly competition or social networking. By taking steps in this direction we can begin to look at the longer term motivations and barriers to self monitoring and management and move towards sustainable models of self-care.

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Appendix 1: Case Study 1

Appendix 1a) PDCue Participant information sheet



Project information sheet for volunteers

Developing a device to reduce drooling in Parkinson's Disease

Purpose of the study

Surveys suggest that the majority of people with Parkinson's experience problems with drooling and that this can have a major impact on their quality of life. Drooling does not happen because more saliva is produced, but because the natural automatic reflex that normally makes us swallow our saliva, even when we are not eating, fails to happen in Parkinson's or it works inefficiently.

In our established consultative groups of people with Parkinson's, members have identified drooling as a feature they wish to have treated.

Current treatments, however, which are oral medication or Botox injections into the glands that produce saliva, can have side effects and can be unpleasant for some people. As a potentially much more acceptable alternative, we have developed a small wrist worn device that gives a small vibratory cue at regular intervals to remind wearers to swallow, and thereby reduce the chance of drooling. Alongside the wrist worn device we use a discrete, commercially available in-ear microphone, connected to a small recording device, which we refer to as the 'swallow detection device'. This device is worn inside the ear and allows us to measure how often you swallow. You will only be asked to wear this device sporadically throughout the study.

Based on the feedback and advice from people with Parkinson's, who tried the 3 earlier versions of the device, we have now developed an improved device. We are inviting individuals to join this study to help us ensure that the new device truly reflect the views and needs of people with Parkinson's and that it does the job it is meant to do, i.e. makes you swallow more frequently and diminishes problems with drooling.

Who can participate in the study?

Participants of any age, gender and disease severity are invited to participate in this study, as long as they feel they experience drooling problems.

What is the device and how does it work?

The device we are asking you to try is a wrist-worn device that looks like a digital watch. It vibrates at regular intervals to remind you to swallow. It does not make any beeping noises and can be hidden under clothing. It can be turned off and on as necessary. It is completely safe and requires no batteries, it just needs to be plugged in for a few hours every 1-6 days by a small charger, similar to one you would use to charge a mobile phone.

What will you have to do if you agree to help us?

If you agree to participate we will ask you to wear the device for at least 2 separate hours per day, for four weeks. You can wear the device at your leisure, at the times and places that you wish. You can wear it for longer or shorter periods of time during the day at times you feel that drooling might be a problem for you.

At the beginning of the study we would like to carry out some assessments on you so that we have some information about your Parkinson's and your drooling. You will also be asked some questions about the frequency and severity of your drooling and be shown how to wear the cueing device and the swallow detection device. At the end of the study you will be visited again to discuss your experience of wearing the cueing device and swallow detection device. We will ask questions about features that you did, or did not, like, how easy the devices were for you to use as a person with Parkinson's, if you felt that the cueing device made a difference to your drooling etc.

We would like you to record the times that you wear the device and for how long. We will give you a small booklet to do this. If it is possible, we would also appreciate if a family member or friend could give us some feedback regarding the severity and frequency of your drooling at times when you are both wearing and not wearing the cueing device. This will help us to evaluate if the device is making a worthwhile difference.

7 days after the end of the study, when you have finished wearing the device, you will be contacted again to discuss if you feel that any changes in your drooling have been maintained.

In order to have an objective measure of whether the device makes any real difference to your swallowing, we will ask you to wear a swallow detection device, which stores data on a recording device, for two 3 hour periods in the week prior to beginning the study, one 3 hour period per week during the study and two 3 hours in the week following the end of the study. We ask you to wear this device for longer periods of time so that we can see what the normal pattern of swallowing is in different people with Parkinson's. This device is a small microphone headset which is worn in the ear and is connected to a small recording device. The microphone in the device detects swallowing sounds, which can then be counted and compared. It does not record your speech as it has special filters which only pick up the characteristic sounds of swallowing. It is completely safe and comfortable to wear.

How does the device work?

The device has a button which enables you to turn it on and off. You simply need to press the button to switch the device on during the specified time periods where drooling might be a problem for you. The researcher will help you identify these times. The device can be switched off when drooling is not occurring.

How much of my time will this study take up?

The project will be spread over 5-6 weeks. This includes demonstrations of how to use the devices, initial assessments and questionnaires, trying the device for four

weeks and giving feedback to a researcher afterwards. We will then assess people after 6 months and at 6 monthly intervals thereafter, as long as this is acceptable to the individual. Anyone is free to withdraw from the study at any time without having to give a reason.

Will I need to change my medication or other treatments?

No. For the sake of this study, no changes will be made to your medication and there will be no restrictions to any of your normal day-to-day activities.

What will happen to my information?

Your privacy will be protected at all times. Your identity will not be known by anyone other than the people directly involved in the study and we will give you a code so that your information will be protected. Your information will be stored securely at Newcastle University and will not be used for any other reason apart from the study.

Do I have to take part?

No. Your participation in this study is voluntary. Even if you agree to join in at the start, you can change your mind later. You do not need to give a reason for not joining in, or for leaving later. This will not affect any services you are receiving now or in the future.

Thank you very much for reading this information.

If you have any questions please feel free to contact:

Róisín McNaney

Culture Lab, Newcastle University

Grand Assembly Rooms

King's Walk

Newcastle Upon Tyne

NE1 7RU

email: r.mcnaney@ncl.ac.uk

telephone: 0191 246 4630 or **07843 157 367**

This research project has been ethically approved by a National Health Service (NHS) ethical committee.

Appendix 1b) PDCue Participant consent form



Consent form for participants

I agree to participate in the study: **Cueing for Drooling in Parkinson's Disease**, being carried out by The University of Newcastle.

(Please initial each box)

- I have read and understood the information sheet about taking part. ☐
- A team member has answered any questions that I had. ☐
- I understand that I will be interviewed following the study and that this interview will be video and audio recorded. ☐
- I understand that the data collected for this study will be stored in a secure location in the Speech and Language Sciences department at Newcastle University. ☐
- I understand that the data will be used only for research purposes. ☐
- I understand that I will not be mentioned by name on any documents or in any presentations about the research. ☐
- I understand that I can withdraw from the study at any time without needing to give a reason. ☐
- Withdrawing from the study will not affect any services I am receiving now or might receive in the future. ☐

Signature of participant.....

Name (in capitals)Date.....

Signature of team member.....

Name (in capitals).....

1c) Patient rated assessment proforma

Subject Number:

Pre/ post intervention

Date:

Delayed / Immediate

Cueing for Swallowing in Parkinson's disease (PDQ)

Assessment Proforma Participant Home Pack 2012

Filled out by (Name): _____

Please tick:

☐ Participant

☐ Other

Relationship to participant: _____

**This page to be destroyed by the
researcher post data input**

Subject Number:

Date:

D / Y

Cueing for Swallowing in Parkinson's disease (PDQ)

Assessment Proforma Participant Home Pack 2012

Contents:

Parkinson's Disease Questionnaire (PDQ-39)

Hospital Anxiety and Depression Scale (HADS)

Radboud Oral Motor Inventory for Parkinson's Disease (ROMP-Saliva)

The Swallowing Quality of Life Survey (Swal-QOL)

PARKINSON'S DISEASE QUESTIONNAIRE (PDQ-39)

Please complete the following

please tick one box for each question

Due to having Parkinson's, how often during the last month have you....

		Never	Occasionally	Sometimes	Often	Always
1	Had difficulty doing the leisure activities which you would like to do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Had difficulty looking after your home, e.g. DIY, housework, cooking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Had difficulty carrying bags of shopping?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Had problems walking half a mile?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Had problems walking 100 yards?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Had problems getting around the house as easily as you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Had difficulty getting around in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Needed someone else to accompany you when you went out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		Never	Occasionally	Sometimes	Often	Always
9	Felt frightened or worried about falling over in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Been confined to the house more than you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11	Had difficulty washing yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Had difficulty dressing yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	Had problems doing up your shoe laces?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	Had problems writing clearly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	Had difficulty cutting up your food?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	Had difficulty holding a drink without spilling it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	Felt depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	Felt isolated and lonely?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	Felt weepy or tearful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	Felt angry or bitter?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	Felt anxious?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	Felt worried about your future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23	Felt you had to conceal your Parkinson's from people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24	Avoided situations which involve eating or drinking in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		Never	Occasionally	Sometimes	Often	Always
25	Felt embarrassed in public due to having Parkinson's?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26	Felt worried by other people's reaction to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

27	Had problems with your close personal relationships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28	Lacked support in the ways you need from your spouse or partner?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>If you do not have a spouse or partner tick here</i>		<input type="checkbox"/>			
29	Lacked support in the ways you need from your family or close friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30	Unexpectedly fallen asleep during the day?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31	Had problems with your concentration, e.g. when reading or watching TV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32	Felt your memory was bad?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33	Had distressing dreams or hallucinations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34	Had difficulty with your speech?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35	Felt unable to communicate with people properly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36	Felt ignored by people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		Never	Occasionally	Sometimes	Often	Always
37	Had painful muscle cramps or spasms?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38	Had aches and pains in your joints or body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39	Felt unpleasantly hot or cold?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS)

Please tick the statement that best applies to you

	Yes, definitely	Yes, sometimes	No, not much	No, not at all
1. I wake early and then sleep badly for the rest of the night				
2. I get very frightened or have panic feelings for apparently no reason at all				
3. I feel miserable and sad				
4. I feel anxious when I go out of the house on my own				
5. I have lost interest in things				
6. I get palpitations, or sensations of 'butterflies' in my stomach or chest				
7. I have a good appetite				
8. I feel scared or frightened				
9. I feel life is not worth living				
10. I still enjoy the things I used to				
11. I am restless and can't keep still				
12. I am more irritable than usual				
13. I feel as if I have slowed down				
14. Worrying thoughts constantly go through my mind				

RADBOUND ORAL MOTOR INVENTORY FOR PARKINSON'S DISEASE (ROMP-Saliva)

Please circle the closest answer

I. Do you experience loss of saliva during the day?

1. I do not lose saliva during the day and do not feel accumulation of saliva in my mouth.
2. I do not lose saliva, but I feel accumulation of saliva in my mouth.
3. I lose some saliva in the corners of my mouth or on my chin.
4. I lose saliva on my clothes.
5. I lose saliva on my clothes, but also on books or on the floor.

II. How often do you experience increased amounts or loss of saliva?

1. Less than once a day.
2. Occasionally: on average, once or twice a day.
3. Frequently: 2 to 5 times a day.
4. Very often: 6 to 10 times a day.
5. Almost constantly.

III. Do you experience loss of saliva during the night?

1. I do not experience loss of saliva during the night at all.
1. My pillow sometimes gets wet during the night.
2. My pillow regularly gets wet during the night.
3. My pillow always gets wet during the night.
4. Every night my pillow and other bedclothes get wet.

IV. Does your (loss of) saliva impair your eating and drinking?

1. No, my (loss of) saliva does not impair my eating or drinking.
1. Yes, my (loss of) saliva occasionally impairs my eating or drinking.
2. Yes, my (loss of) saliva frequently impairs my eating or drinking.
3. 4. Yes, my (loss of) saliva very often impairs my eating or drinking.
5. Yes, my (loss of) saliva always impairs my eating or drinking.

V. Does your (loss of) saliva impair your speech?

1. No, my (loss of) saliva does not impair my speech.
2. Yes, my (loss of) saliva occasionally impairs my speech.
3. Yes, my (loss of) saliva frequently impairs my speech.
4. Yes, my (loss of) saliva very often impairs my speech.
5. Yes, my (loss of) saliva always impairs my speech.

VI. What do you have to do to remove saliva?

1. I do not have to remove saliva.
2. I always carry a handkerchief to remove possible saliva.
3. I daily use 1 or 2 handkerchiefs to remove some saliva.
4. I daily need more than 2 handkerchiefs to remove saliva.
5. I need to remove saliva so frequently that I always keep tissues near me or use a towel to protect my clothes.

VII. Does the loss of saliva limit you in contacts with others?

1. My loss of saliva does not limit me in contacts with others.
2. I have to pay attention, but that does not bother me.
3. I have to pay more attention because I know that others could see me losing saliva.
4. I try to avoid contact when I know that I lose saliva.
5. I notice that others avoid having contact with me because I lose saliva.

VIII. Does your loss of saliva limit you in doing activities inside or outside your home (work, hobbies)?

1. My (loss of) saliva does not limit me in activities.
2. I have to pay attention when I am busy, but that does not bother me.
3. I have to pay more attention, which is rather effortful.
4. My loss of saliva limits me in being active.
5. Due to my loss of saliva, important activities are no longer possible for me.

IX. How bothered are you as a result of your (loss of) saliva?

1. I hardly notice loss of saliva.
2. Feeling more saliva or losing it bothers me a little.

3. I am bothered by my loss of saliva, but it is not my priority concern.
4. My loss of saliva bothers me a lot because it is very limiting.
5. Losing saliva is the worst aspect of my disease.

Thank you for completing the ROMP- Saliva questionnaire

THE SWALLOWING QUALITY OF LIFE SURVEY (SWAL-QOL)

IMPORTANT NOTE: we understand that you may have a number of physical problems. Sometimes it is hard to separate these from swallowing difficulties but we hope that you can do your best to concentrate **only** on your **swallowing problems**.

If you feel that swallowing is **NOT** a problem for you then please try fill out the questionnaire as best you can and tick this box ☐

For each statement circle ONE number on each line

- Below are some general statements that people with swallowing problems might mention. In the last month how **true** have the statements been for you?

	Very much true	Quite a bit true	Somewhat true	A little true	Not at all true
Dealing with my swallowing problem is very difficult	1	2	3	4	5
My swallowing problem is a major distraction in my life	1	2	3	4	5

- Below are aspects of day-to-day eating that people with swallowing problems sometimes talk about. In the last month how **true** have the statements been for you?

	Very much true	Quite a bit true	Somewhat true	A little true	Not at all true
Most days, I don't care if I eat or not	1	2	3	4	5
It takes me longer to eat than other people	1	2	3	4	5
I'm rarely hungry anymore	1	2	3	4	5
It takes me forever to eat a meal	1	2	3	4	5
I don't enjoy eating anymore	1	2	3	4	5

- Below are some physical problems that people with swallowing problems sometimes experience. In the last month how **often** have the statements been for you?

	Very much	Quite a	Somewhat	A little	Not at all
--	-----------	---------	----------	----------	------------

	true	bit true	true	true	true
Coughing	1	2	3	4	5
Choking when you eat	1	2	3	4	5
Choking when you take liquids	1	2	3	4	5
Having thick saliva or phlegm	1	2	3	4	5
Gagging	1	2	3	4	5
Drooling	1	2	3	4	5
Problems chewing	1	2	3	4	5
Having excess saliva or phlegm	1	2	3	4	5
Having to clear your throat	1	2	3	4	5
Food sticking in your throat	1	2	3	4	5
Food sticking in your mouth	1	2	3	4	5
Food or liquid dribbling out of your mouth	1	2	3	4	5
Food or liquid coming out of your nose	1	2	3	4	5
Coughing food or liquid out of your mouth when it gets stuck	1	2	3	4	5

	Very much true	Quite a bit true	Somewhat true	A little true	Not at all true
Figuring out what I can and can't eat is a problem for me	1	2	3	4	5
It is difficult to find foods					

that I both like and can eat	1	2	3	4	5
------------------------------	---	---	---	---	---

4. Next, please answer a few questions about how your swallowing problem has affected your diet and eating in the last month.

5. In the last month how **often** have the following statements about communication applied to you because of your swallowing problems?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
People have a hard time understanding me	1	2	3	4	5
It's been difficult for me to speak clearly	1	2	3	4	5

6. Below are some concerns that people with swallowing problems sometimes mention. In the last month how **often** have you experienced each feeling?

	Almost always	Often	Sometimes	Hardly ever	Never
I fear I may start choking when I eat food	1	2	3	4	5
I worry about getting pneumonia	1	2	3	4	5
I am afraid of choking when I drink liquids	1	2	3	4	5
I never know when I am going to choke	1	2	3	4	5

7. In the last month how often have the following statements been **true** because of your swallowing problem?

	Always true	Often true	Sometimes true	Hardly ever true	Never true
My swallowing problem depresses me	1	2	3	4	5
Having to be so careful when I eat or drink annoys me	1	2	3	4	5
I've been discouraged by my swallowing problem	1	2	3	4	5

My swallowing problem frustrates me	1	2	3	4	5
I get impatient dealing with my swallowing problem	1	2	3	4	5

8. Think about your social life in the last month. How strongly would you agree or disagree with the following statements?

	Strongly agree	Agree	Uncertain	disagree	Strongly disagree
I do not go out to eat because of my swallowing problem	1	2	3	4	5
My swallowing problem makes it hard to have a social life	1	2	3	4	5
My usual work or leisure activities have changed because of my swallowing problem	1	2	3	4	5
Social gatherings (like holidays or get-togethers) are not enjoyable because of my swallowing problem	1	2	3	4	5
My role with my family and friends has changed because of my swallowing problem	1	2	3	4	5

9. In the last month how **often** have you experienced each of the following physical symptoms?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Feel weak?	1	2	3	4	5
Have trouble falling asleep?	1	2	3	4	5
Feel tired?	1	2	3	4	5
Have trouble staying asleep?	1	2	3	4	5
Feel exhausted?	1	2	3	4	5

10. Do you now take any food or liquid through a feeding tube?

(Please circle one)

No	1
Yes	2

11. Please circle the letter of the one description below that best describes the consistency or texture of the food you have been eating most **often** in the last week.

(Please circle one)

A	Circle this one if you are eating a full normal diet, which would include a wide variety of foods, including hard to chew items like steak, carrots, bread, salad and popcorn.
B	Circle this one if you are eating soft, easy to chew foods like casseroles, canned fruits, soft cooked vegetables, ground meat, or cream soups.
C	Circle this one if you are eating food that is put through a blender or food processor or anything that is like pudding or pureed foods.
D	Circle this one if you take most of your nutrition by tube, but sometimes eat ice cream, pudding, apple sauce, or other pleasant foods
E	Circle this one if you take all of your nourishment through a tube

Thank you for completing the SWAL-QOL Survey

**THIS COMPLETES THE HOME ASSESSMENT
PROFORMA**

THANK YOU FOR YOUR TIME

1d) Clinician rated assessment proforma

Subject Number:

Date:

Delayed / Immediate

Pre/ post intervention

Cueing for Swallowing in Parkinson's disease (PDQ)

Subject Details:

Surname:

Forename(s):

Date of birth:

Age:

Address:

Postcode:

Telephone:

Live alone: Y / N

If 'no' what is their relationship to the participant?

**This page to be destroyed by the
researcher post data input**

Administered by [name] _____

Subject Number:

Date:

Delayed / Immediate

Pre/ post intervention

Cueing for Swallowing in Parkinson's disease (PDQ)

Assessment Proforma
Researcher Version
2012

Contents:

Case Report Form

Unified Parkinson's Disease Rating Scale (UPDRS)

Hoehn & Yahr scale

Mini-Mental State Examination

Montreal Cognitive Assessment (MoCA)

Oral Motor Examination

150ml Water Swallow Test

Administered by [initials] _____

<i>Process</i>	<i>Tick when complete</i>
<i>Review of consent</i>	
<i>Review of subject details</i>	
<i>Inclusion decision</i>	
<i>Parkinson's History</i>	
<i>Medical History</i>	
<i>UPDRS Part I</i>	
<i>UPDRS Part II</i>	
<i>UPDRS Part III</i>	
<i>UPDRS Part IV</i>	
<i>Modified Hoehn and Yahr Staging</i>	
<i>Mini Mental State Examination</i>	
<i>Montreal Cognitive Assessment</i>	
<i>Oral Motor Assessment</i>	
<i>150 ml Water Swallow Test</i>	
<i>Go through home pack with participants</i>	
<i>Device use and training</i>	

Inclusion Criteria

Tick if criteria met

Participant is willing and able to give informed consent for participation in the study

☐

Male or female, aged 18 years or above

☐

Diagnosis of Idiopathic PD

☐

Under the care of the Northumbria PD service

☐

Identifies themselves as having a problem with drooling

☐

Exclusion Criteria

*Tick if criteria **not** met*

Unable to provide informed consent for participation in the study

☐

Cognitive impairment (MMSE < 24) which would prevent completion of the study

☐

Insufficient dexterity with which to independently use the device

☐

PDQ Study- Case Report Form

Parkinson's History:

Date of diagnosis: mm/yyyy

Date of first noticing symptoms if different: mm/yyyy

Side which first symptoms started (please circle):

Right

Left

Bilateral

Handedness (please circle):

Right

Left

Drooling:

Mild

Moderate

Severe

Date when drooling first started:

Any prior treatment for drooling received (provide details)?

Medical History:

Current PD medication (inc. Drooling medication):

Any Visual Corrected? Y / N explain:

Difficulties:

Any hearing Corrected? Y / N explain:

Difficulties:

Denture wearer: Y / N comfort and fit:

Any history of dysphagia/ swallowing issues: Y / N give details:

_____	_____	_____ (mm-dd-yyyy)	_____
Patient Name or Subject ID	Site ID	Assessment Date	Investigator's Initials

MDS UPDRS Score Sheet

1.A	Source of information	<input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Patient + Caregiver	3.3b	Rigidity- RUE	
			3.3c	Rigidity- LUE	
Part I			3.3d	Rigidity- RLE	
1.1	Cognitive impairment		3.3e	Rigidity- LLE	
1.2	Hallucinations and psychosis		3.4a	Finger tapping- Right hand	
1.3	Depressed mood		3.4b	Finger tapping- Left hand	
1.4	Anxious mood		3.5a	Hand movements- Right hand	
1.5	Apathy		3.5b	Hand movements- Left hand	
1.6	Features of DDS		3.6a	Pronation- supination movements- Right hand	
1.6a	Who is filling out questionnaire	<input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Patient + Caregiver	3.6b	Pronation- supination movements- Left hand	
1.7	Sleep problems		3.7a	Toe tapping-Right foot	
1.8	Daytime sleepiness		3.7b	Toe tapping- Left foot	
1.9	Pain and other sensations		3.8a	Leg agility- Right leg	
1.10	Urinary problems		3.8b	Leg agility- Left leg	
1.11	Constipation problems		3.9	Arising from chair	
1.12	Light headedness on standing		3.10	Gait	
1.13	Fatigue		3.11	Freezing of gait	
Part II			3.12	Postural stability	
2.1	Speech		3.13	Posture	
2.2	Saliva and drooling		3.14	Global spontaneity of movement	
2.3	Chewing and swallowing		3.15a	Postural tremor- Right hand	
2.4	Eating tasks		3.15b	Postural tremor- Left hand	
2.5	Dressing		3.16a	Kinetic tremor- Right hand	
2.6	Hygiene		3.16b	Kinetic tremor- Left hand	
2.7	Handwriting		3.17a	Rest tremor amplitude- RUE	
2.8	Doing hobbies and other activities		3.17b	Rest tremor amplitude- LUE	
2.9	Turning in bed		3.17c	Rest tremor amplitude- RLE	
2.10	Tremor		3.17d	Rest tremor amplitude- LLE	
2.11	Getting out of bed		3.17e	Rest tremor amplitude- Lip/jaw	
2.12	Walking and balance		3.18	Constancy of rest	
2.13	Freezing			Were dyskinesias present	<input type="checkbox"/> No <input type="checkbox"/> Yes
3a	Is the patient on medication?	<input type="checkbox"/> No <input type="checkbox"/> Yes		Did these movements interfere with ratings?	<input type="checkbox"/> No <input type="checkbox"/> Yes
3b	Patient's clinical state	<input type="checkbox"/> Off <input type="checkbox"/> On		Hoehn and Yahr Stage	
3c	Is the patient on Levodopa?	<input type="checkbox"/> No <input type="checkbox"/> Yes	Part IV		
3.C1	If yes, minutes since last dose:		4.1	Time spent with dyskinesias	
Part III			4.2	Functional impact of dyskinesias	
3.1	Speech		4.3	Time spent in the OFF state	
3.2	Facial expression		4.4	Functional impact of fluctuations	
3.3a	Rigidity- Neck		4.5	Complexity of motor fluctuations	
			4.6	Painful OFF-state dystonia	

Modified Hoehn and Yahr

Circle the participant's current stage

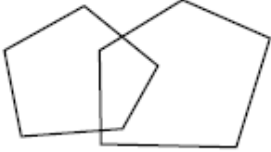
- | | |
|------------------|--|
| Stage 0 | = no signs of disease. |
| Stage 1 | = unilateral disease. |
| Stage 1.5 | = unilateral plus axial involvement. |
| Stage 2.0 | = bilateral disease, without impairment of balance. |
| Stage 2.5 | = mild bilateral disease, with recovery on pull test. |
| Stage 3.0 | = mild to moderate bilateral disease, some postural instability; physically independent. |
| Stage 4.0 | = severe disability, still able to walk or stand unassisted. |
| Stage 5.0 | = wheelchair- bound or bedridden unless aided. |

Mini- Mental State Exam

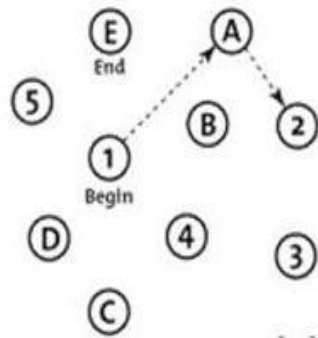
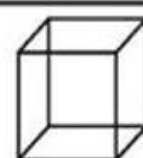
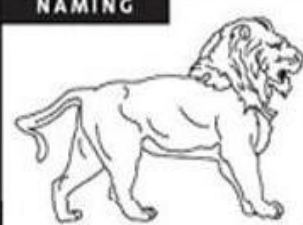
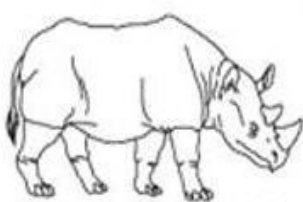
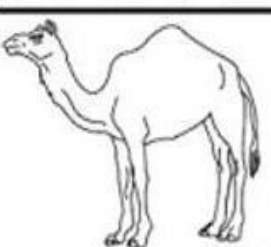
MINI MENTAL STATE EXAMINATION (MMSE)

Patient's name:

Hospital number:

ONE POINT FOR EACH ANSWER						DATE				
ORIENTATION										
Year Month Day Date Time						___/5	___/5	___/5	___/5	___/5
Country Town District Hospital Ward						___/5	___/5	___/5	___/5	___/5
REGISTRATION										
Examiner names 3 objects (eg apple, table, penny) Patient asked to repeat (1 point for each correct). THEN patient to learn the 3 names repeating until correct.						___/3	___/3	___/3	___/3	___/3
ATTENTION AND CALCULATION										
Subtract 7 from 100, then repeat from result. Continue 5 times: 100 93 86 79 65 Alternative: spell "WORLD" backwards - dlrow.						___/5	___/5	___/5	___/5	___/5
RECALL										
Ask for names of 3 objects learned earlier.						___/3	___/3	___/3	___/3	___/3
LANGUAGE										
Name a pencil and watch.						___/2	___/2	___/2	___/2	___/2
Repeat "No ifs, ands, or buts".						___/1	___/1	___/1	___/1	___/1
Give a 3 stage command. Score 1 for each stage. Eg. "Place index finger of right hand on your nose and then on your left ear".						___/3	___/3	___/3	___/3	___/3
Ask patient to read and obey a written command on a piece of paper stating "Close your eyes".						___/1	___/1	___/1	___/1	___/1
Ask the patient to write a sentence. Score if it is sensible and has a subject and a verb.						___/1	___/1	___/1	___/1	___/1
COPYING										
Ask the patient to copy a pair of intersecting pentagons:										
						___/1	___/1	___/1	___/1	___/1
TOTAL						___/30	___/30	___/30	___/30	___/30

Montreal Cognitive Assessment Tool

MONTREAL COGNITIVE ASSESSMENT (MOCA)					NAME : Education : Sex :		Date of birth : DATE :			
VISUOSPATIAL / EXECUTIVE  <div style="display: flex; justify-content: space-around; margin-top: 10px;"> [] [] </div>					 <p>Copy cube</p>		<p>Draw CLOCK (Ten past eleven) (3 points)</p> <div style="display: flex; justify-content: space-around; margin-top: 10px;"> [] [] [] </div>		POINTS <div style="border-top: 1px solid black; width: 100%;"></div> ___/5	
NAMING <div style="display: flex; justify-content: space-around; align-items: flex-end;">    </div> <div style="display: flex; justify-content: space-around; margin-top: 10px;"> [] [] [] </div>					POINTS <div style="border-top: 1px solid black; width: 100%;"></div> ___/3					
MEMORY Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.					FACE 1st trial 2nd trial	VELVET 1st trial 2nd trial	CHURCH 1st trial 2nd trial	DAISY 1st trial 2nd trial	RED 1st trial 2nd trial	No points
ATTENTION Read list of digits (1 digit/sec.). Subject has to repeat them in the forward order [] 2 1 8 5 4 Subject has to repeat them in the backward order [] 7 4 2					POINTS <div style="border-top: 1px solid black; width: 100%;"></div> ___/2					
Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [] FBACMNAAJKLBAFAKDEAAAJAMOF AAB					POINTS <div style="border-top: 1px solid black; width: 100%;"></div> ___/1					
Serial 7 subtraction starting at 100 [] 93 [] 86 [] 79 [] 72 [] 65 <small>4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt</small>					POINTS <div style="border-top: 1px solid black; width: 100%;"></div> ___/3					
LANGUAGE Repeat : I only know that John is the one to help today. [] The cat always hid under the couch when dogs were in the room. []					POINTS <div style="border-top: 1px solid black; width: 100%;"></div> ___/2					
Fluency / Name maximum number of words in one minute that begin with the letter F [] _____ (N ≥ 11 words)					POINTS <div style="border-top: 1px solid black; width: 100%;"></div> ___/1					
ABSTRACTION Similarity between e.g. banana - orange = fruit [] train - bicycle [] watch - ruler					POINTS <div style="border-top: 1px solid black; width: 100%;"></div> ___/2					
DELAYED RECALL Has to recall words WITH NO CUE FACE [] VELVET [] CHURCH [] DAISY [] RED []					POINTS <div style="border-top: 1px solid black; width: 100%;"></div> ___/5					
Optional Category cue Multiple choice cue					Points for UNCUE recall only					
ORIENTATION [] Date [] Month [] Year [] Day [] Place [] City					POINTS <div style="border-top: 1px solid black; width: 100%;"></div> ___/6					
© Z.Nosredine MD Version November 7, 2004 www.mocotest.org					Normat ≥ 26 / 30 TOTAL ___/30 <small>Add 1 point if ≤ 12 yr edu</small>					

Oral Motor Assessment

Task	Score	Notes
<u>Speech diadokinesis</u>	Times:	Comment on the quality of articulator contacts:

Instructions to participant:

"I'm going to ask to repeat 3 words, 10 times, as quickly as you can. Please begin when I say go.

We will do this task 3 times"

Pea	1
	2
	3

Tea	1
	2
	3

Key	1
	2
	3

Alternate: p-t-k (note patticake if easier)	1
	2
	3

NB: begin stopwatch on first vocalisation and end on last.

Frenchay subtests

Any comments:

Lips

- At rest
- Spread
- Seal
- Alternate

Tongue

- Protrusion
- Elevation
- Lateral
- Alternate

Score	Any comments:
<hr/>	
<hr/>	
<hr/>	
<hr/>	

150ml Water Swallow Test

Water swallow Test (Hughes and Wiles, 1996)

150ml

Time (T)	No. Swallows (S)	Volume (V)	V/S Average volume per swallow (ml)	T/S Average time per swallow (s)	V/T Swallowing capacity (ml/s)
-------------	---------------------	---------------	--	---	---

Notes

Scoring

V/S= volume / no. Swallows ____

T/S= time/ no. Swallows ____

V/T= Volume/ time ____

1e) Drooling frequency and severity diaries

Subject Number:
Pre / Post intervention

Date:

D / I

Cueing for Swallowing in Parkinson's disease

DROOLING SEVERITY AND FREQUENCY DIARY

(pre-study 6hr swallow frequency sessions)

**This page will be destroyed by the
researcher to protect your privacy**

Contact: Roisin McNaney (r.mcnaney@ncl.ac.uk) on **07843 157 367** or 0191
246 46 30

Subject Number:
Pre / Post intervention

Date:

D / I

Cueing for Swallowing in Parkinson's disease

DROOLING SEVERITY AND FREQUENCY DIARY

(one week, no intervention)

INSTRUCTIONS

- You (the carer) should observe the person with Parkinson's for one hour per day during this pre-study week, including both of the days that they are wearing the swallow frequency monitor.
- **The observation should be carried out in a discreet manner so as not to alert the participant that they are being monitored**
- Indicate how many minutes [in total] during the hour that you (the carer) felt that drooling was occurring, as well as the number of separate episodes of drooling that you noticed.

- Provide a rating of how severe you felt the drooling was during the hour that you observed. Ratings are from 0-10 with 0 being 'no problem' and 10 being 'as bad as can be'

ON= Symptoms of slowness and tremor controlled

ON with Troubling Dyskinesia= Problems with involuntary twisting, turning movements.

(These movements are different from the rhythmic shaking in Parkinson's disease)

OFF= Problems with stiffness, slowness and tremor

Day 1 [dd / mm / yy]	Time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred?	<input type="text"/>
2. How many separate times did you see drooling happen?	<input type="text"/>
3. Place a cross on the line which shows how severe you think the drooling was overall:	<div style="display: flex; justify-content: space-between;"> 0 (No Problem) 10 (As bad as can be) </div>
Please note what the person was doing during the hour that you observed:	
Did the observation occur when the person was wearing the headset? Y / N	
Day 2 [dd / mm / yy]	Time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred?	<input type="text"/>
2. How many separate times did you see drooling happen?	<input type="text"/>
3. Place a cross on the line which shows how severe you think the drooling was overall:	<div style="display: flex; justify-content: space-between;"> 0 (No Problem) 10 (As bad as can be) </div>
Please note what the person was doing during the hour that you observed:	
Did the observation occur when the person was wearing the headset? Y / N	
Day 3 [dd / mm / yy]	Time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred?	<input type="text"/>

2. How many separate times did you see drooling happen? 3. Place a cross on the line which shows how severe you think the drooling was overall:	<div style="text-align: center; margin-bottom: 10px;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </div> <div style="display: flex; justify-content: space-between; border-top: 1px solid black; margin-top: 10px;"> 0 (No Problem) 10 (As bad as can be) </div>
Please note what the person was doing during the hour that you observed: Did the observation occur when the person was wearing the headset? Y / N	
Day 4 [dd / mm / yy]	Time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred? 2. How many separate times did you see drooling happen? 3. Place a cross on the line which shows how severe you think the drooling was overall:	<div style="text-align: center; margin-bottom: 10px;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </div> <div style="text-align: center; margin-bottom: 10px;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </div> <div style="display: flex; justify-content: space-between; border-top: 1px solid black; margin-top: 10px;"> 0 (No Problem) 10 (As bad as can be) </div>
Please note what the person was doing during the hour that you observed: Did the observation occur when the person was wearing the headset? Y / N	
Day 5 [dd / mm / yy]	Time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred? 2. How many separate times did you see drooling happen? 3. Place a cross on the line which shows how severe you think the drooling was overall:	<div style="text-align: center; margin-bottom: 10px;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </div> <div style="text-align: center; margin-bottom: 10px;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </div> <div style="display: flex; justify-content: space-between; border-top: 1px solid black; margin-top: 10px;"> 0 (No Problem) 10 (As bad as can be) </div>
Please note what the person was doing during the hour that you observed: Did the observation occur when the person was wearing the headset? Y / N	
Day 6 [dd / mm / yy]	Time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias

<ol style="list-style-type: none"> 1. How many minutes during the hour did you feel drooling occurred? 2. How many separate times did you see drooling happen? 3. Place a cross on the line which shows how severe you think the drooling was overall: 	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/> <div style="display: flex; justify-content: space-between;"> 0 (No Problem) 10 (As bad as can be) </div> </div>
<p>Please note what the person was doing during the hour that you observed:</p> <p>Did the observation occur when the person was wearing the headset? Y / N</p>	
Day 7 [dd / mm / yy]	Time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
<ol style="list-style-type: none"> 1. How many minutes during the hour did you feel drooling occurred? 2. How many separate times did you see drooling happen? 3. Place a cross on the line which shows how severe you think the drooling was overall: 	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/> <div style="display: flex; justify-content: space-between;"> 0 (No Problem) 10 (As bad as can be) </div> </div>
<p>Please note what the person was doing during the hour that you observed:</p> <p>Did the observation occur when the person was wearing the headset? Y / N</p>	

Do you have any other notes that you think are relevant?

THANK YOU

Subject Number:

Date:

D / Y

Cueing for Swallowing in Parkinson's disease

DROOLING SEVERITY AND FREQUENCY DIARY

(4 week, intervention)

Completed by [name]_____

Relationship to the participant _____

INSTRUCTIONS

- This diary is to be completed by the carer twice a day throughout the course of the study.
- The carer should observe the person with Parkinson's for one hour a day during a time when the participant is not wearing the wrist worn cueing device [i.e. a **non-treatment hour**].
- The carer should also to observe the person with Parkinson's for one hour a day during the time that the participant is wearing the cueing device and is therefore being regularly reminded to swallow their saliva more regularly [i.e. a **treatment hour**].
- **These observations should be carried out in a discreet manner so as not to alert the participant that they are being monitored**
- Fill in the date at the top of the page each day and the time that each observation began in the spaces provided
- Indicate how many minutes [in total] during the hour that you (the carer) felt that drooling was occurring, as well as the number of separate episodes of drooling that you noticed.
- Provide a rating of how severe you felt the drooling was during the hour that you observed. Ratings are from 0-10 with 0 being 'no problem' and 10 being 'as bad as can be'
- **Please do not discuss the results in the diary until the study is finished.**

Many thanks for agreeing to fill out this diary. The information gained through completing the diary will provide an invaluable insight into the participant's drooling and will help us to evaluate how useful the cueing device is.

Week 1

Day 1	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred? <input type="text"/> 2. How many separate times did you see drooling happen? <input type="text"/> 3. Place a cross on the line which shows how severe you think the drooling was overall:	<input type="text"/> <input type="text"/> <div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>	<input type="text"/> <input type="text"/> <div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>
Day 2	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred? <input type="text"/> 2. How many separate times did you see drooling happen? <input type="text"/> 3. Place a cross on the line which shows how severe you think the drooling was overall:	<input type="text"/> <input type="text"/> <div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>	<input type="text"/> <input type="text"/> <div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>
Day 3	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias

<p>1. How many minutes during the hour did you feel drooling occurred?</p> <p>2. How many separate times did you see drooling happen?</p> <p>3. Place a cross on the line which shows how severe you think the drooling was overall:</p>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <div style="display: flex; justify-content: space-between; align-items: center;"> <div>0</div> <div style="flex-grow: 1; border-bottom: 1px solid black; position: relative;"> <div style="position: absolute; left: 0; bottom: -10px;">10</div> </div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div> </div>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <div style="display: flex; justify-content: space-between; align-items: center;"> <div>0</div> <div style="flex-grow: 1; border-bottom: 1px solid black; position: relative;"> <div style="position: absolute; left: 0; bottom: -10px;">10</div> </div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div> </div>
<p>Day 4</p>	<p>Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias</p>	<p>Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias</p>
<p>1. How many minutes during the hour did you feel drooling occurred?</p> <p>2. How many separate times did you see drooling happen?</p> <p>3. Place a cross on the line which shows how severe you think the drooling was overall:</p>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <div style="display: flex; justify-content: space-between; align-items: center;"> <div>0</div> <div style="flex-grow: 1; border-bottom: 1px solid black; position: relative;"> <div style="position: absolute; left: 0; bottom: -10px;">10</div> </div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div> </div>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <div style="display: flex; justify-content: space-between; align-items: center;"> <div>0</div> <div style="flex-grow: 1; border-bottom: 1px solid black; position: relative;"> <div style="position: absolute; left: 0; bottom: -10px;">10</div> </div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div> </div>
<p>Day 5</p>	<p>Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias</p>	<p>Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias</p>
<p>1. How many minutes during the hour did you feel drooling occurred?</p> <p>2. How many separate</p>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </div>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </div>

<p>times did you see drooling happen?</p> <p>3. Place a cross on the line which shows how severe you think the drooling was overall:</p>	<div><input type="checkbox"/></div> <div>_____</div> <div>0 10</div> <div>(No Problem) (As bad as can be)</div>	<div><input type="checkbox"/></div> <div>_____</div> <div>0 10</div> <div>(No Problem) (As bad as can be)</div>
Day 6	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
<p>1. How many minutes during the hour did you feel drooling occurred?</p> <p>2. How many separate times did you see drooling happen?</p> <p>3. Place a cross on the line which shows how severe you think the drooling was overall:</p>	<div><input type="checkbox"/></div> <div><input type="checkbox"/></div> <div>_____</div> <div>0 10</div> <div>(No Problem) (As bad as can be)</div>	<div><input type="checkbox"/></div> <div><input type="checkbox"/></div> <div>_____</div> <div>0 10</div> <div>(No Problem) (As bad as can be)</div>
Day 7	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
<p>1. How many minutes during the hour did you feel drooling occurred?</p> <p>2. How many separate times did you see drooling happen?</p>	<div><input type="checkbox"/></div> <div><input type="checkbox"/></div>	<div><input type="checkbox"/></div> <div><input type="checkbox"/></div>

<p>3. Place a cross on the line which shows how severe you think the drooling was overall:</p>	<div> <div></div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div></div> <div>(As bad as can be)</div> </div>	<div> <div></div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div></div> <div>(As bad as can be)</div> </div>
<p>Comments:</p>		

Week 2

Day 1	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred?	<input type="text"/>	<input type="text"/>
2. How many separate times did you see drooling happen?	<input type="text"/>	<input type="text"/>
3. Place a cross on the line which shows how severe you think the drooling was overall:	<div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>	<div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>
Day 2	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred?	<input type="text"/>	<input type="text"/>
2. How many separate times did you see drooling happen?	<input type="text"/>	<input type="text"/>
3. Place a cross on the line which shows how severe you think the	<div> <div>0</div> </div>	<div> <div>0</div> <div>10</div> </div>

drooling was overall:	10 (No Problem) (As bad as can be)	(No Problem) (As bad as can be)
Day 3	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred? 2. How many separate times did you see drooling happen? 3. Place a cross on the line which shows how severe you think the drooling was overall:	<div><input type="text"/></div> <div><input type="text"/></div> <div> 0 _____ 10 (No Problem) (As bad as can be) </div>	<div><input type="text"/></div> <div><input type="text"/></div> <div> 0 _____ 10 (No Problem) (As bad as can be) </div>
Day 4	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred? 2. How many separate times did you see drooling happen? 3. Place a cross on the line which shows how severe you think the drooling was overall:	<div><input type="text"/></div> <div><input type="text"/></div> <div> 0 _____ 10 (No Problem) (As bad as can be) </div>	<div><input type="text"/></div> <div><input type="text"/></div> <div> 0 _____ 10 (No Problem) (As bad as can be) </div>
Day 5	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias

<p>1. How many minutes during the hour did you feel drooling occurred?</p> <p>2. How many separate times did you see drooling happen?</p> <p>3. Place a cross on the line which shows how severe you think the drooling was overall:</p>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <div style="display: flex; justify-content: space-between; align-items: center;"> <div>0</div> <div style="flex-grow: 1; border-bottom: 1px solid black; position: relative;"> <div style="position: absolute; left: -10px; top: -10px;">10</div> </div> <div>(As bad as can be)</div> </div> </div>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <div style="display: flex; justify-content: space-between; align-items: center;"> <div>0</div> <div style="flex-grow: 1; border-bottom: 1px solid black; position: relative;"> <div style="position: absolute; left: -10px; top: -10px;">10</div> </div> <div>(As bad as can be)</div> </div> </div>
<p>Day 6</p>	<p>Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias</p>	<p>Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias</p>
<p>1. How many minutes during the hour did you feel drooling occurred?</p> <p>2. How many separate times did you see drooling happen?</p> <p>3. Place a cross on the line which shows how severe you think the drooling was overall:</p>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <div style="display: flex; justify-content: space-between; align-items: center;"> <div>0</div> <div style="flex-grow: 1; border-bottom: 1px solid black; position: relative;"> <div style="position: absolute; left: -10px; top: -10px;">10</div> </div> <div>(As bad as can be)</div> </div> </div>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <div style="display: flex; justify-content: space-between; align-items: center;"> <div>0</div> <div style="flex-grow: 1; border-bottom: 1px solid black; position: relative;"> <div style="position: absolute; left: -10px; top: -10px;">10</div> </div> <div>(As bad as can be)</div> </div> </div>
<p>Day 7</p>	<p>Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias</p>	<p>Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias</p>
<p>1. How many minutes during the hour did you feel drooling occurred?</p>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </div>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </div>

<p>2. How many separate times did you see drooling happen?</p> <p>3. Place a cross on the line which shows how severe you think the drooling was overall:</p>	<div data-bbox="521 256 573 319"><input type="text"/></div> <div data-bbox="510 440 1238 560"><div data-bbox="510 440 573 467">0</div><div data-bbox="510 467 573 494">10</div><div data-bbox="510 494 672 531">(No Problem)</div><div data-bbox="1057 494 1238 531">(As bad as can be)</div></div>	<div data-bbox="1303 256 1355 319"><input type="text"/></div> <div data-bbox="1292 440 2065 507"><div data-bbox="1337 440 1355 467">0</div><div data-bbox="2042 440 2065 467">10</div><div data-bbox="1292 467 1456 507">(No Problem)</div><div data-bbox="1841 467 2065 507">(As bad as can be)</div></div>
<p>Comments:</p>		

Week 3

Day 1	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred? <div><input type="text"/></div>	<div><input type="text"/></div>	<div><input type="text"/></div>
2. How many separate times did you see drooling happen? <div><input type="text"/></div>	<div><input type="text"/></div>	<div><input type="text"/></div>
3. Place a cross on the line which shows how severe you think the drooling was overall: <div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>	<div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>	<div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>
Day 2	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred? <div><input type="text"/></div>	<div><input type="text"/></div>	<div><input type="text"/></div>
2. How many separate times did you see		

drooling happen? 3. Place a cross on the line which shows how severe you think the drooling was overall:	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <hr style="width: 100%; border: 0.5px solid black;"/> <div style="display: flex; justify-content: space-between; width: 100%;"> 0 10 </div> <div style="display: flex; justify-content: space-between; width: 100%;"> (No Problem) (As bad as can be) </div> </div>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <hr style="width: 100%; border: 0.5px solid black;"/> <div style="display: flex; justify-content: space-between; width: 100%;"> 0 10 </div> <div style="display: flex; justify-content: space-between; width: 100%;"> (No Problem) (As bad as can be) </div> </div>
Day 3	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred? 2. How many separate times did you see drooling happen? 3. Place a cross on the line which shows how severe you think the drooling was overall:	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <hr style="width: 100%; border: 0.5px solid black;"/> <div style="display: flex; justify-content: space-between; width: 100%;"> 0 10 </div> <div style="display: flex; justify-content: space-between; width: 100%;"> (No Problem) (As bad as can be) </div> </div>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <hr style="width: 100%; border: 0.5px solid black;"/> <div style="display: flex; justify-content: space-between; width: 100%;"> 0 10 </div> <div style="display: flex; justify-content: space-between; width: 100%;"> (No Problem) (As bad as can be) </div> </div>
Day 4	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred? 2. How many separate times did you see drooling happen? 3. Place a cross on the line which shows how severe you think the	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <hr style="width: 100%; border: 0.5px solid black;"/> </div>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <hr style="width: 100%; border: 0.5px solid black;"/> </div>

drooling was overall:	0 10 (No Problem) (As bad as can be)	0 10 (No Problem) (As bad as can be)
Day 5	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred?	<input type="text"/>	<input type="text"/>
2. How many separate times did you see drooling happen?	<input type="text"/>	<input type="text"/>
3. Place a cross on the line which shows how severe you think the drooling was overall:	0 _____ 10 (No Problem) (As bad as can be)	0 _____ 10 (No Problem) (As bad as can be)
Day 6	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
1. How many minutes during the hour did you feel drooling occurred?	<input type="text"/>	<input type="text"/>
2. How many separate times did you see drooling happen?	<input type="text"/>	<input type="text"/>
3. Place a cross on the line which shows how severe you think the drooling was overall:	0 _____ 10 (No Problem) (As bad as can be)	0 _____ 10 (No Problem) (As bad as can be)
Day 7	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias

		dyskinesias
1. How many minutes during the hour did you feel drooling occurred?	<input type="text"/>	<input type="text"/>
2. How many separate times did you see drooling happen?	<input type="text"/>	<input type="text"/>
3. Place a cross on the line which shows how severe you think the drooling was overall:	<div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>	<div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>
Comments:		

Week 4

Day 1	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
4. How many minutes during the hour did you feel drooling occurred?	<input type="text"/>	<input type="text"/>
5. How many separate times did you see drooling happen?	<input type="text"/>	<input type="text"/>
6. Place a cross on the line which shows how severe you think the drooling was overall:	<div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>	<div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>
Day 2	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias

<p>4. How many minutes during the hour did you feel drooling occurred?</p> <p>5. How many separate times did you see drooling happen?</p> <p>6. Place a cross on the line which shows how severe you think the drooling was overall:</p>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <div style="display: flex; justify-content: space-between; align-items: center;"> 0 <hr style="flex-grow: 1; border: 0.5px solid black;"/> 10 </div> <div style="display: flex; justify-content: space-between;"> (No Problem) (As bad as can be) </div> </div>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <div style="display: flex; justify-content: space-between; align-items: center;"> 0 <hr style="flex-grow: 1; border: 0.5px solid black;"/> 10 </div> <div style="display: flex; justify-content: space-between;"> (No Problem) (As bad as can be) </div> </div>
<p>Day 3</p>	<p>Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias</p>	<p>Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias</p>
<p>4. How many minutes during the hour did you feel drooling occurred?</p> <p>5. How many separate times did you see drooling happen?</p> <p>6. Place a cross on the line which shows how severe you think the drooling was overall:</p>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <div style="display: flex; justify-content: space-between; align-items: center;"> 0 <hr style="flex-grow: 1; border: 0.5px solid black;"/> 10 </div> <div style="display: flex; justify-content: space-between;"> (No Problem) (As bad as can be) </div> </div>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <div style="display: flex; justify-content: space-between; align-items: center;"> 0 <hr style="flex-grow: 1; border: 0.5px solid black;"/> 10 </div> <div style="display: flex; justify-content: space-between;"> (No Problem) (As bad as can be) </div> </div>
<p>Day 4</p>	<p>Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias</p>	<p>Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias</p>
<p>4. How many minutes during the hour did you feel drooling occurred?</p> <p>5. How many separate times did you see drooling happen?</p>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </div>	<div style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </div>

6. Place a cross on the line which shows how severe you think the drooling was overall:	<div> <div>0</div> <div>_____</div> <div>10</div> </div> <div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>	<div> <div>0</div> <div>_____</div> <div>10</div> </div> <div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>
Day 5	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
4. How many minutes during the hour did you feel drooling occurred?	<input type="text"/>	<input type="text"/>
5. How many separate times did you see drooling happen?	<input type="text"/>	<input type="text"/>
6. Place a cross on the line which shows how severe you think the drooling was overall:	<div> <div>0</div> <div>_____</div> <div>10</div> </div> <div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>	<div> <div>0</div> <div>_____</div> <div>10</div> </div> <div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>
Day 6	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias	Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
4. How many minutes during the hour did you feel drooling occurred?	<input type="text"/>	<input type="text"/>
5. How many separate times did you see drooling happen?	<input type="text"/>	<input type="text"/>
6. Place a cross on the line which shows how severe you think the drooling was overall:	<div> <div>0</div> <div>_____</div> <div>10</div> </div>	<div> <div>0</div> <div>_____</div> <div>10</div> </div> <div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>

	(No Problem) be)	(As bad as can	
Day 7	Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias		Non-Treatment time [hh:mm] <input type="checkbox"/> on <input type="checkbox"/> off <input type="checkbox"/> on with dyskinesias
4. How many minutes during the hour did you feel drooling occurred?	<input type="text"/>		<input type="text"/>
5. How many separate times did you see drooling happen?	<input type="text"/>		<input type="text"/>
6. Place a cross on the line which shows how severe you think the drooling was overall:	<div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>		<div> <div>0</div> <div>10</div> <div>(No Problem)</div> <div>(As bad as can be)</div> </div>
Comments:			

1f) Instructions for use of PDCue device

Instructions for use: Cueing device

General Use:

1. This is a wrist worn device and should only be worn on this position. The strap should have sufficient stretch for you to be able to easily slip the device onto your wrist. If you find that you are having difficulty with the sizing of the strap, contact a member of the research team and we will arrange a size alteration for you.
2. To switch the device on simply press the button located on the upper surface of the device. A vibration and flashing light will alert you that you have correctly switched it on.
3. Once on, the device will emit a discreet vibration every minute to remind you to swallow your saliva. This will help increase the overall amount that you are swallowing and will hopefully help to manage any drooling that you might normally experience.
4. Once switched on, a dim light will flash periodically to give you confidence that the device remains on.
5. When you have completed your hour session of wearing the device you can switch it off by pressing and holding the button located on its upper surface. A light will flash to alert you that you have switched the device off correctly.

Charging:

1. We would advise you to charge your device half way through the week. Plug the charger into a wall socket and then insert the smaller end into the hole found on the side of the device. The device should be fully charged within a few hours.
2. If you feel that the device has run out of power, either because it will not switch on or if it switches off whilst you are using it, then please charge it as soon as possible.

If you have any problems at all or have any queries then please do not hesitate to contact a member of the research team.

Appendix 2: Case Study 2

2a) LApp Participant information sheet



Developing technology to prompt loudness in Parkinson's

Project information sheet

You are being invited to take part in a research study. Before you decide if you will take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and to discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like to take part.

Thank you for reading this.

Why is the research being done?

People with Parkinson's often experience difficulties with their volume. They can find it difficult to 'make themselves heard' due to having a quiet voice. Increasing volume is frequently a core goal of speech and language therapy programmes targeted at people with Parkinson's, however remembering to use this louder voice outside of the therapy room can be tough. We think that it might be possible to develop an application which would help people with Parkinson's to practice their loud voice. We expect this application to be able to detect when the person's volume has reduced and then be able to prompt them with reminders to use their loud voice. We are asking you if you would like to work with us and other people with Parkinson's to help us develop an application which will be enjoyable and easy to use. The study is about the mobile phone app only; it does not involve you receiving any additional therapy.

What is involved in joining the study?

We will ask you to come to Newcastle University at a pre-arranged time and spend some time talking to us and other people with Parkinson's, within a group, about how we could use mobile phones to help people with Parkinson's practice speaking louder. We will not ask you any difficult questions or ask you to discuss personal issues.

The discussions we have with the group will be informal. We simply want to talk about the types of features that you think would be good to have in a new application, which would help people with Parkinson's to use the louder voice learned in therapy and how best to design a microphone which will pick up the volume in your voice. We want the application to be fun for you to use as well being useful to you, and for the microphone to be acceptable for you to wear which is why we are involving you in the design process.

After we develop the application we would like you to test it out. We anticipate that this will be an enjoyable activity for you as you will be able to see the outcomes of your thoughts and ideas. We will ask you to use the application and then discuss any issues that arose. During the time that you are using the application we would like to log the times and ways that you are using it so that we can gather additional information about how accessible the application is to you. If you would prefer that we do not have access to this information then please indicate this on the consent form.

We will then try to redesign the application and microphone in accordance with your comments and will ask you to try it out again. We will then have a final chat with you about how helpful they thought the application was.

Are there any disadvantages to taking part?

We would like you to come to Newcastle University for the first discussions session, which may incur travel costs. However, we will reimburse any costs to you, in full, within 1 week of attending the session.

What are the benefits of taking part?

You will be directly involved in the design of an application which will help people with Parkinson's to develop their volume control skills to improve their communication. We think that the experience of taking part in the study will be enjoyable and interesting. You will be able to provide us with vital information about what people with Parkinson's might want in a technology of this kind. This will enable us to design something which will be both fun to use and support the gains made in speech and language therapy. We do not anticipate any risks involved in taking part in the study but should you have any further queries please feel free to contact a member of the research team.

Will I need to change any other treatments?

No. For this study, there will not be any changes to your normal day-to-day activities.

What information will you collect about me?

We would like to video and audio record each of the discussions we have with you and the other people taking part. This is so that we can have a reference to your thoughts and ideas that we can look back on at a later date. Without them it is difficult to be accurate about exactly what you say or the actions you use to show us how you would like to make the application work easily. The recordings we make will NOT be seen by anyone outside of the research team and will be stored securely on a password protected computer in the Computing Science department at Newcastle University.

What will happen to information you collect about me?

Your privacy will be protected at all times. Your identity will not be known by anyone other than the people directly involved in the study. None of your personal details will be stored alongside your recordings and you will be given a code so that your

information will be protected. Any recordings of you will be stored securely at Newcastle University and will not be used for any other reason apart from the study.

What will happen if I do not want to continue with the research?

Participation in the research is entirely voluntary. If you decide you will take part you will be asked to sign a consent form. You will be given a copy of the information sheet and consent form to keep for your records. If you do not wish to carry on with the research you can withdraw at any time, without giving reason. Your decision will not affect the therapy you receive from local services. If you decide to withdraw, the information we hold on you for the research will be destroyed.

Who do I contact if I have a complaint?

If you have a complaint you can contact the Chief Investigator, Patrick Olivier, using the details provided below:

Culture Lab- Newcastle University
Grand Assembly Rooms
King's Walk
NE1 7RU
Patrick.olivier@ncl.ac.uk
0191 246 4630

Thank you very much for reading this information.

If you have any questions or difficulties during the course of the pilot please feel free to contact:

Róisín McNaney

Culture Lab, Newcastle University
Email: r.mcnaney@ncl.ac.uk
Telephone: (0191) 246 4630 or 07843 157 367

This research project has been approved by the Faculty of Science, Agriculture and Engineering Research Ethics Committee, Newcastle University.

2b) LApp Participant consent form



Consent form for participants

I give consent to participate in the study: '**Developing technology to prompt loudness in Parkinson's**', being carried out by The University of Newcastle.
Please **initial** each box

- I have read and understood the information sheet about taking part. ☐
- A team member has answered any questions that I had/ I have no further questions. ☐
- I understand that I will be interviewed following the study and that this interview may be video and audio recorded. ☐
- I understand that information about how often and in what way I use the final mobile phone application will be made accessible to the research team. ☐
- I understand that the data collected for this study will be stored in a secure location in the School of Computing Science at Newcastle University. ☐
- I understand that the data collected about me will be used only for research purposes. ☐
- I understand that I will not be mentioned by name on any documents or in any presentations about the research. ☐
- I understand that I can withdraw from the study at any time without needing to give a reason. ☐
- Withdrawing from the study will not affect any services that I am currently receiving now or might receive in the future. ☐
- I understand that logging information will be gathered relating to how often, and in which ways, I am using the application. ☐

Signature of participant.....
Name (in capitals)Date.....

Signature of team member.....
Name (in capitals)Date.....

<p>Róisín McNaney Culture Lab, Newcastle University Email: r.mcnaney@ncl.ac.uk Telephone: (0191) 246 4630 or 07843 157 367</p>
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2c) LApp design workshop protocol

Workshop protocol: Loudness App

Monday 4th November 2013

Time	Exercise	Resources
10:30-10:40	<p>Introductions and consent: Participants arrive. Refreshments given. Description of study and signing of consent forms.</p> <p>Prompts:</p> <ul style="list-style-type: none"> • Designing an app to prompt louder speech • Want to find out about experiences of SLT and having quiet speech • Design of microphones 	<p>Consent forms</p> <p>Information sheets</p> <p>Refreshments</p> <p>Video cameras and tripods</p> <p>Digital voice recorders</p>
10:40-11:05	<p>Discussions around Everyday experiences of having quiet speech and how it impacts</p> <p>Prompts:</p> <ul style="list-style-type: none"> • Descriptions of everyday speech • What type of issues are experienced day to day • Any methods to overcome quiet speech • How does having this problem make them feel 	Flipchart and pens
11:05-11:30	<p>Discussions around experiences of undergoing SLT for loudness</p> <p>Prompts:</p> <ul style="list-style-type: none"> • What type of SLT have they undergone • Did it help? • Do they still use the strategies? • If not, why? • Do they find it easy to remember strategies? • What type of things do they use to help remind them • Are they always aware of the problem • Would having something to remind them be useful, and in which contexts • How many mobile users • Do they use apps? • How would they feel about being given an app based reminder by their health professional? 	Flipchart and pens

11:30-12:10	Lunch	Lunch and refreshments
12:00-12:45	<p>Design of an app to promote loud speech</p> <p>Uses of app to practice SLT at home and to prompt for loudness in real world.</p> <p>Prompts:</p> <ul style="list-style-type: none"> • What types of features would they like or not like in an app? • Picture based clarification of app features • If they wouldn't use an app then what else could we do? • Which feedback mode would they like (visual, auditory, vibration) <p><u>scenarios</u></p> <ul style="list-style-type: none"> • X3 small groups to go through activity: use of app in situ • When would they want to be switching between feedback modes and in which contexts? • Where are their phones generally kept when at home/ outdoors? 	<p>Flipchart and pens</p> <p>Several mobile phones</p> <p>Several simple to use apps</p> <p>Large sheets with app interface examples</p> <p>Blank interface sheets</p> <p>Activity scenarios</p>
12:45-1:15	<p>Designing microphones</p> <p>Prompts:</p> <ul style="list-style-type: none"> • What types of mics do they already use? • How would they feel about wearing a mic? • Where would they be happy/ not happy wearing it (both geographically and physically on their person) • Place stickers on body drawing to indicate optimal position • What should it look like • Optimal acceptability design summary • How would they feel about their health professional having access to the data? 	<p>Flipchart and pens</p> <p>Microphone examples</p> <p>Glass</p>
1:15-1:30	Goodbye and debriefing	

2d) LApp design workshop scenarios

Workshop scenarios

Mike has Parkinson's and has problems speaking in a loud enough voice. People often ask him to "speak up". Mike is going to the pub with some old friends later on in the week and is feeling worried that they might struggle to hear him.

1. Why do you think Mike is worried?
2. What strategies might Mike use to help him speak louder when in the pub?
3. Could the application be useful in this situation?
4. What type of cue might he choose to use?
5. Where might he be keeping his technology?

Jane has Parkinson's and has problems speaking in a loud enough voice. People often ask her to "speak up". Jane's daughter Laura is getting married soon and so they are going shopping to look for a wedding dress. Jane's two daughters and their friend are all going. Jane knows that they will be walking around a busy town centre between wedding shops and is concerned that her voice might not be loud enough. She would like to join in this happy time as much as possible without having to worry about her speech.

1. Why do you think Jane is worried?
2. What strategies might Jane use to help her speak louder when out with her daughters?
3. Could the application be useful in this situation?
4. What type of cue might she choose to use?
5. Where might she be keeping her technology?

Harry has Parkinson's and has problems speaking in a loud enough voice. People often ask him to "speak up". Harry is part of a Parkinson's UK group and has been asked to give a talk to some students at the University about his experience of having Parkinson's. Harry would like to say yes but he is worried that his speech will not be loud enough, especially when he is feeling nervous.

1. Why do you think Harry is worried?
2. What strategies might Harry use to help him speak louder when in the pub?
3. Could the application be useful in this situation?
4. What type of cue might he choose to use?
5. Where might he be keeping his technology?

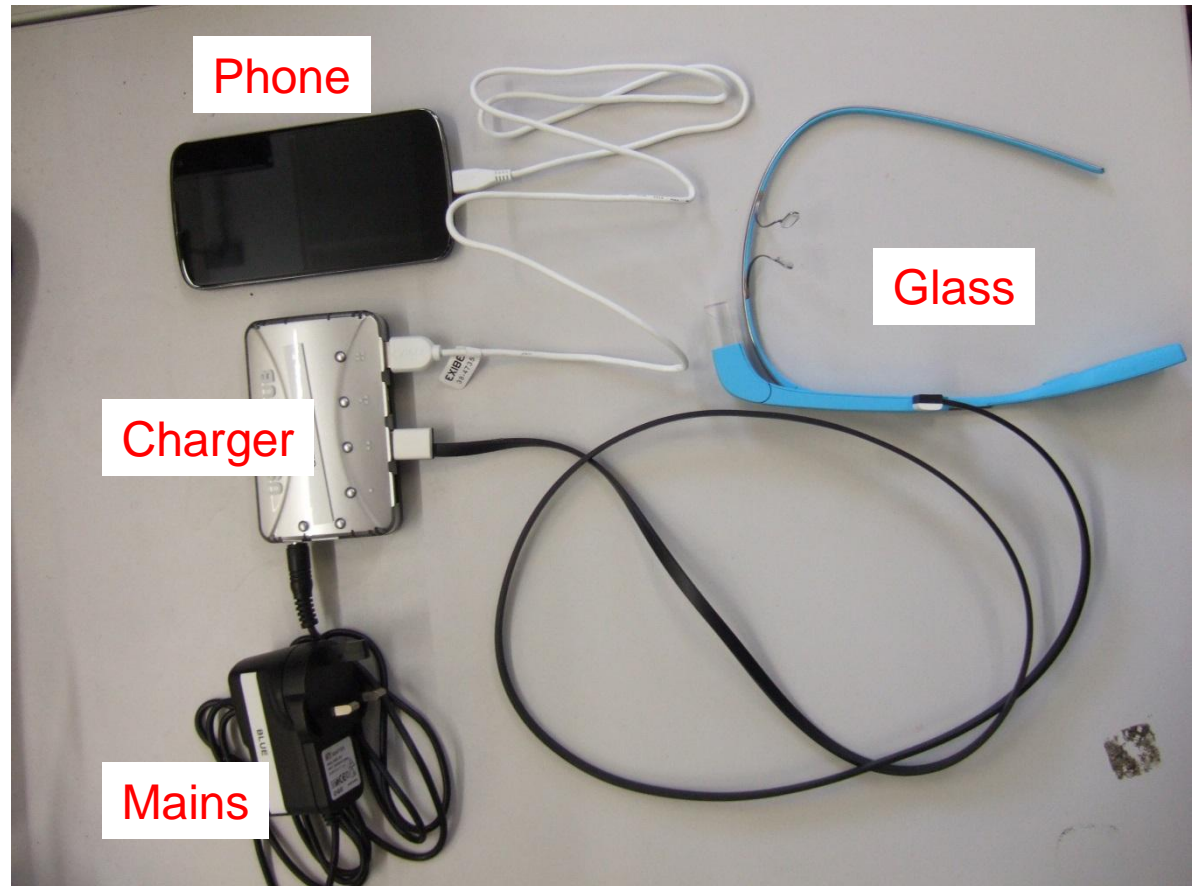
2e) Glass User Manual

2f) LApp deployment instruction manual

Glass user manual

Charging the system

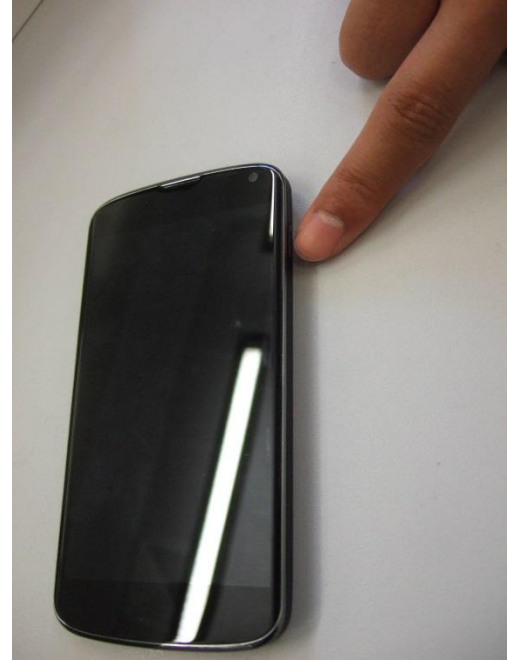
- Every evening!
- Charge:
 - Glass
 - Phone



Turning it on

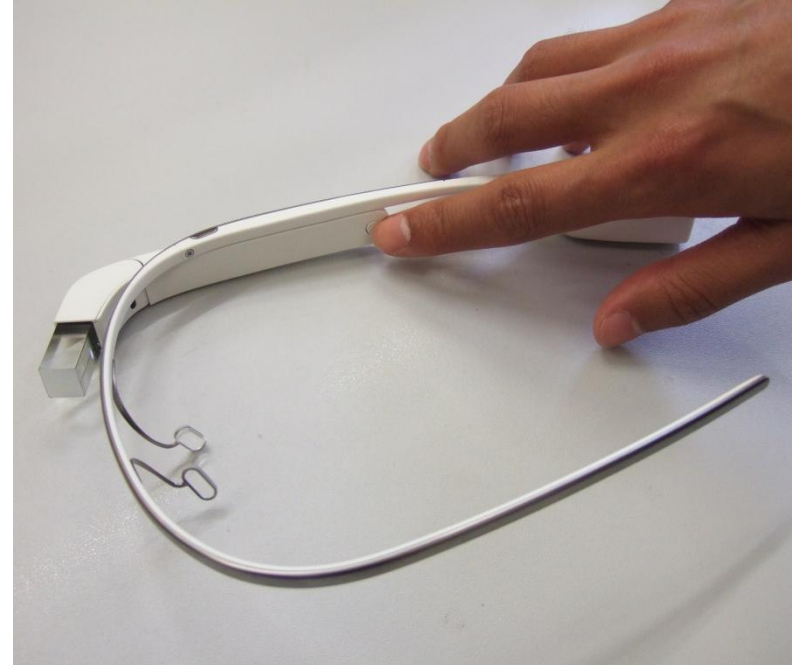
1. Turn on the phone

1. Press the button
2. Wait about 1 minute



2. Turn on Glass

1. Press the button ~2 sec
2. Screen stays black ~1mn
3. "Glass" logo appears
4. ~one more minute to wait
5. Glass is ready



You know Glass is ready when you see this

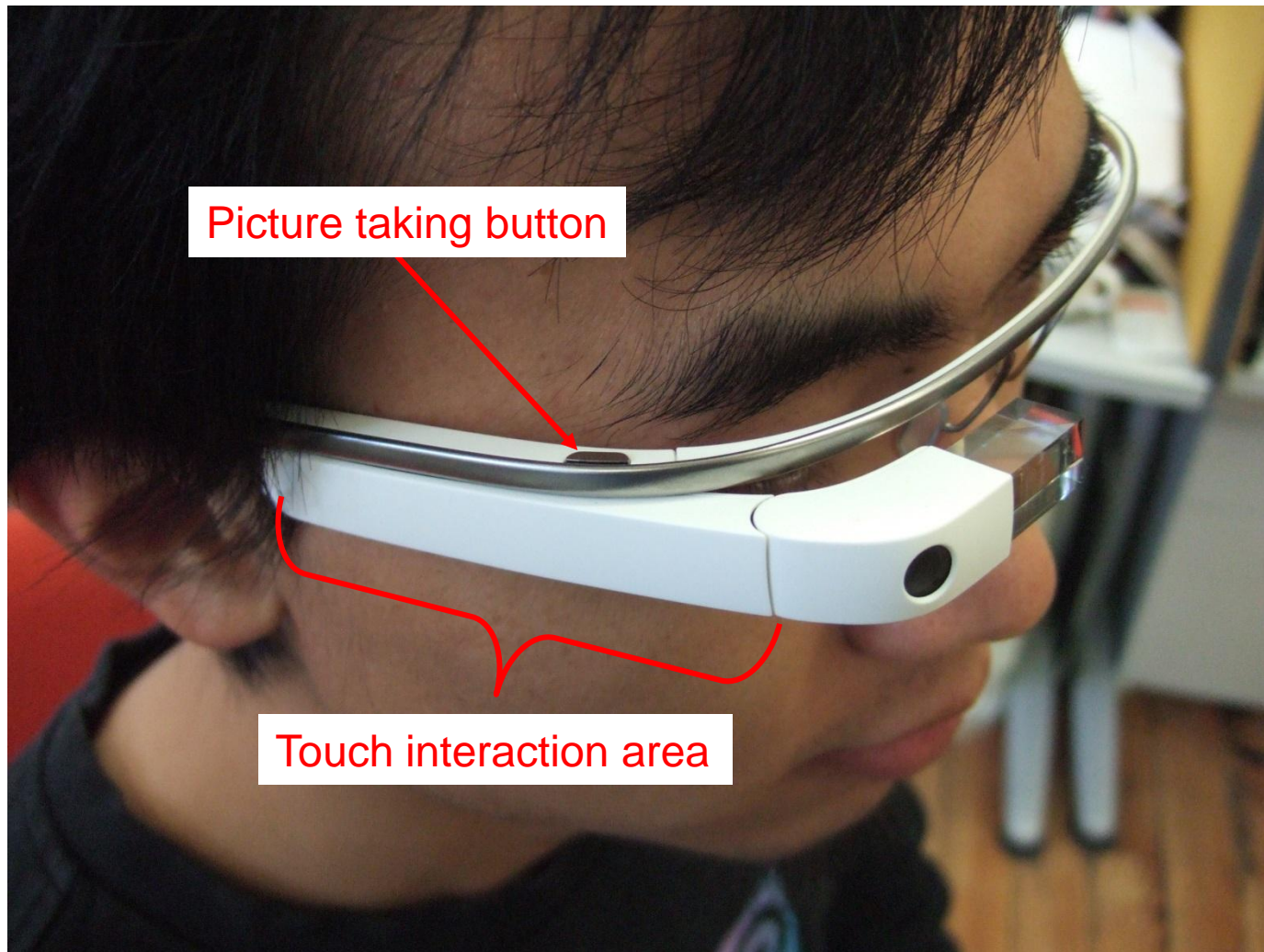
EN B:14% CPU:31% 340MHz M:222MB

3:19

" ok glass "

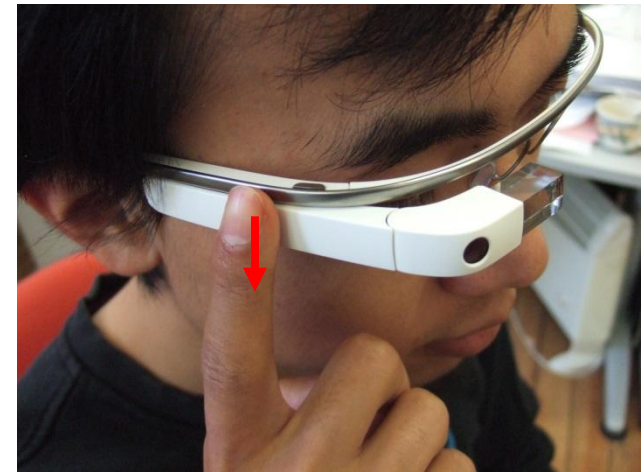
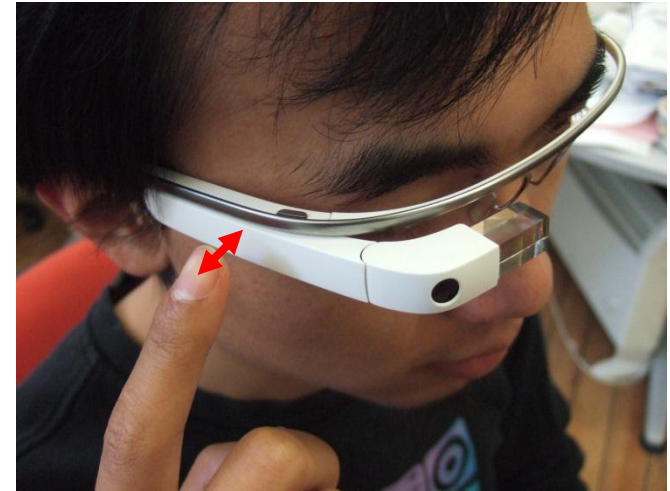


Interacting with glass



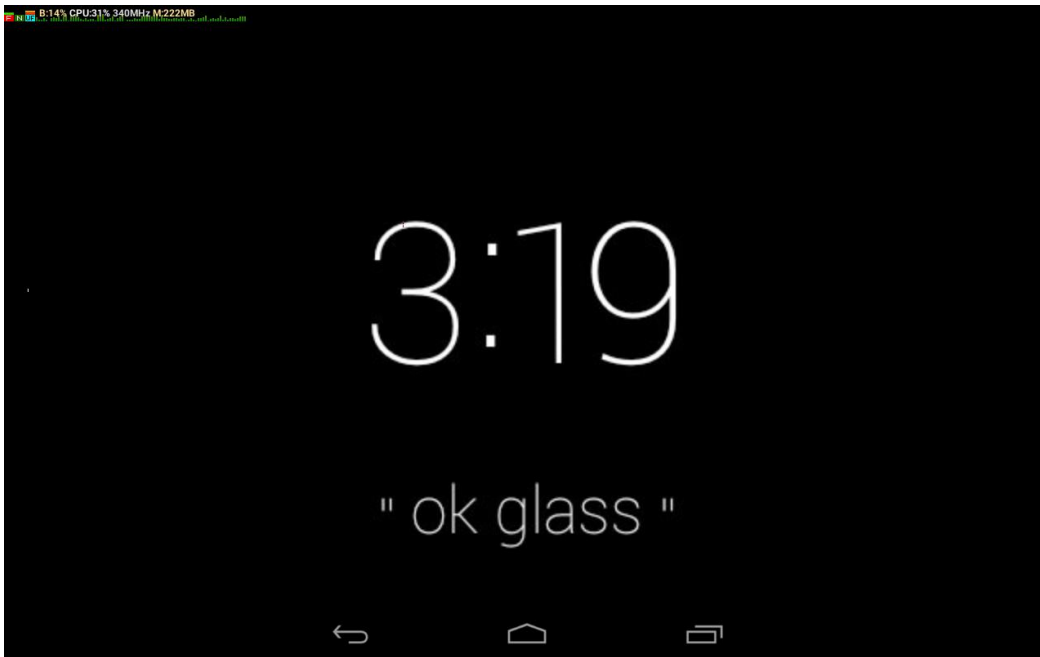
Commands on the touch area

- Tapping
 - “Wakes up” Glass
 - Or “selects” the current option
 - (tap just once!)
- Sliding down
 - Exits from the current menu
 - In main menu: turns the screen off



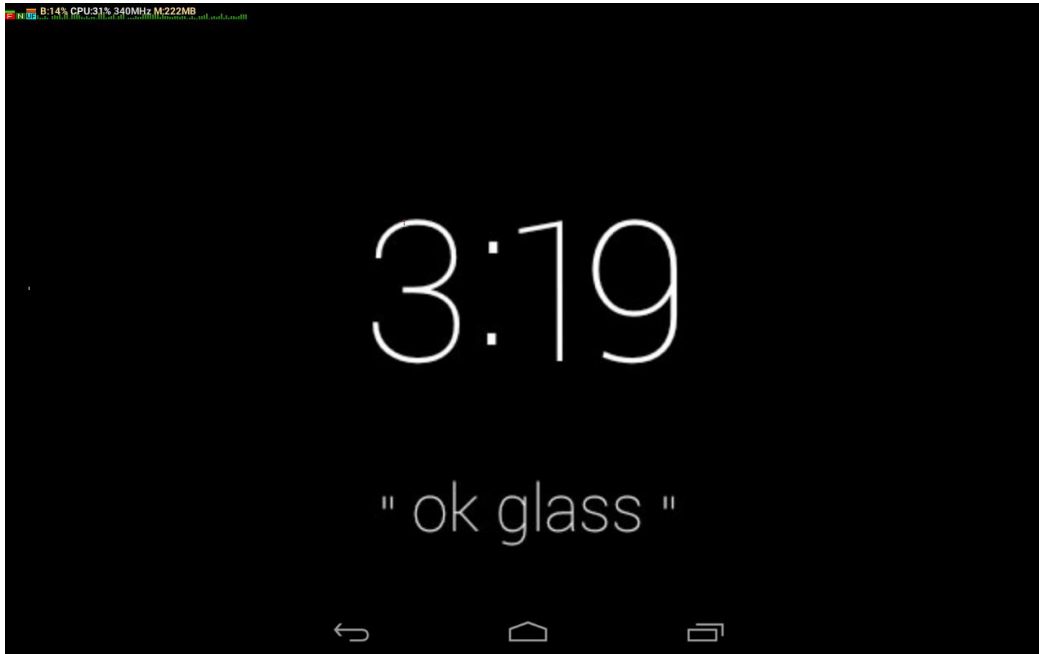
“Wake-up” glass

- If you do nothing with Glass, the screen turns off
- Tap (just once) on the side

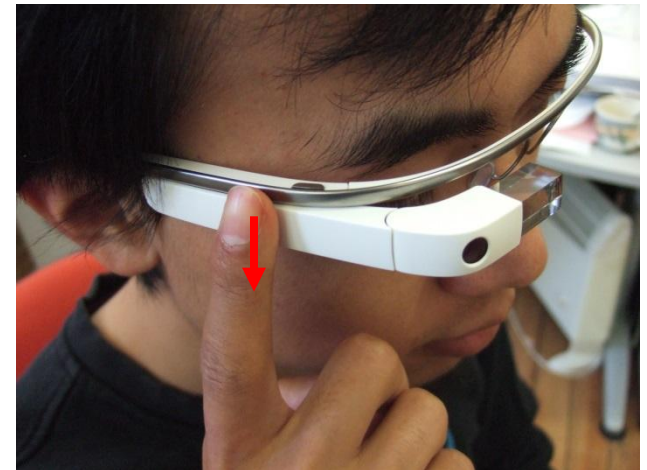


- You will see the “start” screen with the time and “ok glass”
- If not, try again... if still not: is Glass turned on or charged?

Putting Glass to sleep



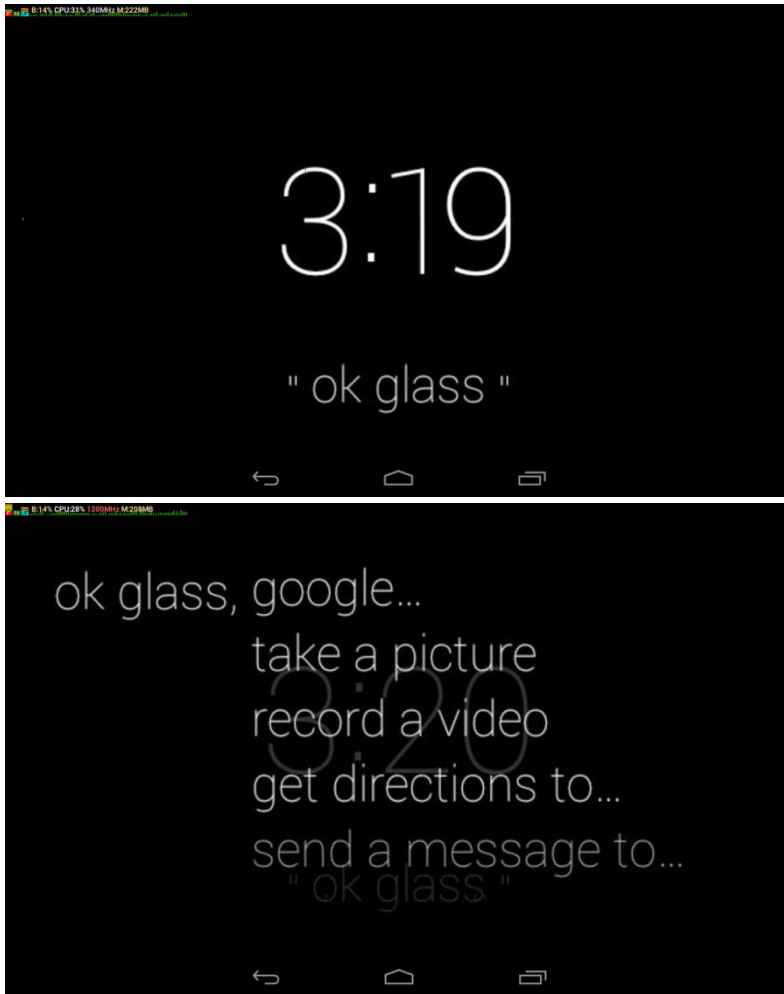
From here



Slide down

And the screen turns off...
(wake up by tapping!)

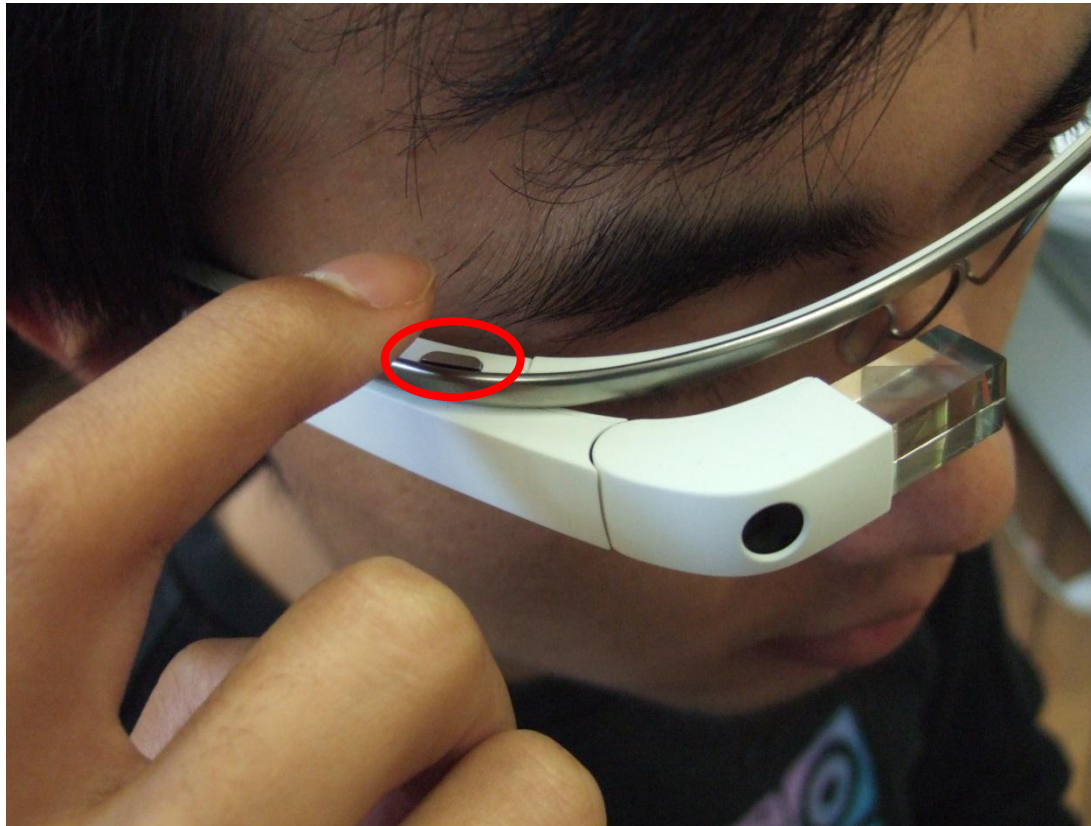
Take a picture by “voice commands”



- “Wake up glass” by tapping
- When here, speak “ok glass”
- A new screen appears
- You can speak any of the commands shown (do not say “ok glass” though)
- So, say now “take a picture”
- Try other commands: “record a video”, “get directions to”...

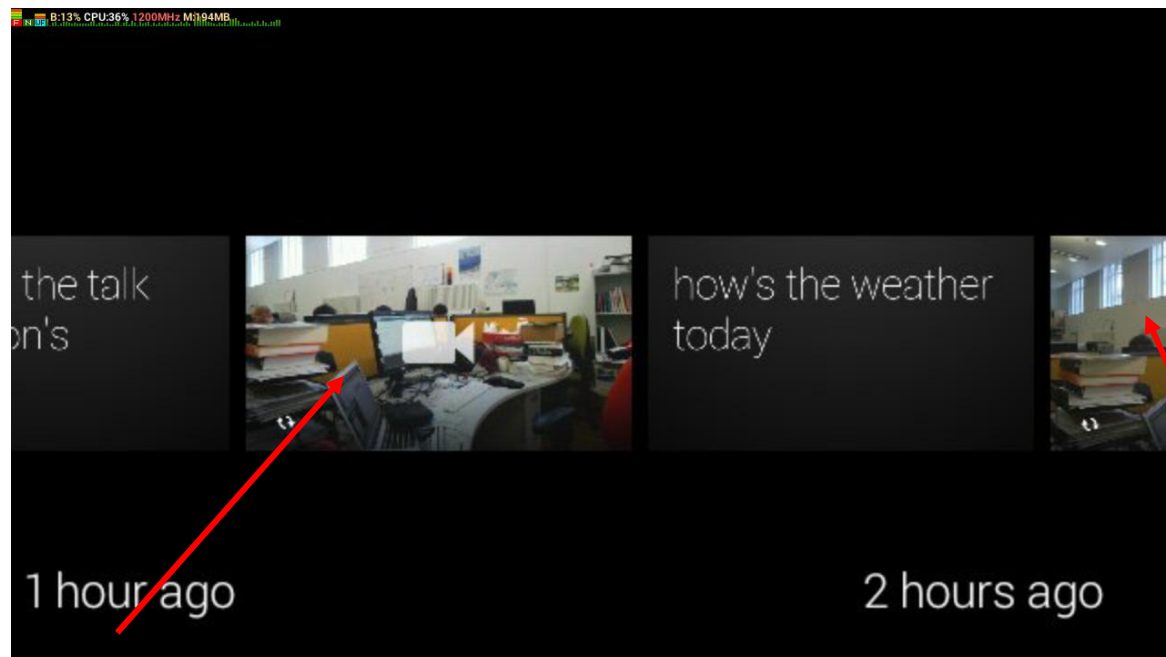
Picture taking button

- You can always take pictures pressing this button



A main concept of Glass: the “timeline”

- It is a “digital memory”
- It shows what you did, or what Glass told you
- It shows pictures/videos, messages/calls, news, notes,
- You can use it to browse through the pictures you have just taken! See the next page...

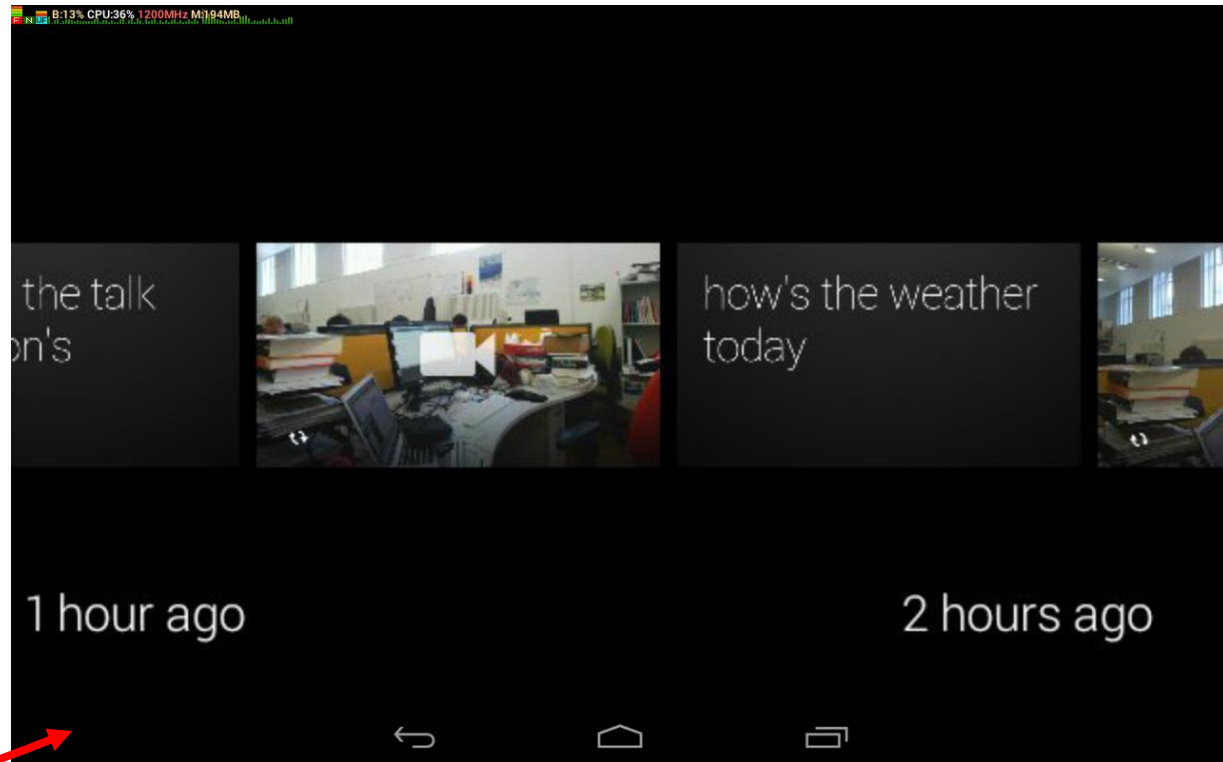
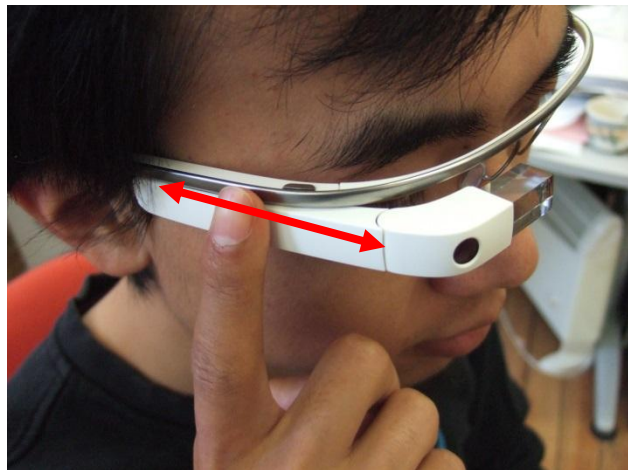


More recently, about 1 hour ago, you
Recorded a video...

About 2hrs ago you took a picture
Then asked for the weather....

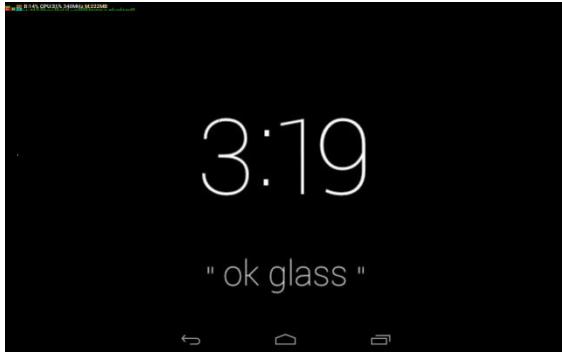
Sliding back and forth

- Selects the previous or next option
- Shows the previous or next event in timeline
 - Use it to browse the pictures you have taken
 - (wake up Glass beforehand)

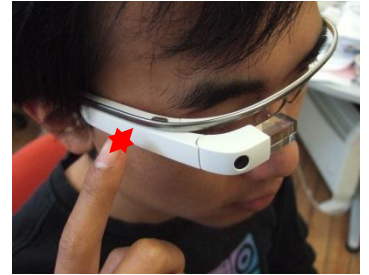


Sliding moves through the timeline

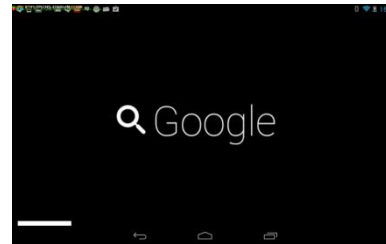
Interaction without voice



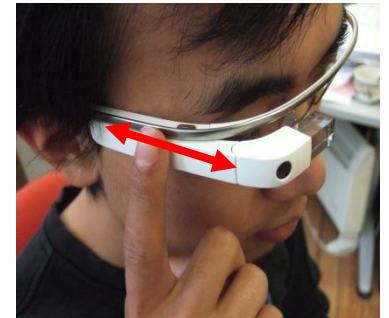
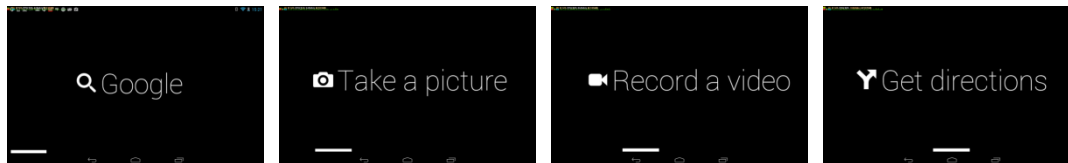
- When here, just tap



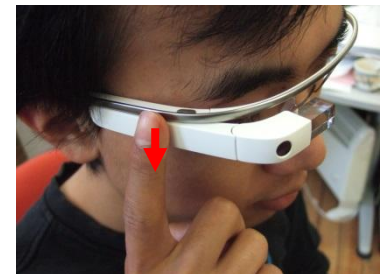
- A new screen appears



- Slide back/forth to see other options

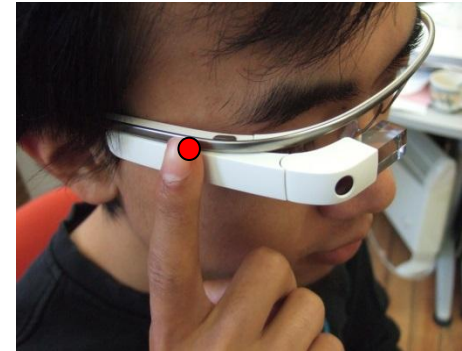
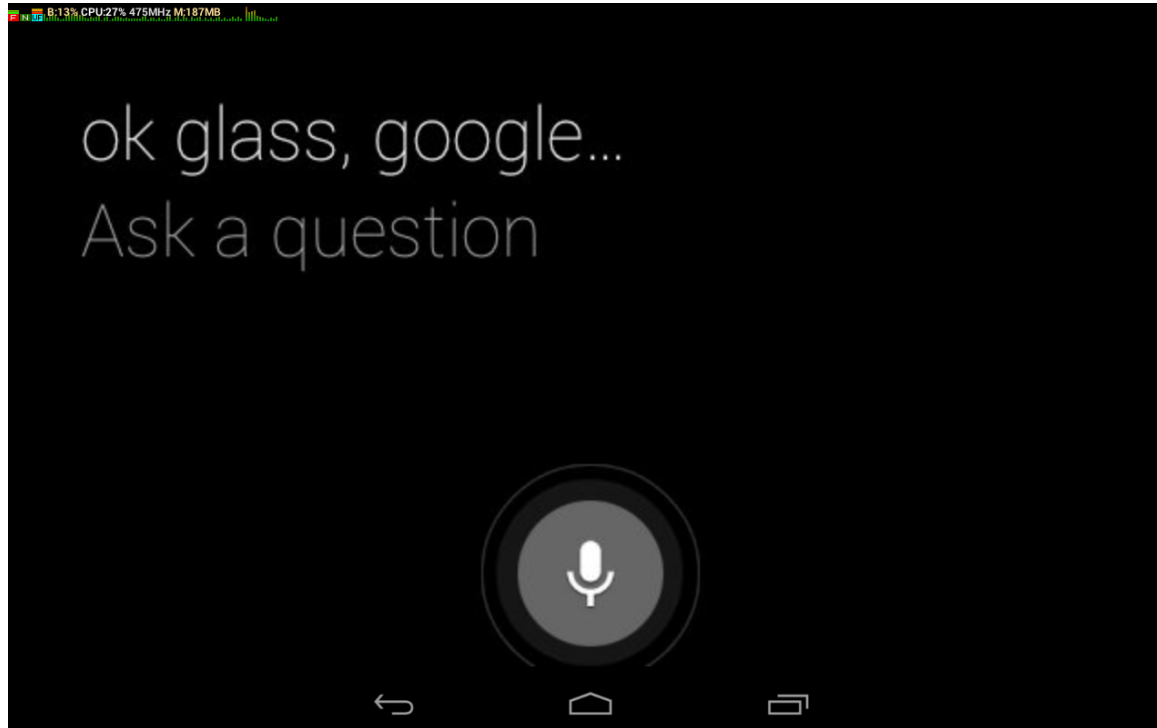


- Tap to select what you want....
- Or slide down to come back/exit



Use google to search

- Press 2 seconds on the side bar



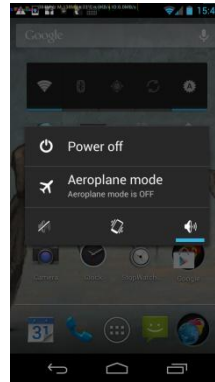
- A new screen appears....
- Speak what you want to search (e.g. say "Newcastle")

Turning it off

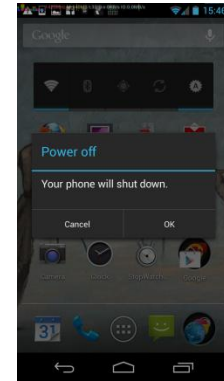
1. Turn off the phone



Long press the button

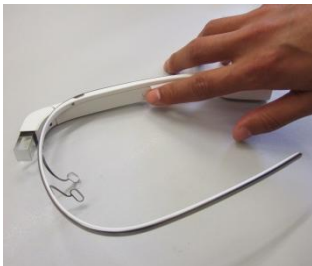


Select "power off"



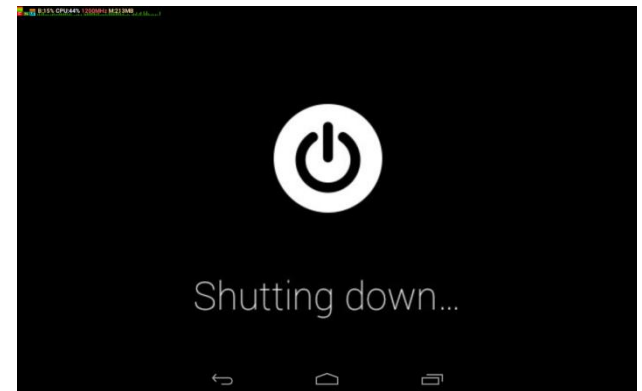
Select "Ok"

2. Turn off Glass



Long press the button

Glass "beeps"



And shows it is shutting down

Remarks

- Always carry the phone we provide with Glass (the phone is used to access internet)
- Charge every night
- Don't be afraid to play with Glass, at home or outside!
- Just experiment: you can't break it!

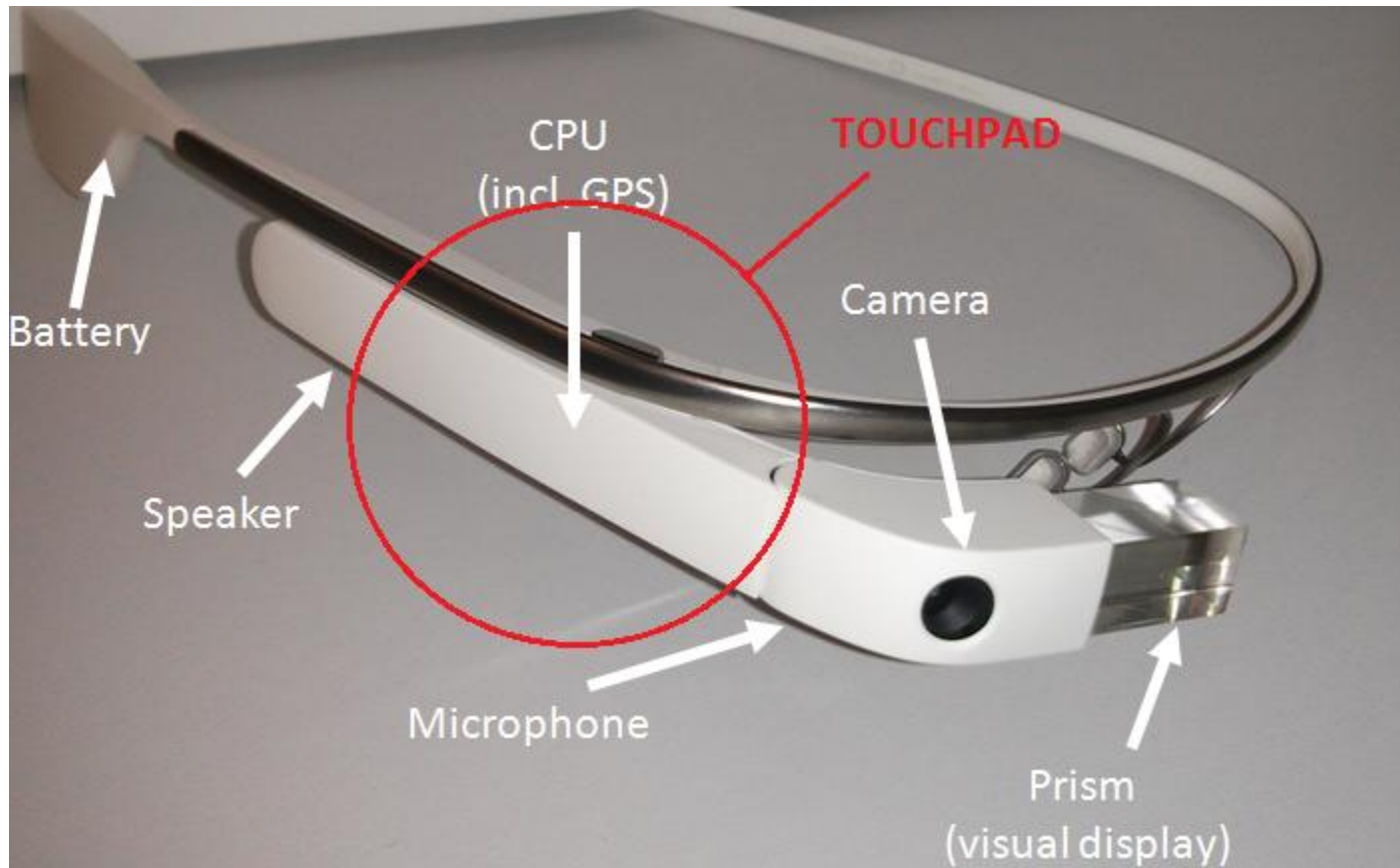
Lapp on Glass: A loudness application for Parkinson's



Contents

Pg.3	The Glass
Pg.4	Charging Glass
Pg.5	How to turn Glass on
Pg.6	Making the screen fit for you
Pg.7	Accessing the Loudness App
Pg.9	Setting the volume so that it is comfortable for you
Pg.11	Using the Loudness App
Pg.12.	Your task
Pg.14	Changing from a quiet to a noisy setting
Pg.16	Turning the App off
Pg.17	Turning the Glass off
Pg.18	Quick Troubleshooting: Q&A

The Glass



Charging Glass

- Every evening!
- Connect the charger to the Glass as shown in the picture and plug into a wall socket.

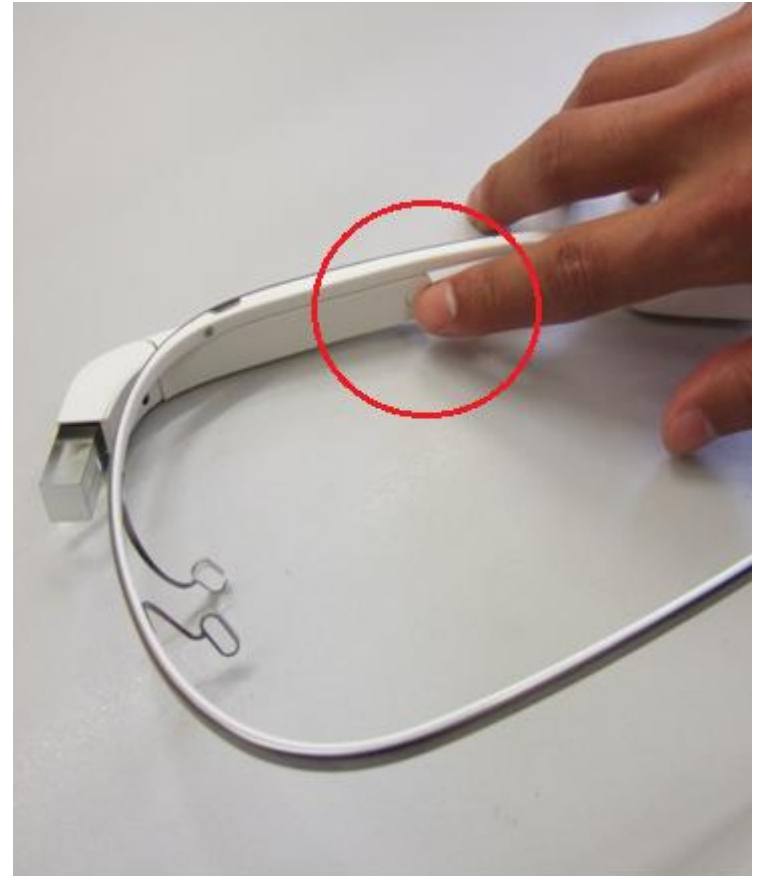
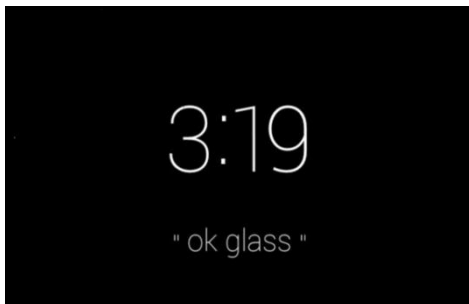


How to turn Glass on

- ✓ Press the button indicated in the picture for around 2 seconds
- ✓ The screen will stay black for around 1 minute before the Glass logo appears

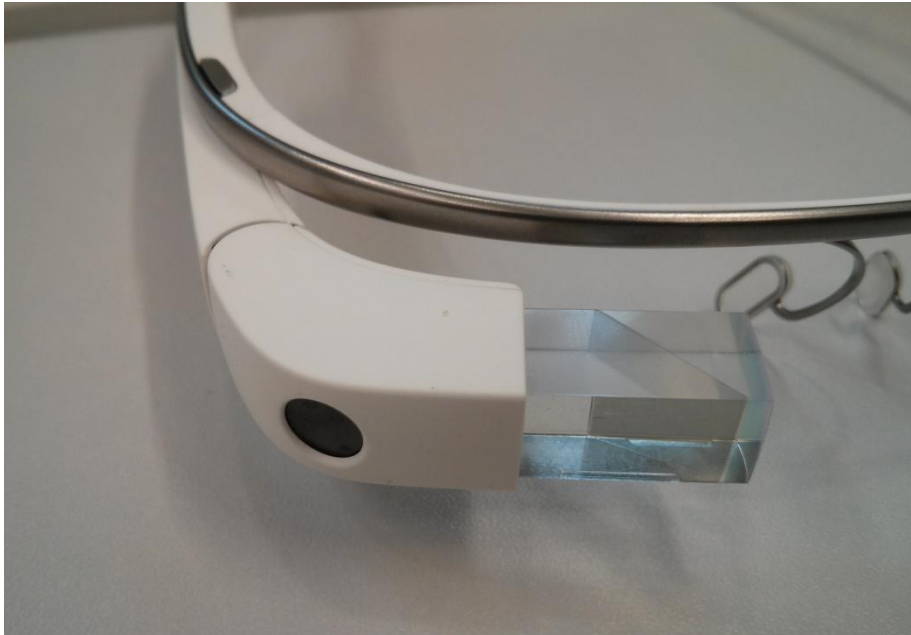


- ✓ when you see the "OK Glass" home screen then Glass is ready to use



Making the screen fit for you

- Put Glass on and check if you are able to see everything on the screen
- If not, you can adjust the eye piece by moving it forwards and back



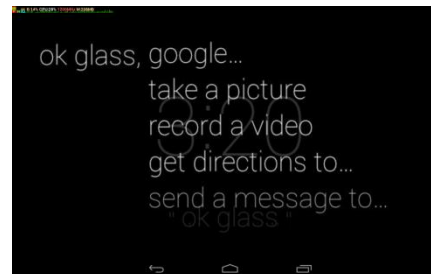
Accessing the Loudness App

There are two ways to access the application:

1. Voice activation



- Simply say “OK Glass”
- You will see a list of options, show loudness will be at the top



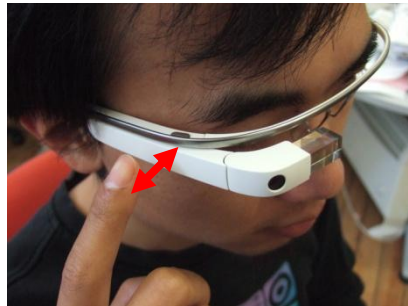
- Simply say “show loudness” and the application will open.

Accessing the Loudness App

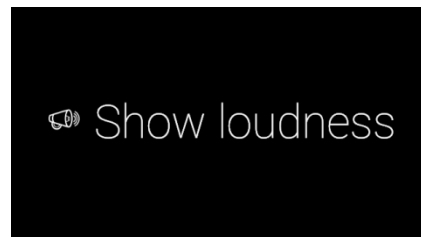
2. Hand gestures



- Tap the touchpad on the right hand side

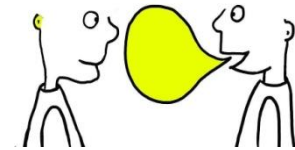


- Tap the “show loudness” screen and the application will open.



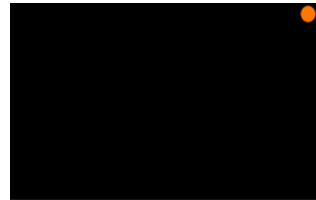
Setting the volume so that it is comfortable for you

- Please complete this exercise with your partner!



- Once you have accessed the App you will hear some instructions. Ignore these for now and set the volume so it is comfortable for you.

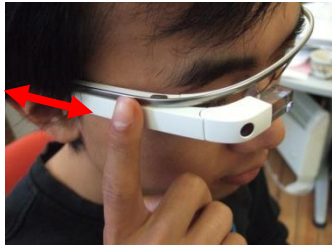
- You should see this screen:



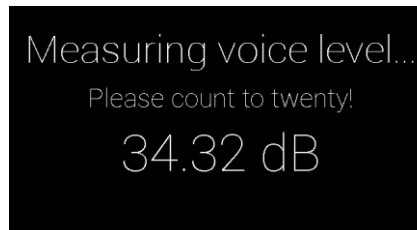
- Tap the touchpad on the right hand side of Glass.
 - This will bring you a screen that says “stop X”



- Using your finger on the touchpad, slide forwards until you see “sample voice” and then tap again to open



- You will hear *“The glass will now record a sample of your voice, after the beep please count to 20 in your loud voice”*. Please count to 20 but note that you might not reach 20 before the recording finishes.



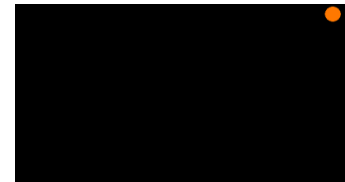
- You will hear *“Was your voice loud enough for your partner to understand?”*. Please ask your partner to indicate the answer and select either **YES**, by tapping the touchpad, or **NO**, by sliding forward on the touchpad to find **NO** and tapping.
- You will hear *“Were you comfortable speaking at this volume?”*. Please select **YES** or **NO** in the manner described above.
- If you select **NO** you will need to repeat the process again.

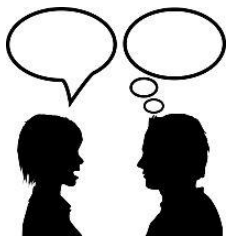
Using the Loudness App

- You have now set your target volume. You know your voice can be heard by your partner and is a comfortable volume for you. You are now ready to use the App in conversation.
- When you access the App you will hear *“The glass will show you a thumbs up icon when your voice can be heard comfortably by others. Try adjusting your voice volume so that it gives you a thumbs up every time you speak”*
- Simply speak with your loud voice. When you speak at a loud enough level you should see the thumbs up icon.

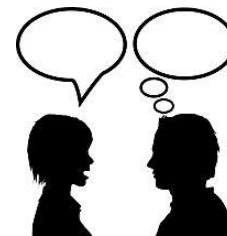


- You will see a small yellow circle in the right hand upper corner of the screen if you are **not** speaking loud enough. Please note that this circle will **also** be present if you are **not** speaking.





Your task



- You can have a conversation about whatever you wish, we are **NOT** recording **ANYTHING** that you say. We have supplied some conversation topics on the next page in case you get stuck for something to say.
- **Please note that the application is intended to be used peripherally, you should not need to look at the screen directly when in conversation or for long periods of time. You should be able to see the thumbs up icon even when not looking directly at the screen. Please be safe when using Glass and pay attention to your surroundings, particularly when walking or in public spaces.**
- We would like you to use the App as much as possible and in any situations you like, however to help ensure you get a full experience with the App please make sure you vary the conversational settings you are in.

Conversation topic examples

- Holidays
- Recipes
- Weather
- Sports
- Family and friends
- Current affairs from the news
- Television programmes
- Favourite books or movies
- Hobbies
- Music

Changing from a quiet to a noisy setting

- If you enter a different setting which is noisy then you might need to re-sample the background noise so that the app can adapt to your voice.

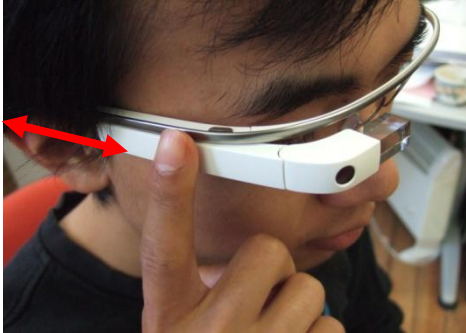
➤ You should see this screen:



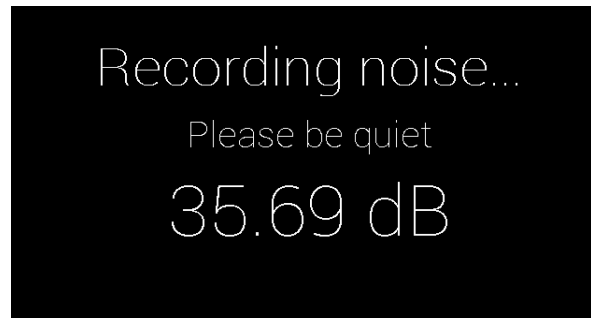
- Tap the touchpad on the right hand side of Glass.
- This will bring you a screen that says “stop X”



➤ Using your finger on the touchpad, slide forwards until you see “sample noise” and then tap again to open



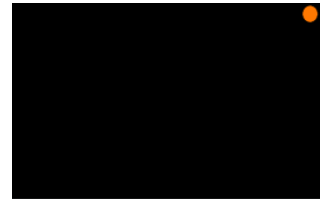
➤ Please be as quiet as possible so a good sample of the background noise can be collected.



Turning the app off

- If you wish to stop the App please follow these instructions:

- You should see this screen:

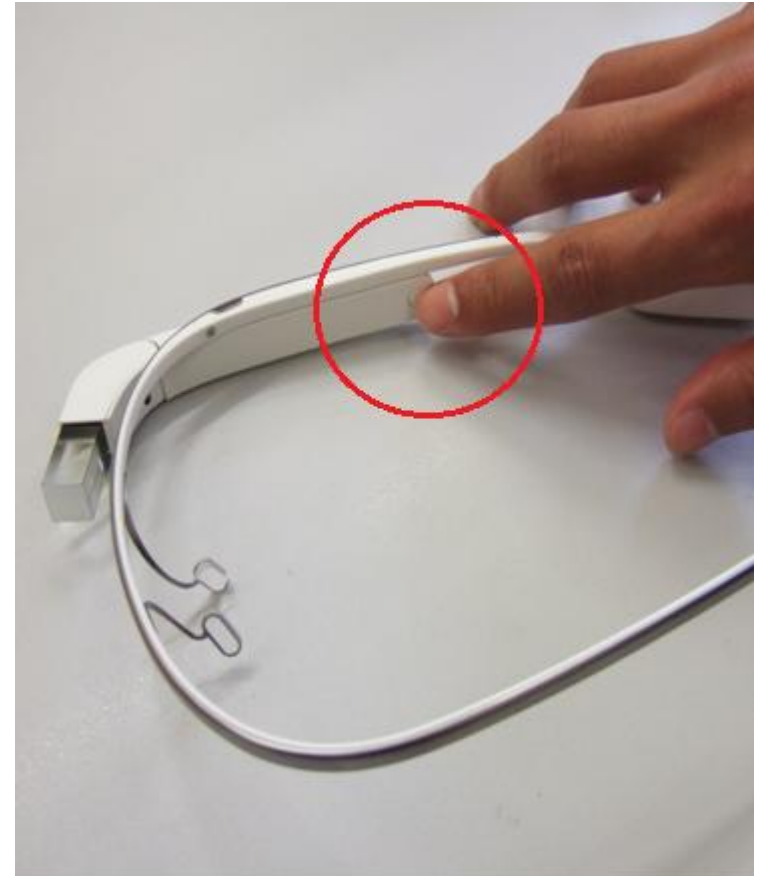


- Tap the touchpad on the right hand side of Glass.
 - This will bring you a screen that says “stop X”
 - Tap to stop the App



Turning Glass off

- Simply press the button indicated in the picture for approximately 2 seconds. The Glass will beep and the light will go off.



Quick Troubleshooting: Q&A

- What should I do if the app is telling me to speak louder but I feel like I'm loud enough?
 - You probably need to re-sample the background noise, see page 13 for how to do this.
- What should I do if I don't feel I am loud enough, or my partner cannot hear me, but Glass is giving me thumbs up?
 - You probably need to give Glass another sample of your voice, see page 9 for how to do this.
- The screen keeps going off, what should I do?
 - Glass might be going to sleep to save battery, simply tap the touchpad to wake it up.
 - You might need to re-charge the Glass, see page 4 for how to do this.
- The app won't start, what should I do?
 - Try switching Glass on and then off again, if this doesn't work give Roisin a call on 07843157367 or 01912464630 and she will help you

If you have any problems at all please feel free to call Roisin on 07843157367 (any time) or 01912464630 (office hours) at any time.

When we come to collect Glass we will have a short interview with you about your experiences using the Loudness App.

Thank you!

Appendix 3: Case Study 3

3a) Speeching Participant information sheet



Crowdsourcing Intelligibility: The use of crowdsourcing techniques for the assessment and monitoring of the intelligibility of the speech of people with Parkinson's

Project information sheet

You are being invited to take part in a research study as either a person with Parkinson's who has difficulty being understood by others or an age matched control subject who does not have Parkinson's. Before you decide if you will take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and to discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like to take part.

Why is the research being done?

Speech problems are common in people with Parkinson's. They often experience difficulties such as speaking quietly, slurring and less expression in their voice. All of these issues cause problems with the person's ability to be understood by others (their intelligibility) and this can be distressing and embarrassing, particularly when speaking with strangers.

Speech and Language therapy (SLT) targets these difficulties in an attempt to improve the person with Parkinson's speech, however, once therapy has finished, it is difficult to know whether or not the person with Parkinson's is continuing to use a clearer speaking voice away from the clinic.

Having a way to capture small samples of a person's speech within their everyday lives and testing its clarity could serve as an invaluable way of both informing speech therapists of how good the therapy techniques are, as well as providing feedback to the person with Parkinson's to allow them to monitor their speech and recall strategies learned in SLT when necessary.

One way of collecting these small speech samples is by using a mobile phone. The phone can record speech quickly, easily and in everyday settings and we can use a technique called **crowdsourcing** to test how easy the speech collected is to understand.

Crowdsourcing refers to giving mini tasks to a large network of people. Mini tasks (i.e. rating a small sample of speech on how easy it is to understand) are given to the 'crowd' enabling a larger task (i.e. the long process of testing speech clarity often completed by a speech therapist) to be completed quickly, easily and inexpensively.

Please note that, in the context of this study, when referring to 'the crowd' (the crowdsourcing workers) we refer to students and staff at Newcastle University. These participants will have no background in linguistics, acoustic analysis or speech and language therapy and will therefore correspond to a person with Parkinson's 'stranger' population. By asking them to provide the analysis we can figure out the degree to which a person with Parkinson's might be understood by a stranger encountered in their everyday lives.

What is involved in joining the study?

We will either come to your home or meet you at University or your local Parkinson's UK meeting, at a pre-arranged time, and ask you to complete some reading samples and picture descriptions. We will then ask a 'crowd' to rate your speech on how easy it is to understand and compare their ratings to those done by a speech therapist. We will be collecting speech samples from people with Parkinson's and people of a similar age without Parkinson's so we can compare the ratings between the two groups.

If you are a person with Parkinson's we will then make a mobile phone application which we will ask you use for one week. The mobile phone will ask you to provide a speech sample at random times throughout your everyday lives. The speech samples will be describing a picture or reading a sentence. You will have control over when the phone collects your speech, it will not record you without your permission. We will then explore how effective the crowd is at rating your speech. Please note that only very brief snippets of your speech will be collected, thus minimizing the risk that another person's voice, who has not consented to be part of the study, will be audible.

Following this week we would like to talk to you one last time, at a time and place of your choosing, to find out whether or not you liked using the mobile phone and any difficulties you might have had.

You do not need to own a mobile phone to take part in this study. If you do not have a phone we will provide one for you. Full training will be given to show you how to use the phone and application and a team member will be available at all times via telephone in case you have any technical difficulties.

Are there any disadvantages to taking part?

If you accidentally give recording permission there is a very small chance that something might be recorded that you feel is private. We will give you full training on how to use the mobile phone and how to delete samples that you would not want someone to hear. If you struggle to do this, there will be a researcher available at all times to guide you through the process or do this for you. We will NEVER ask you to give a reason why you want to delete a recording.

What are the benefits of taking part?

You will be directly involved in the development and testing of a mobile phone application which will help us to understand whether we can use a 'crowdsourcing' to provide valid ratings of speech. In the future this could help a speech and language therapist gather vital information on the types of difficulties that the person with Parkinson's is having on a daily basis, which can help to structure future therapy, as well as giving feedback to the person themselves about their speech so they can make independent changes. We think that the experience of taking part in the study will be enjoyable and interesting. You will be able to provide us with vital information about what people with Parkinson's might want in a mobile phone technology of this kind. This will enable us to design something which will be both fun to use and support the gains made in speech and language therapy. We do not anticipate any risks involved in taking part in the study but should you have any further queries please feel free to contact a member of the research team.

Will I need to change any other treatments?

No. For this study, there will not be any changes to your normal day-to-day activities or medications.

What information will you collect about me?

We would like to audio record your voice during the speech collection period as well as audio recording the final interview with you. This is so that we can have a reference to your thoughts and ideas that we can look back on at a later date. Without them it is difficult to be accurate about exactly what you say. The interview recordings we make will NOT be heard by anyone outside of the research team and will be stored securely on a password protected computer in the Computing Science department at Newcastle University.

The reading samples and picture descriptions will be heard by the 'crowd' however they will never be told your name, nor will they know any information about you.

What will happen to information you collect about me?

Your privacy will be protected at all times. Your identity will not be known by anyone other than the people directly involved in the study (Roisin McNaney and Paul Dunphy). None of your personal details will be stored alongside your recordings and you will be given a code so that your information will be protected. Any recordings of you will be stored securely at Newcastle University and will not be used for any other reason apart from the study.

What will happen if I do not want to continue with the research?

Participation in the research is entirely voluntary. If you decide you will take part you will be asked to sign a consent form. You will be given a copy of the information sheet and consent form to keep for your records. If you do not wish to carry on with the research you can withdraw at any time, without giving reason. Your decision will not affect the therapy you receive from local services. If you decide to withdraw, the information we hold on you for the research will be destroyed.

Who do I contact if I have a complaint?

If you have a complaint you can contact the Chief Investigator, Patrick Olivier, using the details provided below:

Culture Lab- Newcastle University
Grand Assembly Rooms
King's Walk
NE1 7RU
Patrick.olivier@ncl.ac.uk
0191 246 4630

Thank you very much for reading this information.

If you have any questions or difficulties during the course of the pilot please feel free to contact:

Róisín McNaney

Culture Lab, Newcastle University
Email: r.mcnaney@ncl.ac.uk
Telephone: (0191) 246 4630 or 07843 157 367

This research project has been approved by the Faculty of Science, Agriculture and Engineering Research Ethics Committee, Newcastle University.

3b) Speeching Participant consent form

Consent form for participants



I give consent to participate in the study: '**Crowdsourcing Intelligibility: The use of crowdsourcing techniques for the assessment and monitoring of the intelligibility of the speech of people with Parkinson's disease**', being carried out by The University of Newcastle.

Please **initial** each box

- I have read and understood the information sheet about taking part. ☐
- A team member has answered any questions that I had/ I have no further questions. ☐
- I understand that I will be interviewed following the study and that this interview will be audio recorded. ☐
- I understand that information about how often and in what way I use the final mobile phone application will be made accessible to the research team. ☐
- I understand that the data collected for this study will be stored in a secure location in the School of Computing Science at Newcastle University. ☐
- I understand that the data collected about me will be used only for research purposes. ☐
- I understand that I will not be mentioned by name on any documents or in any presentations about the research. ☐
- I understand that I can withdraw from the study at any time without needing to give a reason. ☐
- Withdrawing from the study will not affect any services that I am currently receiving now or might receive in the future. ☐

Signature of participant.....

Name (in capitals)Date.....

Signature of team member.....

Name (in capitals)Date.....

Róisín McNaney

Culture Lab, Newcastle University

Email: r.mcnaney@ncl.ac.uk

Telephone: (0191) 246 4630 or 07843 157 367

3c) Speeching Deployment protocol

Speeching: Study protocol

Stage 1: Lab deployment (non Parkinson's)

Purpose

To trial the app and crowdsourcing tasks and ensure there are no issues before our deployment with the Parkinson's group

Participants

6 users and 12 crowd members (6 local, 6 non-local).

Method

Pre deployment: Before running the stage 1 deployment we need to keep note of how long the set of tasks takes to complete both in terms of collecting and rating the speech. We will pilot the whole set and study procedure on ourselves (Roisin and Dan) as a run through first.

Users will be given the app and brief description of how to use it. They will be given approximately 20/30minutes to find their way around the app and record some speech samples. The user will be asked to record their assessment data (quickfire single words, a short reading sample (just pull this from wiki- 3/4 sentences) and the Pizza scenario (for more natural sounding data)). They will receive feedback about their speech with 1 hour and will be directed to explore the practice area, following instructions to complete certain tasks. Following this practice time they will be directed to provide another assessment for analysis by the crowd. They will receive feedback on their speech within 1hour.

Interview: The users will be interviewed on their experience of using the app. They will be asked about how easy to use/ intuitive the app was and how useful the feedback on their speech was. They will be asked to direct us on whether there are any changes that need to be made before the deployment with our Parkinson's group.

Once the speech samples have been collected (x2 points) they will be uploaded to the crowdsourcing platform and outsourced to our crowd for analysis. The crowd members will be alerted via email that they have a job waiting. They will be asked to transcribe the sample and rate the speech they have received for its understandability, accent, volume, rate and pitch variance. They will also be asked to complete the quickfire single word task.

Interview: The local crowd (x6) will be interviewed on their experience of using the crowdsourcing platform. They will be asked about how easy it was to use and how easy the tasks were to complete. They will be asked to direct us on whether there are any changes that need to be made before the deployment with our Parkinson's group.

Stage 2: Real world deployment (Parkinson's group)

Purpose

To trial the Speeching app with a group of real users with Parkinson's who have speech problems.

Participants

6 users and 12 crowd members (6 local, 6 crowdflower).

Method

Pre deployment: Any changes identified during the stage 1 study are to be implemented prior to deployment.

Users will be visited at home to be given the app and brief description of how to use it. They will be asked to complete the assessment session during the initial visit (if they feel comfortable) so that any issues with the app use can be discussed with the researcher. Following this they will be instructed that they should receive feedback within 12-24hours. The researcher will then help them to navigate to the practice area and will show them the types of practice tasks that they might be prompted to complete. The users will be left with the app for 2weeks, during which time they will be instructed to use the practice area as much as they wish. They will be instructed that they can upload their speech for analysis at any point during the deployment phase, to gain a direct comparison of their speech before and after practice. They will be instructed that they do not need to complete the entire assessment phase (we need to have an option that they can upload a sample for e.g. volume analysis if they are practicing on this) but that they should complete a full assessment at least one point nearing the end of the deployment phase at 2 weeks. Participants will be reminded that they should expect to receive feedback within 12-24hours. Users will be contacted via telephone at 4 points during the deployment to go over any issues they might be having with the researcher. During the final telephone contact, which will also serve to remind them to complete the full assessment, the researcher will confirm an appointment to collect the device.

Interview: The users will be interviewed on their experience of using the app. They will be asked about how easy to use/ intuitive the app was and how useful the feedback on their speech was. They will be asked to direct us on whether there are any changes that need to be made to make the outcomes of the study more meaningful to them.

Once the speech samples have been collected (at multiple points) they will be uploaded to the crowdsourcing platform and outsourced to our crowd for analysis. The crowd members will be alerted via email that they have a job waiting. They will be asked to transcribe the sample and rate the speech they have received for its understandability, accent, volume, rate and pitch variance. They will also be asked to complete the quickfire single word task.

3d) Stage 1 App feedback

Speeching stage 1: Feedback on the app (from 6 users)

- Text is too small on the home page (need a way to make it bigger if required, especially for people with sight issues)
- When you press the info button on the assessment page it crashes (can we disable it here?)
- Remove the 'share recording' option
- Need a prompt page to advise people to keep the phone at a consistent distance from the mouth each time (I would say not to use actual distances like 12inches as some people won't know what this is off the top of their head. Perhaps say something like "the phone should be kept at the same distance each time, approximately the length of your hand" and then maybe show a picture of this)
- The blue-red-blue for recording is confusing- maybe animate the record button so you know it's recording or change to start-stop and have green and red. Another suggestion for the assessment was to simply have a splash screen to explain that everything will be recorded and a start button (rather than record) which counted down (3,2,1) and prompted next and finish at the end (I like this idea)
- Unsure what the separate scenarios are for (remove or put under an additional practice tab). Everyone thought that they had to do these
- It is unclear how to set the volume (the instructions should be clearer and prompt for counting) or even what this task is for. It needs prompting generally when you enter into the task. This is the same for the rate task.
- Changing between the two task modes was found to be difficult to grasp (they could be two separate, clear tabs at the top? Or have a prompt page and a more natural choice between the two- clearly presented at all times- I do know this is tricky with the size of the phone but we need to do something around this)
- The info button was unclear, maybe it should pop up when you enter into each task. They didn't feel that the navigation through the app was particularly intuitive. Suggestion to put the info button at the bottom when doing the rate and volume tasks or pulse it to say there is added info (although just popping it up the first time would also be useful)
- Uploading tasks in the practice area was again unclear. This needs another pop up prompt
- Assessment section was very clear and upload easy- more like this for the rest of the app would be good
- We talked about the fact that on sign in there should be a loading sign and the button should be greyed out once you have pressed it. It feels like it doesn't work at the moment and leads to multiple button presses
- In the volume task it was difficult to read and watch the colour/ number at the same time- suggestion to put the number closer to the text or make it bigger, change the background instead of the number (I think this would be distracting though) or remove the number altogether and use something like a radio scale or graph (this would be my preference considering the dB numbers won't actually mean anything to our participants)
- The voice talking when you tap the screen is a surprise and wasn't felt to be needed- remove

- The pacing video was too much information, it should be clear that there is a progression through the tasks and that one pacing method is different from the other- people weren't really sure which one they should be doing. (Maybe if we show the first method- prompt "you have a try"- prompt with selection "move to the next level" which shows the next video or "I'll stick with this for now"). Again the pacing task needs better prompting, no one was really sure what to do.

3e) Speeching instruction manual

Speeching: A mobile application for the assessment and practice of speech issues in Parkinson's

We have developed a mobile phones application to help people with Parkinson's monitor and manage several common speech issues. We will be using a method called crowdsourcing to analyse the speech that you give us. This basically means that speech samples are given to an anonymous crowd of online workers, who provide an analysis for us to feed back to you via the application. Any sample that you provide is given an automatically generated code, your identity will **NEVER** be disclosed to the crowd workers. However, if you feel, or begin to feel uncomfortable with the concept you are free to pull out of the study at any time. We have worked carefully alongside an expert in Parkinson's speech in order to design the assessment and practice tasks.

The 'Speeching' application has 3 functions:

- To collect speech data from you in the form of an assessment, which can be analysed by a crowd of anonymous people. We completed a study last year which showed us that anonymous online worker provided, in many cases, equivalent ratings around speech issues in Parkinson's when compared to expert ratings. The positives of using a crowd to complete analysis of speech is that it is very quick and there are lots of different people available to help, meaning that the user of the application (you) gets feedback about their speech quickly.
- To provide feedback to you on your speech via the application. Once your speech has been analysed by five different people, we take the average scores and feed them back to you. This means you can see how people have perceived, for example, your overall speaking clarity, how

loud you have been, how quick your speech was. Having these ratings can act as a piece of mind, can be used for your own interest or can be used to help you set goals for your speech practice.

- To provide an area to help you practice your speech. For the purposes of the study we have chosen the practice activities of 1) increasing loudness and 2) improving rate of speech, to help you slow down and speak more clearly. The tasks are both centred around reading, there will something new to read each day. There are also a couple of extra activities based around scenarios like ordering a pizza, or getting the bus, which will help you practice more natural conversation.

We would like you to spend a week with the application, using it and thinking about how it might fit into your life. We will call you on the telephone regularly to make sure you are not having any issues. At the end of the week we would like to ask you about your experiences with the application, what you liked and what you didn't like so that we can have some ideas of how to best improve it for the future.

If you have any issues at all, please feel free to call Roisin on **07843 157 367**

THANK YOU

USER MANUAL

NB: the phone you have been given is a touchscreen smartphone. If you are having any issues there are several accessibility features that we can activate, just give us a call and we will talk you through it. The phone should last between 2-3 days if it is not being used very often, we have provided you with a wall charger in order to charge the phone as and when it is needed.

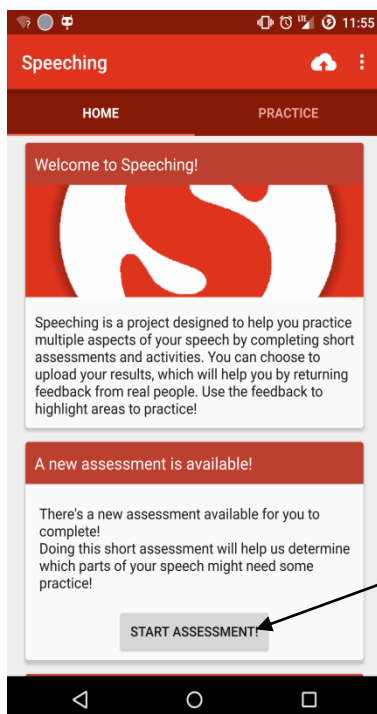
Accessing the application



Simply tap this icon on the screen

Submitting an assessment

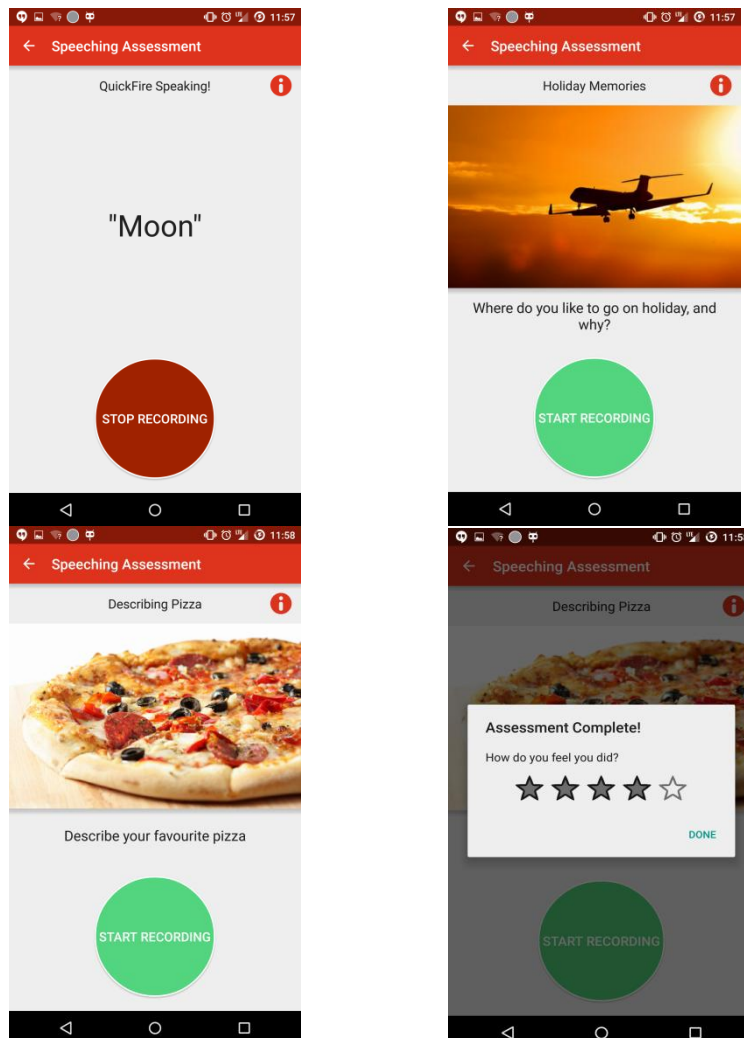
You are free to submit an assessment as many times as you wish, they are available each day. Every time you submit an assessment you will receive feedback on your speech. We estimate that this will take between 45 minutes and an hour but it could potentially be longer.



Click 'start assessment' to begin

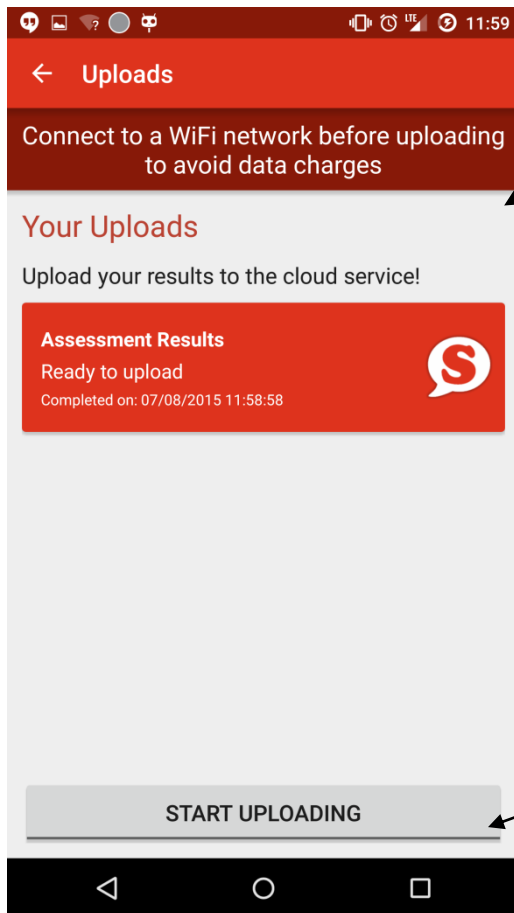
Completing the assessment

There are a couple of different tasks to do; reading single words and completing a scenario, which asks you to read and to provide your own answers to questions. You can control the recording of your sample via a large stop and start button near the bottom of the page. Simply press the start button when you are ready to record and press stop when you have finished. The next task will appear automatically. At the end of the assessment, you will be asked to rate how you felt you did.



Uploading your assessment

When you have completed your assessment you will be asked to upload it for analysis. The upload page will appear automatically. Simply click 'start uploading'

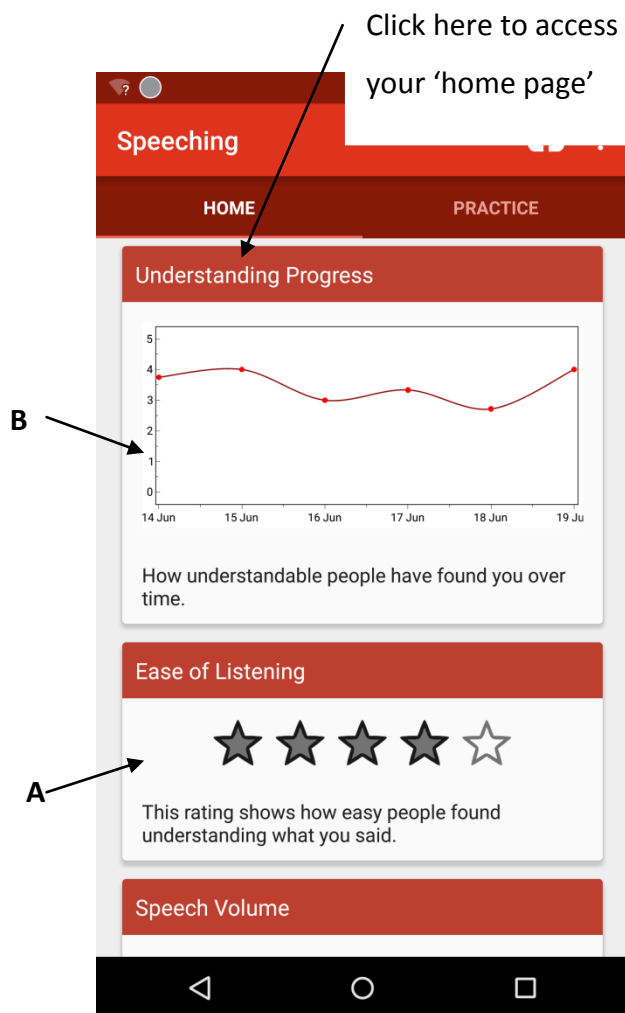


Don't worry about this message, we have fitted your phone with a pre-paid sim card.

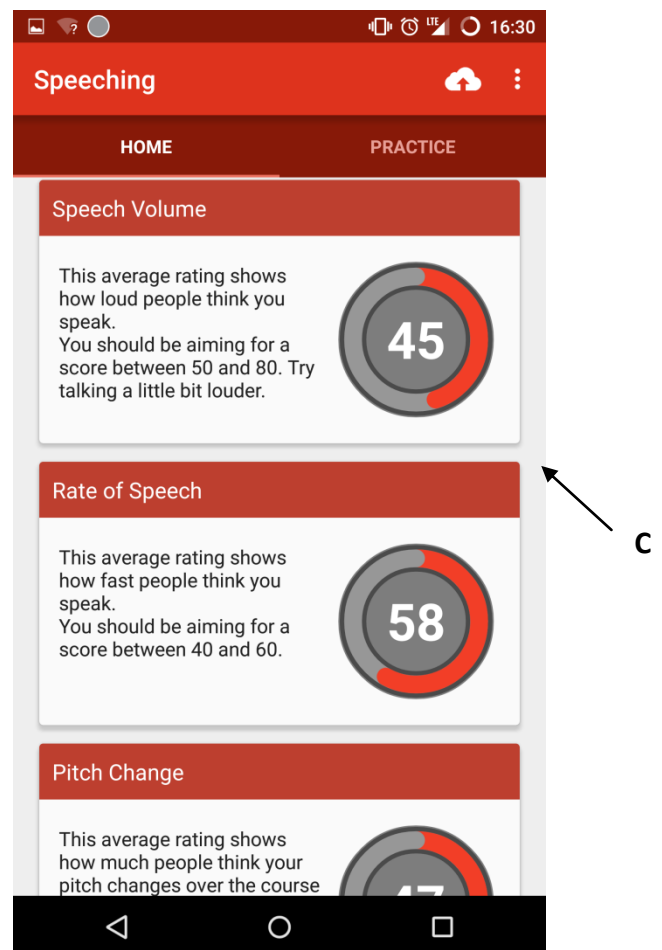
Click 'start uploading'

Viewing your results

Once you have uploaded your assessment it will be given to the crowd for analysis. After approximately 1 hour you should receive some results which can be viewed on your 'home page'.



Picture 1



Picture 2

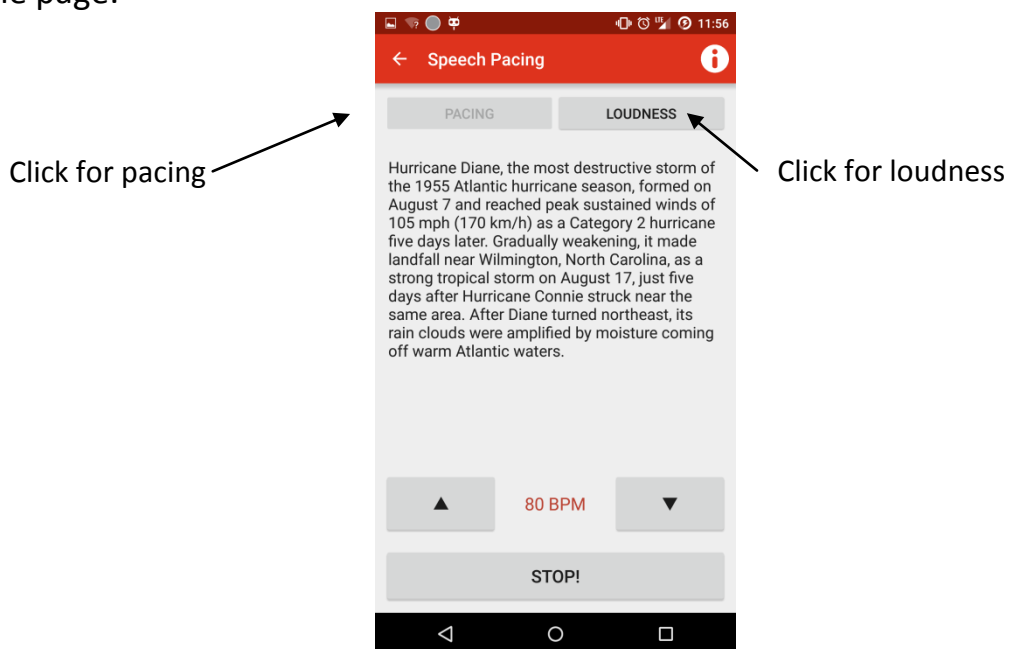
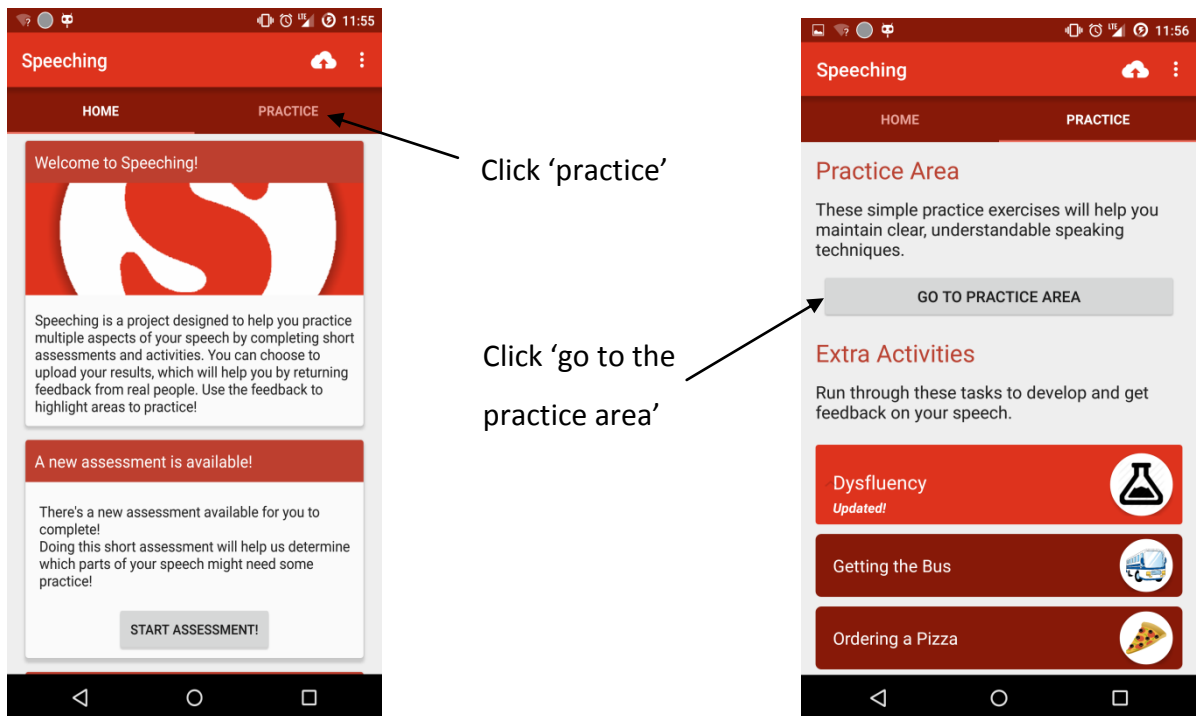
There are several things that the crowd have rated.

Picture 1: A) how easy you were to understand overall and B) how this rating has changed over time (the more assessments you submit the more this graph will be filled).

Picture 2: C) The score out of 100 that you received for volume, rate and pitch. The range you should aiming for will be clearly stated.

Practicing your speech

To enter the practice area tap the practice button, and then 'go to practice area'



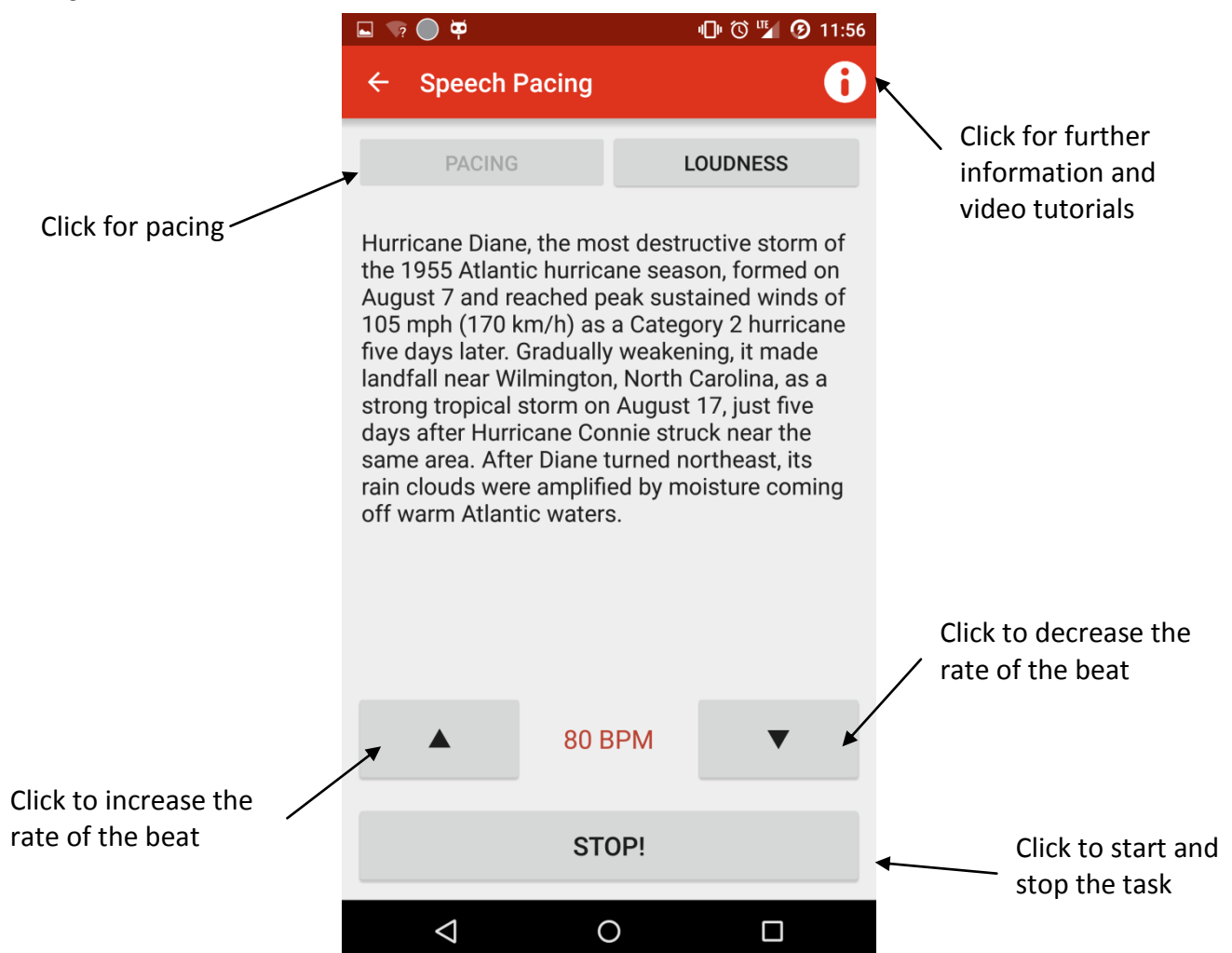
Practicing pacing your speech

In this task you will see a passage to read. In order to help you slow your speech down and speak in a clearer voice there is a beat, which you can read along to.

There are two ways to do this. If you want to begin getting use to slowing your speech down then you can read syllable by syllable (e.g. what-time-will-the-train-be-come-ing).

Once you are able to do this, you can try using a more natural beat (e.g. what TIME will the TRAIN be COMING) placing stress on the key words. You can set the speed of the beat to be slower or faster depending on your preference and ability.

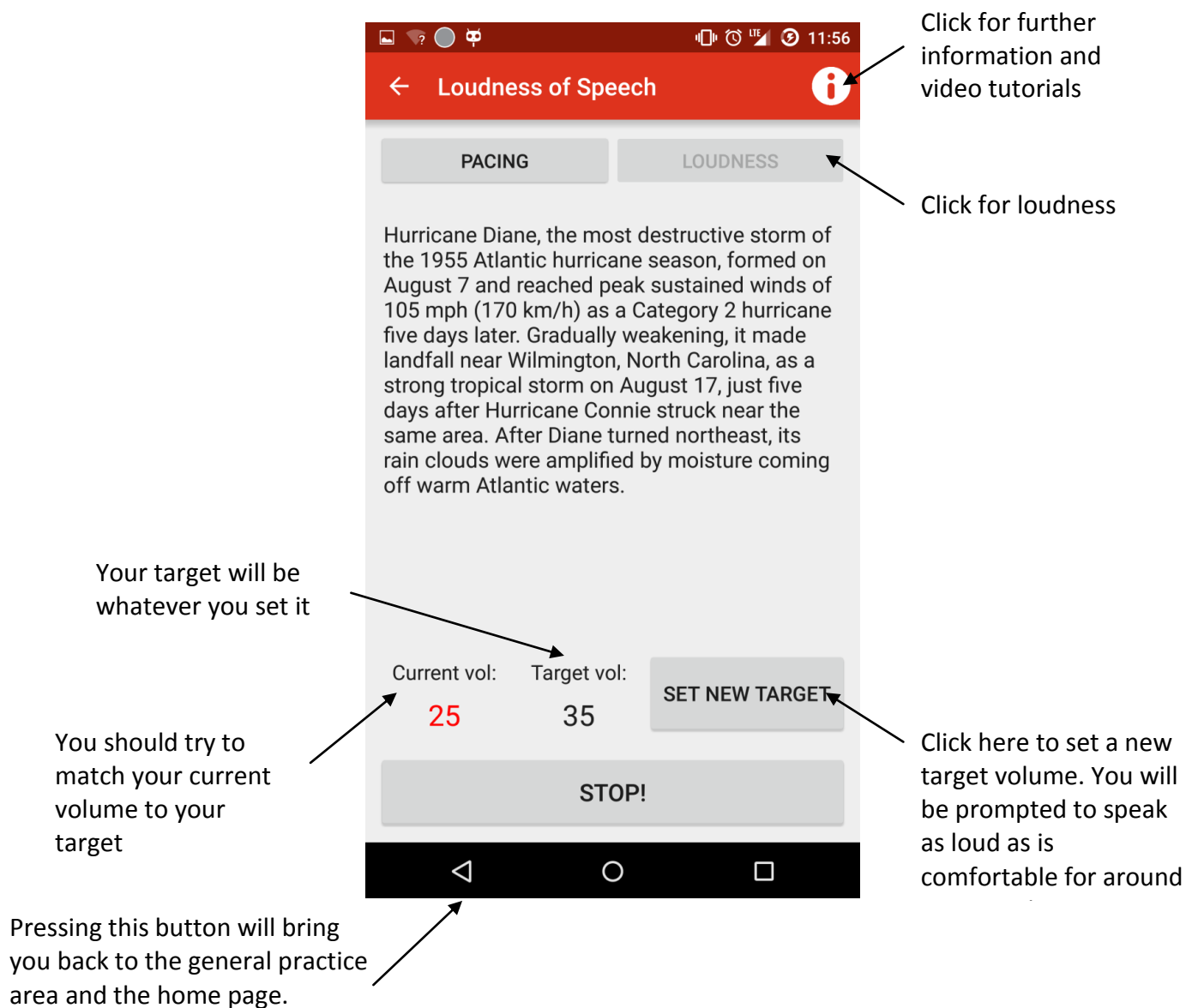
Clicking the information button will provide you with further information of what to do, and a set of video tutorials to watch, which will show you the two types of pacing that were metioned above. The start and stop button at the bottom will start and stop the beat. Your voice will also be recorded (but not uploaded) at this time, so you can listen back to your attempt if you wish.



Practicing increasing your loudness

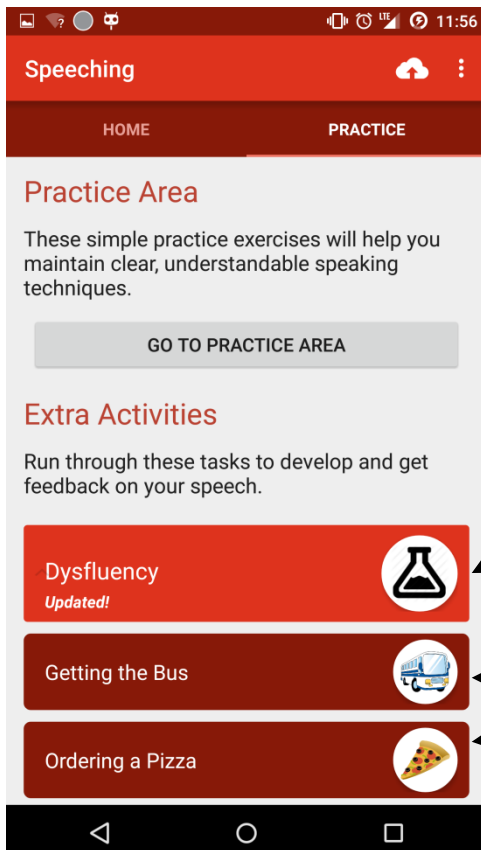
In this task you will see the same passage to read. This task aims to help you try to reach a target volume (which you can set depending on your own ability) and maintain it.

The target you have set is displayed under target volume. You should aim to reach this target volume by getting your current volume to match, or be louder than the target. When you reach the target the current volume number will go green. Clicking the information button will provide you with further information of what to do, and a set of video tutorials to watch. The start and stop button at the bottom will start and stop the application looking for your volume. Your voice will also be recorded (but not uploaded) at this time, so you can listen back to your attempt if you wish.



Extra practice (these can be uploaded for analysis if you wish)

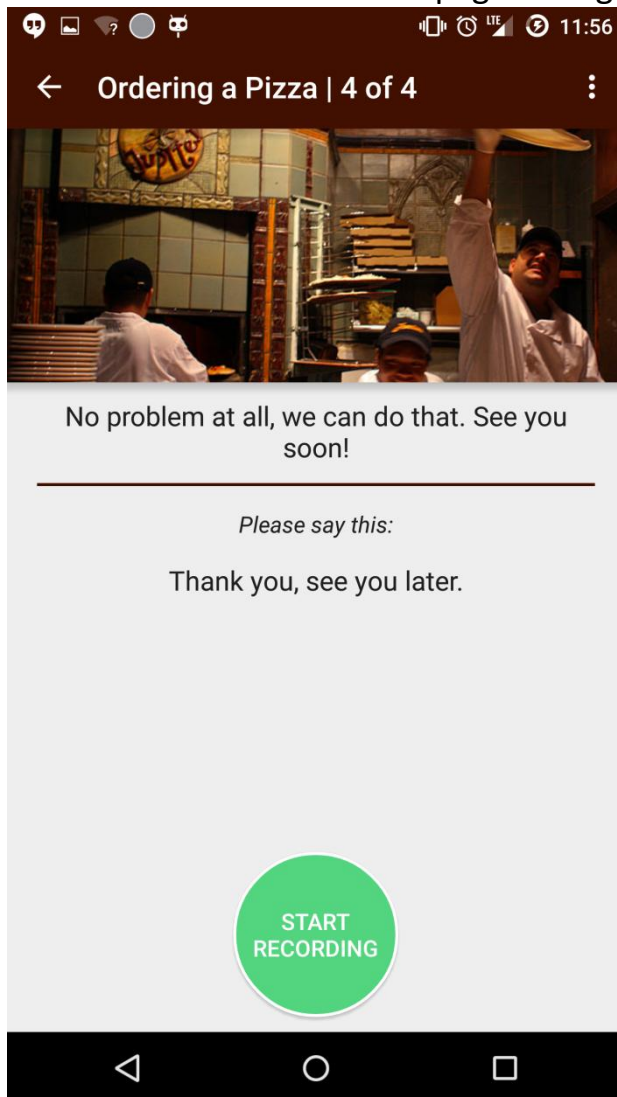
Once you have finished practicing your skills you might like to try them in a more conversational setting. There are couple of additional practice tasks that can be completed and uploaded for analysis if you wish. These take the form of every day scenarios.




This one does not
work unfortunately

Click for extra
practice scenarios

These tasks are similar to the assessment tasks. Simply press the start/stop button at the bottom of the page to begin and end your recording.



Once you have finished, there will be a little button at the top of the page that

looks like this  this is the upload button. If you would like additional feedback on these practice tasks feel free to upload them for analysis.

Good luck, have fun and remember, any problems, do not hesitate to call:

07843 157 367

3f) Speeching crowd task screenshots

Word recognition task

Instructions

Please listen to the audio clip(s) and complete the following tasks, making sure that your computer's volume is loud enough to hear the voice samples clearly

0:02

Choose the word that is closest to what you can hear

☐ Heap

☐ Cop

☐ Cape

☐ Hub

☐ Sheep

☐ Keep

☐ Cup

☐ Cub

☐ Carp

☐ Coop

☐ None of the above

How hard was it to understand the person in this clip?

1

2

3

4

5

☐

☐

☐

☐

☐

Please give a rating where 1 is 'I understood everything' and 5 is 'I couldn't understand a thing they said'

How much did the person's accent affect how easy they were to understand?

1

2

3

4

5

☐

☐

☐

☐

☐

Please give a rating where 1 is 'Not at all' and 5 is 'Their accent was so broad I couldn't understand a thing'

Volume rating

Below you will hear two sentences being spoken. Press the play buttons in each box (1 and then 2) to hear them separately. The second one is the person's previous upload - think about how the person was talking in sentence 1 compared to sentence 2.



The score representing the average loudness of the person's voice the last time they submitted a recording for analysis was 50, where 0 is 'so quiet I could barely hear them' and 100 is 'very loud'. We are looking to see if there is a change.

Please enter a number from 0-100 indicating how loud you felt the first sentence was, where 0 is 'so quiet I could barely hear them' and 100 is 'very loud'

Please enter a number between 0-100, using the previous score given to the second recording as a comparison

Did the volume change over the course of the first sentence?

- ☐ No, it stayed the same
- ☐ It got louder as the sentence went on
- ☐ It got quieter as the sentence went on

Rate rating

The score representing the average speed of the person's voice the last time they submitted a recording for analysis was 50, where 0 is 'very slow' and 100 is 'So fast I could barely understand them'. We are looking to see if there is a change.

Please enter a number from 0-100 indicating how fast you felt the person in the first sentence was talking, where 0 is 'very slow' and 100 is 'So fast I could barely understand them'.

● Please enter a number between 0-100, using the previous score given to the second recording as a comparison

Did the speed change over the course of the first sentence?

- ☐ No, it stayed the same
- ☐ It got faster as the sentence went on
- ☐ It got slower as the sentence went on

Pitch rating

Think about how much the person's pitch varied in sentence 1 compared to sentence 2. (Pitch refers to the ups and downs in a person's voice which give it feeling. Someone with a varied pitch might sound excited and interested, someone with little change to their pitch might sound monotonous or bored)

The score representing how much the person's pitch varied in their voice the last time they submitted a recording for analysis was 50, where 0 is 'not at all, they spoke with a monotonous voice and sounded bored' and 100 is 'a lot, they sounded excited and interested'. We are looking to see if there is a change.

Please enter a number from 0-100 indicating how much you felt the pitch in the first sentence varied, where 0 is 'is not at all, they spoke with a monotonous voice and sounded bored' and 100 is 'a lot, they sounded excited and interested'

● Please enter a number between 0-100, using the previous score given to the second recording as a comparison

Did the pitch change over the course of the sentence?

- ☐ No, it stayed the same
- ☐ It got more excited as the sentence went on
- ☐ It got more bored as the sentence went on

3g) Speeching word lists

**Was
One
Fall
What
Wash
Waltz
Wool
Watts
Wad
Want**

**Cub
Coop
Cup
Carp
Keep
Sheep
Cape
Heap
Cop
Hub**

**Bun
Moon
Budge
Botch
Bond
Buzz
Bus
Bowl
But
Boss**