



PHD

TOWARD BETTER HEALTH COMMUNICATION AMONG DEAF PEOPLE: A MIXED METHODS APPROACH TO UNDERSTANDING THE FEASIBILITY AND EFFICACY OF A NOVEL MHEALTH VIDEOCONFERENCING TOOL

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TOWARD BETTER HEALTH COMMUNICATION AMONG DEAF PEOPLE: A MIXED
METHODS APPROACH TO UNDERSTANDING THE FEASIBILITY AND EFFICACY
OF A NOVEL MHEALTH VIDEOCONFERENCING TOOL

Elizabeth Kaplunov

A thesis submitted for the degree of Doctor of Philosophy

University of Bath

Department for Health

April 2019

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ABSTRACT

Deaf people experience healthcare communication issues due to a lack of British Sign Language interpreters and health staff overly relying on written information (Henning et al., 2011; Reeves & Kokoruwe, 2005; Smeijers & Pfau, 2009). These communication issues negatively affect Deaf people's health access, outcomes and motivation (Atkinson & Woll, 2012; Emond et al., 2015a; lezzoni et al., 2004). mHealth interventions for Deaf people were shown to be as effective as face-to-face methods, whilst also helping to reduce costs (Blaiser et al., 2013; Wilson et al., 2015). The present thesis analyses the effects of a new Deaf videoconferencing intervention (InterpreterNow), which was created following a survey about Deaf health needs (Emond et al., 2015a, 2015b). Self-Determination Theory (STD; Deci & Ryan, 2000) was used to examine underlying mechanisms for how Deaf attitudes and motivation in healthcare settings could change due to InterpreterNow use. In Study 1, the appropriateness of SDT for explaining Deaf health motivations was analysed. In Study 2, a waitlist randomised controlled trial was conducted with the aim of examining the changes in healthcare access and communication of Deaf people before and after using InterpreterNow. Study 3 included qualitative interviews and focus groups with British Sign Language interpreters, health professionals and deaf people, which were conducted to gain detailed insight into benefits and issues of InterpreterNow use. Lastly, Study 4 was a feasibility study about the demand for InterpreterNow, how acceptable InterpreterNow was and running costs. Deaf people who were interested in using online methods for health communication found the service particularly useful for making appointments as well as during brief appointments. It was also found that motivation, communication and access were improved by InterpreterNow and that InterpreterNow use supported cost reduction. Lastly, the thesis highlighted individual differences in Deaf people's communication preferences.

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CHAPTER 1: REVIEW OF LITERATURE

1.1 Introduction to the Review

The World Health Organisation (WHO) provides a classification of disability called International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). This WHO classification defines disability as limited functioning because of one's health condition as well as environmental effects (WHO, 2011). People living with a disability experience health inequality with more unmet healthcare needs within healthcare settings than the general population (for example: Emond, Ridd, Sutherland, Allsop, Alexander, & Kyle, 2015b; Alexander, Ladd, & Powell, 2012; Nocon & Sayce, 2008). Health inequality can result in a range of negative health outcomes for disabled groups such as: increased risk of heart disease, respiratory disease, obesity, and mental health issues (Nocon & Sayce, 2008; Elliot, Hatton & Emerson. 2003; Emond et al., 2015b; Disability Right Commission, 2006). In addition, health inequity can result in disabled people's health experiences being negatively affected that leads to low health knowledge, limited access to services, and negative effects on relationships with healthcare staff and confidence within healthcare settings (Mastebroek, Naaldenberg, Lagro-Janssen, van Schrojenstein Lantman de Valk, 2014; Alexander et al., 2012; Ubido, Huntington, & Warburton, 2002). Deaf people represent one group defined as living with a disability and experience health inequality and compromised health communication (Emond et al., 2015b). Deaf people are the population that this thesis is largely focused on.

Good communication between patients and healthcare staff has been shown to have positive effects on health and emotional outcomes such as more satisfaction during the healthcare interactions, increased health knowledge, better treatment regimen adherence, reduction in hospitalisations, faster symptom resolution, lower blood pressure and greater pain control (Stewart, Meredith, Brown, & Galajda, 2000; Stewart, 2001; De Jong, Ros, & Schrijvers, 2014). According to a report by Marie Curie charity (McDonald & Sherlock, 2016), poor communication costs £1 billion due to poor adherence to medication regimens, unnecessary repeat visits and disagreements between patients

and healthcare staff. Therefore, improvements in communication has been a strategic priority by the NHS since 2011 (McDonald & Sherlock, 2016). High quality communication can help to reduce financial burden, improve health outcomes, and patients' healthcare experiences (McDonald & Sherlock, 2016). Furthermore, the report shows that patients actively want to be engaged in decisions made about their health.

The first part of this literature review therefore, focuses on further clarifying definitions of communication, access and inequity for disabled people, as well as how different communication approaches affect health outcomes. Subsequently, Deaf healthcare access and communication will be considered along with existing non-technological health interventions. The review is focused on Deaf people as they have particular issues related to their preferred method of communication not being employed within healthcare settings (i.e., British Sign Language). Healthcare staff often communicate to Deaf people in English or through writing (Emond et al., 2015b; Alexander et al., 2012; McKee et al., 2011). Therefore, Deaf people, are at particular risk of experiencing communication issues in healthcare settings.

Health interventions have been used to try and improve health outcomes for deaf people. Non-technological health interventions for Deaf people have led to some improvements in health outcomes, as well as behaviour change maintenance and better health knowledge. (Choe et al., 2009; Harry et al., 2012; Jensen et al., 2013; Kaskowitz et al., 2006; Sacks et al., 2013; Shabaik et al., 2010; Yao et al., 2012; Zazove et al., 2012; Barnett et al., 2014; Garnefski & Kraaij, 2011; Taegtmeyer et al., 2009). However, non-technological interventions have been limited in terms of participant numbers, length of the study, poor methodological rigor and too many communication options for Deaf people, as well not accounting for Deaf participants' literacy levels. A solution to some of the limitations to non-technological interventions may lie in mHealth ("health care and public health practice supported by mobile devices", (p. 1, Hamine, Gerth-Guyette, Faulx, Green & Ginsburg, 2015)). mHealth allows more flexibility in terms of how and when Deaf people can communicate within healthcare settings. This may help to improve Deaf people's health knowledge, treatment access, health literacy, treatment engagement and health outcomes (Price, Yuen, Goetter, Herbert, Forman, Acierno, & Ruggiero, 2016). According to a review conducted by Hamine and colleagues (2015), around 75% of the world population has access to mobile phones, and mobile technology is already used in

healthcare for collecting data, monitoring, patient education and to facilitate adherence to treatment. Research has also shown that mHealth interventions are successfully used by adults who have diabetes, multiple sclerosis, cancer and chronic obstruction of pulmonary disease (Hamine et al., 2015; Griffin & Kehoe, 2016).

Videoconferencing has been shown to be effective in improving health outcomes and supporting positive health experiences for a range of disabled groups. Videoconferencing can be used to deliver information, provide therapy and advice, remote monitoring and follow-up care via mobile phones, tablets or computers (Bradbury, Patrick-Miller, Harris, Stevens, Egleston, Smith, Mueller, Brandt, Stopfer, Rauch, Forman, Kim, Fetzer, Fleisher, Daly, Domchek, 2016). Videoconferencing is one of the most common intervention delivery methods identified in a WHO survey (Kay, Santos, & Takane, 2011). For instance, videoconferencing has been used by the following disabled populations: people living with PTSD (Egede, Acierno, Knapp, Lejuez, Hernandez-Tejada, Payne, & Frueh, 2015; Morland, Pierce, & Wong, 2004; Tuerk, Yoder, Ruggiero, Gros, & Acierno, 2010; Yuen, Gros, Price, Zeigler, Tuerk, Foa, & Acierno, 2015), depression (Choi, Marti, Bruce, Hegel, Wilson, & Kunik, 2014; Moreno, Chong, Dumbauld, Humke, & Byreddy, 2012; Ruskin, Silver-Aylaian, Kling, Reed, Bradham, Hebel, & Hauser, 2004), cardiovascular disease ((Chumbler, Quigley, Li, Morey, Rose, Sanford, Griffiths, & Hoenig, 2012; Cikajlo, Rudolf, Goljar, Burger, & Matjačić, 2012; Vitacca, Bianchi, Guerra, Francchia, Spanevello, Babi, & Scalvini, 2009; Gellis, Kenaley, & Have, 2014), multiple sclerosis (Finlayson, Preissner, Cho, & Plow, 2011; Zissman, Lejbkowitz, & Miller, 2012), and physical disabilities (Huijgen, Vollenbroek-Hutten, Zampolini, Opisso, Bernabeu, van Nieuwenhoven, & Marcellari, 2008; Sanford, Griffiths, Richardson, Hargraves, Butterfield, & Hoenig, 2006). Videoconferencing may also be effective for deaf people, due to its frequent use within this population over 15 years as it allows the visual format of sign language to be employed (a visual mode of delivery) (Wilson & Schild, 2014).

However, the evidence about mHealth access, use and acceptability is mixed as a review shows that the disabled populations were under-represented in mHealth intervention studies (Jones, Morris, & Deruyter, 2018a). According to Jones et al., (2018a), only a small number of mHealth interventions are available to disabled people, most of which did not affect health outcomes. The disabled people that did use the mobile health applications (17% of all disabled people, according to Jones et al., 2018a), were

using fitness and activity tracking apps the most (Jones, Morris, & Deruyter, 2018b). Therefore, there is a lack of evidence concerning how Deaf people (and indeed, all disabled people) might benefit from the use of videoconferencing in healthcare setting. The present literature review aims to pull together the existing literature in order to synthesize the literature on videoconferencing as a means of improving healthcare communication and access of the disabled people, with an additional detailed review of videoconferencing interventions for Deaf population. This review is divided into two sections. First, evidence showing that healthcare communication and access lead to positive health outcomes for Deaf people. Second, an overview of current uses and efficacy of videoconferencing in health interventions for disabled populations in general and Deaf populations more specifically.

1.2 COMMUNICATION AND ACCESS

1.2.1 DEFINITIONS AND GUIDELINES OF HEALTHCARE ACCESS AND COMMUNICATION.

Healthcare access is defined as “the degree to which [patients] are able to obtain needed services from the medical system” and “the timely use of personal health services to achieve the best possible outcome” (Sudore, Mehta, Simonsick, Harris, Newman, Satterfield, Rosano, Rooks, Rubin, Ayonayon, & Yaffe, 2006; p.1). Epidemiological studies suggest that there are three indicators of healthcare access, namely; access to primary care, access to preventative services, and access to medications (Baker, Gazmararian, Williams, Scott, Parker, Green, Ren, & Peel, 2004; Baker, Shapiro, & Schur, 2000; de Rekeneire, Rooks, Simonsick, Shorr, Kuller, Schwartz, & Harris, 2003; Holcombe & Griffin, 1993; Scott, Gazmararian, Williams, & Baker, 2002; Sudore et al., 2006). To achieve healthcare access, patients must be able to be admitted into the healthcare system, find the necessary health services within travelling distance and have a healthcare professional with whom they are able to have a trusting relationship and feel comfortable communicating (Agency for Healthcare Research and Quality, 2016). Notably, this standard definition highlights the central role of health communication in healthcare access and therefore health.

Health communication appeared as a health improvement objective in the Healthy People 2010 report (Centre for Disease Control, 2010). Within the Healthy People 2020 objectives, health communication appears together with health information technology, which reflects the increased use of mobile health applications and information sharing between providers (DeSalvo, 2015; Moorhead, Hazlett, Harrison, Carroll, Irwin, & Hoving, 2013). In the United Kingdom (UK) in 2004, just 1.6% of adults used a mobile phone (Ofcom, 2015a). This increased to 65% of adults in 2015 (Ofcom, 2015a) and to 72% in 2017 (Ofcom, 2017). As such, communication channelled through mobile technology is a highly salient aspect of modern health communication and access.

Health communication can be doctor-centred or patient-centred. Doctor-centred communication is more traditional and tends to involve a physician who makes unilateral decisions and is focused on disease and the body (Hall, Roter, & Junghans, 1995). On the other hand, patient-centred communication involves healthcare staff paying attention to the needs and preferences of patients. This includes the physician communicating in a way which will support patients to be actively involved in their care and to encourage patients to feel that the doctor and the patients are mutual partners in the shared decisions being made about their health in a “whole person” approach (Hall et al., 1995; Hibbard, Stockard, Mahoney, & Tusler, 2004; Saha, Beach, & Cooper, 2008).

The patient-centred approach is preferred if better health outcomes are to be achieved and maintained. The mechanism of the relationship between patient-centred communication style and health outcomes has been shown to follow an indirect pattern (Street, Makoul, Arora, & Epstein, 2009). Patient-centred communication leads to patient understanding, as well as trust and agreement between the doctor and the patient. These factors then positively affect more immediate outcomes such as better self-care skills of the patients. The immediate outcomes, in turn, impact on better health outcomes. Street et al. (2009) highlight that communication can improve health through patients gaining better access to care, increased patient health knowledge, better relationships between doctors and patients as well as more empowerment for patients.

The above mechanism is supported by a review of 21 studies (Stewart, 1995). In the review, the participants were patients with different illnesses (such as peptic ulcers, breast cancer, diabetes, hypertension, headache, breast cancer, coronary artery disease, gingivitis, tuberculosis, prostate cancer). Studies about patients with less acute symptoms (such as women at gynaecologist appointments and GP surgery patients) were also included. Studies were focused on communication during doctors taking patient history as well as doctors and patients discussing the management plan. Stewart (1995) found that if the physicians used the patient-centred communication style, patients' health outcomes were more likely to be positive. The positive health outcomes included: emotional health, symptom reduction, better pain management and better daily functioning. This review shows a relation between patient-centred communication and better outcomes for patients with different illnesses. The patients experienced different levels of illness/symptom severity as well as being based at study sites across different services (for instance, GP surgeries, hospitals, gynaecology practices and outpatient clinics). Stewart (1995) suggests that patient-centred communication includes the physician asking patients about their feelings and worries, therapy expectations, helping patients to formulate decisions about the management plan, encouraging patients to ask questions, providing emotional support and clear information about treatments and medication. Therefore, there is clear evidence of the link between patient-centred approaches to health communication and better health.

Complementing the work of Stewart (1995), in the UK, the National Health Service (NHS) has focused on healthcare access equality since 1948 (Goddard & Smith, 2001). National Institute for Health and Care Excellence (NICE, 2012) provides a guidance document for improved healthcare access in the UK. This report is titled "Patient experience in adult NHS services: improving the experience of care for people using adult NHS services" (Clinical Guidance CG138). The clinical guidance document is focused on five aspects: patient as an individual, care requirements, tailoring healthcare, continuity of care and enabling active patient participation. NICE advocates a patient-centred approach and the health communication guidance is provided within the guidance on healthcare access. In all, evidence from both research and practice shows that health communication is critical to health outcomes, provided that such communication is patient-centred. There are five key aspects of patient-centred provision are: (a) patient as an individual, (b) care requirements, (c) tailoring healthcare

services, (d) continuity of care, and (e) active patient participation (NICE, 2012). A description of each follows:

PATIENT AS AN INDIVIDUAL.

In order to provide patient-centred communication, healthcare staff should be attuned to several key criteria for treating patients as individuals (NICE, 2012). These are: (a) knowledge of the individual experience of the condition by the patient, (b) understanding physical or learning disability-based needs, or any other difficulties with understanding English, (c) awareness of domestic, work, social situations, and previous experience of healthcare, (d) listening to patient views and complaints, and (e) not making any assumptions about patients based on personal characteristics and accounting for the Equality Act 2010 in regard to accessible services and discussing patients' needs for any psychological, social and financial support.

CARE REQUIREMENTS.

There are also several care requirements for patient-centred communication. These are key to providing a high level of care and equal access, and encapsulate: (a) respecting the patient, (b) dealing with concerns in a sensitive and non-judgemental manner, (c) receiving training on and implementing actions related to the importance of nutrition, (d) pain management and meeting personal needs, (e) providing patients with independence support, and (f) obtaining patients' informed consent and assessing the patients' capacity of giving consent.

TAILORING HEALTHCARE SERVICES.

Tailoring is equally central to patient-centred communication. To tailor healthcare services to the individual, healthcare professionals should take (a) personal preferences and ability to access services into account, (b) allow enough time for discussions and encourage patients to express their needs and preferences about care, and (c) involve family members or carers with the patients' consent and respond to any feedback provided.

CONTINUITY OF CARE.

There is also a need for continuity of care when communicating in a patient-centred manner. The criteria for providing continuity of care are: (a) healthcare staff should assess patient needs, (b) ensure effective coordination between services, (c) introduce themselves to the patient, (d) let the patient know about different roles of their care team, and (e) provide information for dealing with an “out of hours” emergency.

ACTIVE PATIENT PARTICIPATION.

Finally, active patient participation in healthcare is fundamental to patient-centred communication. When patients participate actively in their healthcare, health staff; (a) ensure adequate, clear, and supportive communication, (b) provide patients with information in accessible formats, (c) solicit shared decision making by explaining the aims of treatment and allowing the patient to express their needs or concerns, and (d) provide evidence-based and appropriate patient education programmes.

CONCLUSION.

In conclusion, the current guidance document (NICE, 2012) presents the key factors for providing equal and appropriate access to healthcare. It is of note that health communication is presented as a key part of obtaining health access, in concordance with health access and communication definitions. Another message of the guidance document concerns the importance of patient-centred focus in healthcare settings for improved outcomes.

1.2.2. EFFECTS OF GOOD AND POOR ACCESS AND COMMUNICATION.

The above review highlights the importance and components of patient-centred communication, but what is the evidence for this approach in terms of health outcomes? Research suggests that health can be affected by health communication and access to

healthcare. Health communication and healthcare access affect illness prevention and health promotion (Rimal & Lapinski, 2009). Good levels of communication and access can help to reduce the rates of disability and death as well as to improve the overall life quality and ensure health equity (Rimal & Lapinski, 2009). Poor healthcare access and communication lead to negative health effects. Research has shown that people receive around 55% of care that has been recommended by healthcare professionals when access and communication are suboptimal (Asch, Kerr, Keeseey, Adams, Setodji, Malik, & McGlynn, 2006; Kerr, McGlynn, Adams, Keeseey, & Asch, 2004; McGlynn, Asch, Adams, Keeseey, Hicks, DeCristofaro, & Kerr, 2003).

In terms of health communication, different effects on outcomes of doctor-patient compared to patient-centred communication styles have been found. Doctor-centred or paternalistic communication has been shown to involve less actively participating patients, to result in less doctor-patient partnership building, as well as more health-related problems such as doctors withholding treatment, delays in treatment, frustration and low satisfaction of patients, and increased rehospitalisation (Bradley, Sparks, & Nesdale, 2001; King & Hoppe, 2013; Street, Krupat, Bell, Kravitz, & Haidet, 2003; van Ryn & Fu, 2003). However, if the doctor communicated in a patient-centred manner and was focused on the behavioural, psychological, physical and social aspects of the illness, better outcomes were obtained. Examples of good outcomes shown in research include: patients expressing their concerns and opinions openly, improved health outcomes (better mental and emotional health, symptom improvement, lower blood pressure, more pain control), patients feeling more confident in their doctors and being more willing to accept treatment, and higher patient satisfaction (Cousin, Mast, Roter, & Hall, 2012; Krupat, Rosenkranz, Yeager, Barnard, Putnam, & Inui, 2000; Saha & Beach, 2011; Stewart, 1995; Street et al., 2003). Based on the evidence, it appears that when healthcare staff communicate in a patient-centred way, better health outcomes can be obtained compared to doctor-centred communication.

It should be noted that, the current evidence base is limited as it is more focused on the communication styles employed by doctors and there is sparse evidence about the communication styles of allied health professionals. Yet, a review of 7 studies (Charlton, Dearing, Berry, & Johnson, 2008) found that allied health professionals (nurse practitioners) were likely to use patient-centred communication. The study

designs in the review were descriptive pre-post study, correlational study, randomized and non-randomised trials. Therefore, investigating the communication of allied healthcare professionals in more detail could be useful, as evidence from allied healthcare professionals could confirm the reasons why this population is more likely to use patient-centred communication with patients compared to doctors.

People with low access to healthcare may especially benefit from patient-centred communication. This is because they are more likely to have limited health literacy and health knowledge, more hospitalisations, and to have a range of illnesses such as diabetes mellitus and depression as well as poor self-rated health (Bindman, Grumbach, Osmond, Komaromy, Vranizan, Lurie, Billings, & Stewart, 1995; Raso, Utzinger, Silue, Outtara, Yapi, Toty, Matthys, Vounatsou, Tanner, & N'goran, 2005; Sudore et al., 2006). Disabled patients, in particular, experience more barriers to obtaining healthcare access than the general population due to their specific needs (Davis & O'Brien, 1996; Long, Coughlin, & Kendall, 2002). Barriers include communication with staff, time constraints, care coordination, transportation, physical environment, cost of services, equipment and treatments, the insufficient awareness of disability shown by staff, staff not taking patients seriously, and staff being unwilling to provide care and showing little respect for patients (Drainoni, Lee-Hood, Tobias, Backman, Andrew, & Maisels, 2006). The consequences of low access for disabled people are social (such as impact on relationships with family and friends and lack of social participation), psychological (depression, stress and feeling devalued), physical (worse health and less ability to do activities), economic (financial strain, extra costs for health services) and issues related to being more dependent on others (Kroll & Neri, 2009). Conversely, better access has been linked with patients' health awareness, higher satisfaction, higher likelihood of seeking treatment, fewer hospitalisations and less emergency services use, as well as better health (Ansari, Laditka, & Laditka, 2006; Fenton, Jerant, Bertakis, & Franks, 2012).

In England, the cost of treating patients due to health inequality is estimated to be £5.5 billion (NICE, 2012). Disabled people are more likely to experience health inequity than the general population (Barnett, McKee, Smith, & Pearson, 2011; Beange & Durvasula, 2001; Cooper, Melville, & Morrison, 2004; Sakellariou & Rotarou, 2017; Ubido et al., 2002). According to the World Health Organization (WHO, 2018), disabled

people have more unmet needs, with up to 50% of disabled people in developed countries and up to 85% of disabled people in developing countries not receiving necessary mental health treatment. The WHO (2018) documentation also suggests that disabled populations are more vulnerable to secondary, co-morbid, age-related conditions, higher premature death rates and are more likely to engage in health risk behaviours such as smoking or physical inactivity. WHO (2018) highlighted the following barriers: high costs on services and transport, physical barriers such as building access and finally, lack of awareness of healthcare staff. According to a NICE (2012) report titled "Health inequalities and population health", tackling health inequality can support service cost reduction, reduce premature death, promote symptom improvement, and create happier and healthier communities.

1.2.3 HEALTHCARE ACCESS AND COMMUNICATION FOR DEAF POPULATION.

One disabled population with particular healthcare needs in terms of health communication is the Deaf population. Deaf people have similar issues in terms of healthcare access to other disabled people, but also have needs related to deafness. Research has shown that Deaf people experience worse healthcare access than the general population (Emond et al., 2015b; Fellingner, Holzinger, & Pollard, 2012; Kyle, Sutherland, Allsop, Ridd, & Emond, 2013; Royal National Institute for Deaf, 2004). Good healthcare experiences of Deaf people include the provision of qualified medically experienced British Sign Language interpreters, being able to communicate in their preferred way, good relationships with British Sign Language interpreters and staff (for instance, when staff have a warm demeanour and hold eye contact), staff awareness of Deaf needs (for instance, using simple words and diagrams, short sentences and proving more time for appointments, checking comprehension), as well as staff being aware of the limited health knowledge and literacy of Deaf people, and being able to use fax and text messaging (Deaf people found it easy and immediate) (MacKinney, Walters, Bird, & Nattinger, 1995; Middleton, Turner, Bitner-Glindzicz, Lewish, Richards, Clarke, & Stephens, 2010; Patel, Gill, Chackathayil, Ojukwu, Stemman, Sheldon, Meelu, Lane, Tracey, Lip, & Hughes, 2011; Pollard & Barnett, 2009; Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006). Positive outcomes of good healthcare experiences involve compliance with treatment, higher use of preventative service, as well higher appointment and communication satisfaction levels, and improved preventative

outcomes (more likely to receive pap tests, mammography and rectal examinations in the last three years) (Fellinger et al., 2012; MacKinney et al., 1995; Middleton et al., 2010; Steinberg et al., 2006).

Poor healthcare experiences for Deaf people include Deaf people not being able to communicate to use their preferred method of communication, issues when attempting to contact healthcare services (difficult to make contact with GP/health centre, unhelpful receptionists at health centres, being unable to make contact online/by text), lack of available British Sign Language interpreters, lack of two-way communication with healthcare staff, doctors being poor at listening, not having trust or confidence in their doctor, feeling frustrated or embarrassed during appointments, poor Deaf awareness of staff, not being alerted for their turn in waiting rooms, loss of privacy and independence when family members or friends translate during appointments, and having to use speech intercoms (Emond, Ridd, Sutherland, Allsop, Alexander, & Kyle, 2015a; Kyle, Allsop, Clarke, Reilly, & Dury, 2005). The outcomes of negative health experiences appear to include a lack of understanding and awareness of chronic conditions, treatment non-adherence, and worse health outcomes (higher rates of obesity, higher blood pressure, inadequate control of hypertension, higher cholesterol, increased cardiovascular disease rates, blood sugar at pre-diabetic or diabetic levels, more mental distress, more depression and anxiety symptoms (Emond et al., 2015b; Fellinger et al., 2012; Kvam, Loeb, & Tambs, 2007; Pollard & Barnett, 2009). In a study on the mental health in the Deaf population, it was similarly highlighted that when Deaf people (participants became Deaf after acquiring speech) experienced communication issues and less acceptance of hearing loss in mental health services, they were more likely to have lower self-esteem and more mental distress (around 33%) than the general population (de Graaf & Bijl, 2002). One of the key facilitators for improving Deaf access and healthcare outcomes may be patient-centred health communication within commonly used technologies (Kuenburg, Fellinger, & Fellinger, 2016). It is to these topics that the attention now turns.

1.2.4 HEALTH INTERVENTIONS FOR THE DEAF POPULATION.

INTRODUCTION.

Mental health, obesity, HIV and cancer are some of the largest causes of mortality and illness in the world (WHO, 2016, 2018). Deaf populations have a larger prevalence of these issues than the general population. For instance, 39-42% of the Deaf population experience depression and anxiety (Landsberger, Diaz, Spring, Sheward, & Sculley, 2014), but only 5% of the general population do (WHO, 2017). It has also been found that obesity (BMI over 30) is more prevalent in the Deaf population compared to the hearing population. Studies have shown that 30-34% of Deaf participants (Barnett, Klein, Pollard, Samar, Schlehofer, Starr, Sutter, Yang, & Pearson, 2011; Emond et al., 2015) are obese compared to 23-27% of the general population (Health Survey for England, 2011). In terms of HIV, evidence suggests that Deaf populations are twice as likely to have HIV (1.6%) (Hanass-Hancock & Satande, 2010) compared to 0.8% of adults in the general population (which equals to 34.9 million people) (The Joint United Nations Programme on HIV/AIDS, 2017). Whilst prevalence rates for cancer are not available for Deaf populations, a study estimated Deaf people are at least as likely as hearing people to have cancer (Woodcock & Pole, 2007). Therefore, as the worldwide cancer prevalence of the overall population is 18 million a year (Bray, Ferlay, Soerjomataram, Siegel, Torre, & Jemal, 2018), it might be surmised that the Deaf population prevalence rates are considerable.

Deaf people experience inequity in terms of health knowledge, access and communication (Emond et al., 2015). For instance, Deaf people's cancer knowledge involves misconceptions on issues such as cancer risk factors, screening and treatment (Berman, Jo, Cumberland, Booth, Britt, Stern, Zazove, Kaufman, Sadler, & Bastani, 2013; Orsi, Margellos-Anast, Perlman, Giloth, & Whitman, 2007). This may lead to Deaf people under-reporting symptoms and not obtaining timely treatment and screening. However, it was also shown that screening rates for cancer (breast, cervical and

colorectal) and pap smears were similar to general population rates. For instance, 90% of female Deaf respondents and 92% of women in the general population reported ever having a pap smear; 90% of Deaf women aged 50 and older reported ever having a mammogram, and 80% had one within the previous two years (in the general population, these estimates are 89% and 78%); 48% of Deaf men and 48% of hearing men reported ever having a colonoscopy; 76% of Deaf men reported ever having a digital rectal exam, which is higher than the general population (55%) (Orsi et al., 2007). The discrepancy between low knowledge and the same levels of screenings as the population suggests factors apart from knowledge affect the likelihood of Deaf participants attending screenings. Some potential factors may be communication issues, hearing status of the Deaf person's partner, how many sources of information the Deaf person uses (Zazove, Meador, Reed, Sen, & Gorenflo, 2012), ease of use and acceptability of the intervention (Yao, Merz, Nakaji, Harry, Malcarne, & Sadler, 2012), health literacy levels and motivation.

In this review, rigorously designed trials of health interventions for Deaf adult populations (controlled and randomised controlled) will be synthesised in terms of their intervention components and key results. Following a systematic literature search, 11 studies were identified. Randomised controlled trials, controlled trials and pilot studies with a control group which included health interventions were included in the review. The population was adults who were Deaf. Interventions were focused on cancer, weight loss, HIV, and mental health and I reviewed each of these broad health domains in turn.

CANCER.

Most of the existing interventions for Deaf populations focus on cancer (cancer knowledge and awareness of early detection options). In particular, studies have been conducted about general cancer prevention (Zazove et al., 2012) and on different types of cancer (ovarian (Jensen, Nakaji, Harry, Gallegos, Malcarne, & Sadler, 2013), testicular (Sacks, Nakaji, Harry, Oen, Malcarne, & Sadler, 2013), cervical (Choe, Lim, Clark, Wang, Branz, & Sadler, 2009; Yao et al., 2012), skin (Harry, Malcarne, Branz, Fager, Garcia, & Sadler, 2012), colorectal (Shabaik, Iahousse, Branz, Gandhi, Khan, & Sadler, 2010), and prostate (Zazove et al., 2012). Health promotion and education were

intervention themes. Video education was the intervention component. Three studies involved randomised controlled designs (Choe et al., 2009; Harry et al., 2012; Zazove et al., 2012) and the other studies were non-randomised controlled trials (Jensen et al., 2013; Sacks et al., 2013; Shabaik et al., 2010; Yao et al., 2012).

Deaf communication access for the videos was ensured by providing videos in which actors/native signers communicated in sign language (Harry et al., 2012; Yao et al., 2012), adding a corner box on the screen with a sign language interpreter signing content and captioning (Zazove et al., 2012) and optional captioning of the American Sign Language script and English voiceover without background music (Jensen et al., 2013). These methods are Deaf friendly, as they account for the Deaf participants' needs and preferences and are based on Deaf people's suggestions.

Findings can be split into two categories: (a) knowledge and (b) factors affecting the relationship between knowledge and behaviour (provided via subjective assessment outcomes of interventions by the participants). The knowledge findings were not conclusive. In most studies, any knowledge gains spread across intervention and control groups (Harry et al., 2012; Jensen et al., 2013; Kaskowitz, Nakaji, Clark, Gunsauls, & Sadler, 2006; Sacks et al., 2013; Yao et al., 2012; Zazove et al., 2012).

However, a notable number of studies showed a preference for the intervention (Choe et al., 2009; Shabaik et al., 2010). In the studies where knowledge did improve there was a control group, a large sample size (n=130 in Shabaik et al. (2010) and n=144 in Choe et al. (2009)) and participants were shown an education video translated into American Sign Language. Cervical (Choe et al., 2009) and colorectal cancer (Shabaik et al., 2010) were the topics of the videos. The fact that knowledge was improved in these studies suggests that in order for the intervention to have an effect on participants, it is important to use a design with a control group and a large sample. Overall, there is some limited evidence that non-technological interventions can help to increase Deaf knowledge of cancer, but only under certain circumstances.

In some cases, the post-test knowledge of the intervention group was higher than the control group pre-test knowledge (when control group participants were hearing) (Sacks et al., 2013; Yao et al., 2012). This means that the interventions succeeded in

reducing the knowledge gap between Deaf and hearing populations. The reason that closing the knowledge gap was achieved could be due to the preferred method of communication used (sign language), as well as the fact that the intervention programme was created with input from the Deaf community (Young & Hunt, 2011). The interventions in which the knowledge gap was reduced most were educational videos about cervical cancer (Yao et al., 2012) and testicular cancer (Sacks et al., 2013). Most of the sample (94.5%) found the information “very easy to somewhat easy” to understand (Yao et al., 2012), 95.2% of the sample reported that the information was useful (Sacks et al., 2013) and 97.6% Deaf women and 78.6% Deaf men were “very willing” and comfortable to share the video with others (Sacks et al., 2013; Yao et al., 2012). Therefore, the intervention was seemingly useful, at the correct level of understanding, and acceptable and comfortable for Deaf people. Sacks et al. (2013) designed the videos to be appropriate for men of all ages, which could be why participants were comfortable to share it with friends/relatives. In both studies, the intervention was created with advice from the Deaf community. Also, sign language interpreters were used to deliver the information in both studies, making the interventions easy to understand. However, while it was shown that the knowledge gap was significantly reduced at post-test, no follow-up data were collected. This means that it’s possible that the knowledge gap would not necessarily be maintained at follow-up.

This evidence notwithstanding, health education interventions using videos do not always reduce the gap between cancer knowledge of Deaf and hearing people. This was shown in Jensen et al. (2013). Here, although knowledge increased for both groups, the hearing controls had higher pre-test levels than the Deaf intervention participants at post-test. This was an ovarian cancer video intervention, created with advice from the Deaf community and delivered by sign language interpreters. The intervention was different from Sacks et al. (2013) and Yao et al. (2013) in that there were more options about the videos (open captioning of the American Sign Language script and English voiceover without background music to reduce audio competition with the spoken text). Whilst the aim was to make the videos more accessible and give Deaf people more control over their knowledge intervention, the null results indicate that perhaps Deaf participants found the many options confusing. In this study, 64% of Deaf participants found the video “very easy” to understand, which are lower percentages than in the cervical cancer knowledge intervention (Yao et al., 2012).

Also, significantly more of the hearing participants (96%) found the video “very easy” to understand, which suggests that the video was more appropriate for the hearing participants. Yet despite the differences in ease of understanding, both the intervention and control group showed around 86% willingness to share the video. This suggests that Deaf people felt that the video was useful and to some extent acceptable. Similarly, to the above studies, this trial didn’t involve follow-up data collection, which means that while knowledge differences between hearing/Deaf groups were found at post-test, they may not be maintained at follow-up.

In two studies (Choe et al., 2009; Shabaik et al., 2010), the intervention was preferred over and above previous methods of obtaining cancer knowledge. Also, in studies where hearing participants were in the control group, it was shown that post-test knowledge of the intervention group became at least the same as the pre-test knowledge of hearing participants. This suggests that Deaf interventions can be useful in moving the Deaf participants’ cancer knowledge closer to that of the hearing population and that both new intervention methods (videos, peer education, PowerPoint slideshows) and previous information sources should be used for improving Deaf cancer knowledge and awareness.

As is evident from this brief review, there is much variability in results for healthcare communication interventions on cancer knowledge among Deaf participants. This suggests that factors other than healthcare communication may affect cancer knowledge. For instance, Zazove et al. (2012) highlighted communication with the physicians, the number of information sources used, and hearing status of the partner as affecting knowledge of cancer. Other factors which could also be accounted for in interventions include type of cancer, gender, age, use of technology and personality (Choe et al., 2009; Emond et al., 2015a, 2015b; Kritzinger, Schneider, Swartz, & Braathen, 2014; Sacks et al., 2013; Thoren, Oberg, Wanstrom, Andersson, & Lunner, 2013). Another aspect which could affect findings is the design of the studies. Zazove et al. (2012) conducted a randomised controlled trial. In this study, the intervention included using educational videos (with sign language, captions and printed English options) to increase cancer prevention knowledge of Deaf men. The intervention group results were compared to a control group who watched a video in spoken English, which had been originally designed for hearing samples. A sign language interpreter

(recorded as a corner box, with captions placed below the interpreter) delivered post-video surveys and the video information. Both control and intervention groups gained knowledge at post-test, which was also maintained at follow-up. There was no significant difference in knowledge gains between the intervention and control groups. Across both groups, it was found that participants were more likely to improve in terms of cancer prevention knowledge if they had a hearing or Hard of Hearing spouse (as opposed to no spouse or Deaf spouse), poor communication with their physician, and the more healthcare information sources (such as physicians, family, books) the participants used. Therefore, the results of a more rigorous trial did not show a complete preference for the intervention (Deaf) group but did show a modest improvement for Deaf participants.

The above intervention study is a rare example of a randomised controlled trial, with a reasonably long follow-up period. Other studies on cancer knowledge and awareness have shorter timescales (one day to two months) and less rigorous methodology (non-randomised pre-post-test group comparison designs). Also, most of the other studies have smaller participant numbers (107 to 175 participants) and use hearing participants in the control group. Smaller participant numbers, shorter timescales and non-randomised trial designs lead to research evidence being more likely to be biased, as well as there being not enough time in the trial for relevant changes to occur. Also, using hearing participants in a trial for Deaf populations might not be appropriate as hearing people have different experiences in terms of healthcare communication and access to Deaf people.

Overall, it is possible to use health education/promotion interventions to increase Deaf women's ovarian and cervical cancer knowledge, men's colorectal, prostate cancer and testicular cancer knowledge as well as awareness of early detection options for prostate cancer and Deaf men's and women's cancer prevention and skin cancer knowledge. Across the literature, it seems that 95.2% of the Deaf men report that the testicular cancer video provided useful knowledge and that 78.2% would be comfortable showing the video to friends/relatives (Sacks et al., 2013), as well as that 40.2% of women had either viewed the video again or shared it with others (Choe et al., 2009). Additionally, participants seemed more likely to improve in terms of cancer prevention knowledge if they had a hearing or Hard of Hearing spouse (as opposed to no spouse

or Deaf spouse) and poor communication with their physician. Lastly, preventive interventions (e.g., pap smear and prostate exams) appear weakest in terms of effects (Zazove et al., 2012).

WEIGHT LOSS.

In order to ascertain whether it is possible to help Deaf people to reduce their weight, one healthy lifestyle intervention study has been conducted (Barnett, Sutter, & Pearson, 2014). The intervention theme was self-monitoring and education. Motivational interviews delivered by a Deaf counsellor was the intervention component. Waitlist randomised controlled trial design was used. The participants were 104 overweight or obese Deaf people. The intervention was a 16-week healthy lifestyle programme. Group meetings in which participants learned about self-monitoring, healthy eating, cooking and exercise were used to provide intervention content. A hearing intervention was adapted into the Deaf population intervention (Barnett et al., 2014) by using input from the Deaf community to adapt the intervention for the sample as well as employing Deaf counsellors with expertise in counselling or public health. In the waitlist control group, participants received the intervention after one year. Participants' health markers and subjective health were recorded at baseline and six months. The outcomes were recorded using sign language video surveys. This means that Deaf people would be likely to understand and respond accurately during data collection.

It was found that, at six months, the intervention group lost 3.35 kg more than the control group and showed a BMI reduction which was 1.35 points more than the control group. Most of the intervention group's participants (58.3%) lost at least 5% of their baseline weight, compared with 14.3% of the delayed group. Lastly, the intervention group completed more physical activity and had a healthier diet (as measured by the Dietary Risk Assessment questionnaire) than the control group. Therefore, this study shows that the intervention led to Deaf people's changes in health knowledge as well as objective health markers. However, as this study did not include a follow-up, it is not possible to ascertain whether the changes would be maintained in the long-term.

Key lessons about weight loss for Deaf populations is that evidence is mixed in terms of showing whether health interventions can be used to implement changes in

weight and weight management. This study highlighted that motivational interviews presented in the preferred method of communication (in-person and sign language) can help Deaf people to learn more about healthy eating and exercising. Deaf people's increases in healthy eating and exercising knowledge then led to weight loss and healthier eating habits. Therefore, despite some limitations, the study showed the effects on weight loss and health knowledge from a non-technological intervention targeting the Deaf population.

MENTAL HEALTH.

There is to date only one study committed to improving mental health in Deaf participants (Garnefski & Kraaij, 2011) using a randomised controlled trial design. A mental health self-help programme was the intervention component. Fifty-five Deaf people with at least mild depression or anxiety participated in the study. Participants completed a cognitive-behavioural self-help programme which was made up of a workbook, a CD and a work programme. Relaxation techniques, challenging irrational thoughts and self-efficacy were the topics. The programme was adapted from a physical impairments self-help programme for hearing people. Before running the trial, a pilot study was conducted to ascertain that depression and anxiety predictors are the same for Deaf and hearing people. This was found to be the case, which means that the programme can be deemed Deaf friendly. In the waitlist control condition, participants received the programme after the intervention group finished (one month).

Participants' depression and anxiety scores were measured at pre-test, immediately after the intervention was completed and after two months (follow-up). It was found that intervention scores on depression and anxiety were lower than that of the control group and that these results were maintained at follow-up. Therefore, this study was able to show the effectiveness of a cognitive-behavioural self-help programme on improving Deaf people's mental health. However, the intervention itself was brief (one month long), which means that not enough time may have passed for all the possible changes to mental health to occur. The follow-up period was also reasonably short (two months), so it is possible that the effects may not be maintained in the long term. Additionally, the analyses were focused solely on written materials, which was not appropriate for Deaf people who have a low health literacy

level. Therefore, this study is not fully culturally appropriate for this sample. Lastly, the study sample was small, leading to the suggestion that the findings are not representative of all Deaf people.

The study in this thesis built on the limitations of the above study by providing Deaf people with written questionnaires, British Sign Language videos and also support from project workers reasonably fluent in British Sign Language (level 3 or above). Ensuring that Deaf people have more communication choices makes the current study Deaf friendly than that of Granefski and Kraaij (2011). Also, the current thesis study allowed more time for the intervention (12 months), which means that it was more likely to work. However, the current thesis study had the same methodology as the Granefski and Kraaij (2011) study (a randomised controlled design with a waitlist control group). The randomised controlled design is rigorous, allowing to control for differences between participants. The waitlist aspect of the design means that all participants receive access to the intervention.

As it currently stands, interventions have not been entirely effective in supporting improvements in mental health improvement. The self-help programme in Granefski and Kraaij (2011) study reduces the need for communicating with the hearing doctors, which may make the Deaf people more comfortable in mental health care settings. Additionally, this programme was made with advice from the local Deaf community. Although not all Deaf people will have the required reading skills that the programme requires, the fact that the local Deaf community suggested that this programme is accessible shows that there is a large enough number of Deaf people for whom such a programme is indeed appropriate. Therefore, future programmes for Deaf people should be focused on encouraging Deaf people to learn new skills and take ownership of their mental health, as well as being based on input from Deaf people.

HIV.

One intervention study (i.e., Taegtmeyer, Hightower, Opiyo, Mwachiro, Henderson, Angala, Ngare, & Marum, 2009) was focused on the education and raising awareness of HIV for Deaf people during a peer education programme. A non-randomised comparison test with a sample of 1709 Deaf and 1649 hearing participants

who engaged with HIV services over two years was conducted. A peer education programme to educate Deaf people about the available HIV screening and counselling was the intervention. This was the first attempt at establishing an HIV service in Africa which would be appropriate for Deaf people. The control group was made up of hearing people who had not attended a peer education programme but who had engaged with the HIV service.

The participants were asked about their HIV knowledge and safe sex, as well as about how they had learned of the HIV service. Additionally, the rates of people who were HIV positive were recorded. No significant differences between hearing and Deaf participants in terms of condom use and uptake with non-steady partners were reported. The use of HIV services was greater for Deaf people who had attended peer education programmes. Lastly, Deaf people's HIV rates were lower (7% HIV positive) than that of hearing people (15% HIV positive). Therefore, this study supported the idea that a peer education programme can positively influence the attendance of Deaf people to an HIV service.

Yet, the study by Taegtmeyer et al. (2009) had some notable limitations. For instance, there were three different locations used which may have varied in terms of peer education programme quality. The Deaf people's HIV positive rates varied from 6.4% to 15% across locations, which may have been due to differences in programme quality. Another limitation was that the design was not randomised. If more rigorous methods (a randomised controlled trial) could have been employed, it might have been possible to conclude with more certainty as to the effectiveness (or otherwise) of the peer education programme. Additionally, comparing hearing and Deaf samples may not be appropriate as hearing people did not have a peer education programme. Lastly, this study was only able to show that using the peer education service led to more attendance at the HIV service but did not show the changes in HIV rates or knowledge gains due to peer education attendance.

CONCLUSION.

In this review, studies about health interventions for Deaf people were presented. The health topics under investigation were cancer, weight loss, mental health and HIV.

To summarise, there is some important evidence available on health interventions for Deaf people. Most of the evidence available (eight studies) was focused on cancer, and there was one study each available on weight loss, mental health and HIV.

The current evidence can provide some useful information and direction for future research. For instance, it has been shown that health interventions can support Deaf health to an extent, as well as leading to improvements in knowledge gains and behaviour change. The intervention components used were participant education, raising awareness, and health promotion (Choe et al., 2009; Harry et al., 2012; Jensen et al., 2013; Kaskowitz et al., 2006; Sacks et al., 2013; Shabaik et al., 2010; Yao et al., 2012; Zazove et al., 2012), self-monitoring (Barnett et al., 2014), self-help (Garnefski & Kraaij, 2011) and peer education (Taegtmeyer et al., 2009). Therefore, these intervention components could be recommended for use in future health interventions.

This short review shows that it is important for interventions to promote Deaf people's ownership of their health and to encourage the learning of new skills as well to allow Deaf people to communicate in their preferred way. Also, the interventions which had positive health outcomes were based on input from the local community. Additionally, it seems that interventions that have had positive effects were about making Deaf people feel more involved by increasing social support (through better communication and peer education), increasing knowledge and awareness, as well as promoting the individual to take over after learning how to help themselves (through self-help and self-monitoring). These useful aspects of interventions could be harnessed in the development of future interventions that take advantage of recent technological innovations to support Deaf health outcomes in the future. It is to these recent technological that the attention now turns.

1.3 TECHNOLOGY USE IN HEALTH INTERVENTIONS FOR DISABLED POPULATIONS

Technology may provide a way of reducing the disparity between the health of disabled and able-bodied people. Technology could be used to provide information, interact with other patients about experiences of illnesses and for doctors to provide healthcare (Powell, Darvell, & Gray, 2003). It has been suggested that technological

interventions will help to increase access if interventions include options that can be changed to fit in with patient needs (Fortney, Burgess, Bosworth, Booth, & Kaboli, 2011). Additionally, Fortney et al. (2011) suggested that mobile interventions can help to overcome geographical (offering more services via multiple online appointments at the same time), cultural (providing education about illnesses and disabilities) and timing (encouraging patients to choose a time for interaction that is convenient to them) access problems.

The usefulness of technology for health interventions has been shown in a review (Murray, Burns, See Tai, Lai, & Nazareth, 2005). This review included 24 randomised controlled trials of interactive health communication applications (computer information packages with social support, decision support or behaviour change support modules). Patients with chronic disease participated. After using the applications, patients reported knowledge increases, higher self-efficacy, more social support, maintenance of behavioural outcomes and better health outcomes. Collectively, the findings of the review suggest that any technological interventions which affect health communication are useful in attempting to improve health.

In general, technological innovations intended to improve have been categorised as mHealth interventions. mHealth is defined by WHO as “mobile and wireless technologies to support the achievement of health objectives” (Kay et al., 2011; p.9). Previous literature has reviewed the use of mHealth technologies across different types of disability such as stroke (Thilarajah, Clark, & Williams, 2016), spina bifida (Daihua, Parmanto, Dicianno, & Pramana, 2015), alcohol dependence syndrome (Gamito, Morais, Rebelo, Silva, & Cacoete, 2016) and mental illnesses (Ben-Zeev, Davis, Kaiser, Krzsos, & Drake, 2013). Positive changes have been documented for chronic disease management, improving chronic pulmonary diseases symptoms and heart failure symptoms, reducing deaths and hospitalization, improving quality of life, and improving glycemic control in diabetes patients and blood pressure levels in hypertensive patients (Marcolino, Oliveira, D'Agostino, Ribeiro, Alkmim, & Novillo-Ortiz, 2018).

According to a WHO survey by Kay et al. (2011), the most frequently reported mHealth interventions were health call centres (59%), emergency toll-free telephone services (55%), emergencies (54%), and mobile telemedicine (49%). This review will

therefore focus on mobile telemedicine which is defined as “the communication or consultation between healthcare professionals about patients using the voice, text, data, imaging, or video functions of a mobile device”, as well as using it for managing treatment at home (Kay et al., 2011; p. 34). The main benefit of this method is that it allows patients’ access to treatment and care when resources are limited. This means that healthcare professionals and patients can be connected in both urban and rural locations, and that unnecessary appointments may be reduced.

1.3.1 VIDEOCONFERENCING HEALTH INTERVENTIONS FOR DISABLED POPULATIONS.

INTRODUCTION.

In the following narrative review, extant literature available on videoconferencing mHealth interventions for all people experiencing disabilities of any kind will be synthesised. This will be followed by a review of videoconferencing mHealth interventions for disabled populations more specifically. The intention here is to summarise issues relating to health topics, design and key results that can inform future mHealth research for disabled populations. The studies in this review will be categorised based on health topics. This review includes diverse health topics such as mental health (depression awareness, management and psychotherapy and PTSD therapy), disease management and rehabilitation for heart disease, MS and physical disabilities, and Deaf/Hard of Hearing children’s language delays. Following a systematic literature search, 15 studies were retrieved. The studies were trials with a control group containing a health and videoconferencing intervention component. All the trials used quantitative methods to explore the benefits and barriers of mHealth for improving health.

MENTAL HEALTH.

Seven studies were identified that have examined the effect of mHealth on mental health outcomes of disabled populations. The mental health issues covered are PTSD (four studies) (Egede et al., 2015; Morland et al., 2004; Tuerk et al., 2010; Yuen et al., 2015) and depression (three studies) (Choi et al., 2014; Moreno et al., 2012;

Ruskin et al., 2004). Most of the research investigated the feasibility of using videoconferencing for teletherapy provision (Choi et al., 2014; Egede et al., 2015; Morland et al., 2004; Tuerk et al., 2010; Yuen et al., 2015), and two studies were focused on telepsychiatry (Moreno et al, 2012; Ruskin et al., 2004). Teletherapy is the delivery of talking therapy by videoconferencing (Turgoose, Ashwick, & Murphy), whereas telepsychiatry involves videoconferencing-delivered psychiatric assessments and care (Hilty, Luo, Morache, Marcelo, & Nesbit, 2002). Randomised controlled trial and controlled trial were the study designs, whereas the study duration was between eight weeks and six months.

Study findings related to depression or PTSD symptoms show limited promise for improvement. Indeed, across most studies, mental health illness symptoms were reduced to the same extent in the control and intervention group (Acierno et al., 2015; Choi et al., 2014; Morland et al., 2004; Ruskin et al., 2004; Tuerk et al., 2010; Yuen et al., 2015). This could be due to the short time frame (eight to 12 weeks) used in some of the studies (Acierno et al., 2015; Morland et al., 2004; Tuerk et al., 2010; Yuen et al., 2015), low participant numbers (from n=17 to n=52) (Morland et al., 2004; Tuerk et al., 2010; Yuen et al., 2015). Notably, randomised controlled trials with larger participant numbers and longer timescales also showed no differences between intervention and control groups (Choi et al., 2014; Ruskin et al., 2004). In Choi et al. (2014), the effect of symptom reduction was maintained longer, which suggests that there may be a preference for the intervention in symptom reduction maintenance (as opposed to just symptom reduction). Such a finding highlights the importance of symptom reduction maintenance as an index for improvement for mental health patients.

Only one study showed higher reduction rates for the intervention group (Moreno et al., 2012). This was a randomised controlled trial in which 167 mental health patients with depression received psychiatric treatment for six months. The intervention group received treatment via videoconferencing and the control group received treatment as usual. In the intervention group, participants communicated with the psychiatrist via Webcam once a month. The first session (45-60 min) included psychiatric evaluation and creating a treatment plan. Evaluation, psychoeducation, and medication management were the topics of the next sessions (20-30 min). Treatment as usual was provided to the control group. Treatment as usual was determined by the primary care

provider, such as antidepressants and counselling from behavioural health clinicians. Depression symptom reduction in both the control group and the intervention group was found (according to clinicians' ratings). Symptoms were reduced to a higher extent for the intervention group. A preference for the intervention group indicates that videoconferencing can be beneficial for mental health outcomes, provided that long term trials with rigorous designs integrated alongside medication management are used.

CARDIOVASCULAR DISEASE.

Four mHealth studies have been conducted on the effectiveness of mHealth technologies in supporting cardiovascular disease patients. Studies focused on stroke (Chumbler et al., 2012; Cikajlo et al., 2012), chronic respiratory failure (including COPD) (Vitacca et al., 2009), as well as both chronic obstructive pulmonary disease (COPD) and congestive heart failure (Gellis et al., 2014). Videoconferencing was used to provide telerehabilitation (Chumbler et al., 2012; Cikajlo et al., 2012) as well as monitoring and care management (Gellis et al., 2014; Vitacca et al., 2009). The study design was controlled and randomised controlled trials. Study duration was between six weeks and one year.

Study findings were varied. No difference between control and intervention groups were found in some studies (Chumbler et al., 2012; Cikajlo et al., 2012), whereas preference for the intervention group was found in others (Gellis et al., 2014; Vitacca et al., 2009). In Cikajlo et al. (2012), the intervention included the rehabilitation of six stroke patients via videoconferencing from home. Videoconferencing was used by physiotherapists and physicians to follow the process. Training included participants completing virtual reality tasks for balance. The control group completed balance training in clinical settings. An improvement was shown in the participants' physical function (balance and walking) at post-test for the control and intervention group participants to the same extent. This was maintained at follow-up.

In Chumbler et al. (2012), participants were 52 veterans with stroke. The intervention group received a messaging device for three months which helped to provide patients with physical exercises and adaptive strategies (such as assistive

technology and environmental modifications). Usual care (rehabilitation prescribed by physicians) was provided to the control group. There was a non-significant preference for the intervention group who had higher levels of physical functioning independence compared to the control group. These changes were maintained at follow-up. Together, the Cikajlo et al. (2012) and Chumbler et al. (2012) studies show that videoconferencing can work as well (and occasionally better) as usual care for supporting patients with stroke. The reasons for the lack of significance in these studies could be linked to less rigorous design (controlled trial), low participant numbers (n=52 and 26), as well as small timescales (six weeks and three months).

Other evidence, too, suggests that videoconferencing may have positive effects on cardiovascular health (Gellis et al., 2014; Vitacca et al., 2009). In Vitacca et al. (2009) study, 240 patients with chronic respiratory failure (including 101 patients with COPD) received tele-assistance in the intervention group or usual outpatient follow-up in the control group. Tele-assistance included a 24-hour service for communicating with nurses as well as provision of a device to measure how much oxygen there is in the body (pulse oximetry). It was found that the intervention group had few hospital visits and urgent GP calls as well as less acute exacerbation than the control group at post-intervention. This suggests that videoconferencing may more effective than as usual care in a care management treatment. Additionally, the intervention was shown to cost 33% less than usual care indicating that as well as health benefits, mHealth interventions may be highly cost-effective in supporting chronic respiratory failure patients.

Preference for the intervention group was also shown for patients with congestive heart failure and chronic obstructive pulmonary disease (Gellis et al., 2014). In this study, 102 participants were randomised to either the intervention or control group. The intervention was three months long and included telemonitoring of chronic illness and depression symptoms, weight and appropriate medication use with a nurse, online communication with primary care physicians and problem-solving treatment provided by videoconferencing. The control group received usual care, psycho-education and in-home nursing services. It was found that the intervention group experienced a 50% reduction in their depression symptoms and increased self-efficacy for managing their illness more than the control group, as well as having fewer emergency department

visits over 12 months than the control group. These changes were maintained at post-test and six months. This study was a randomised controlled trial and had a large sample (n=102) but a short timescale (three months). In all, available evidence suggests that videoconferencing is a useful tool for improving the health outcomes of those with cardiovascular disease.

MULTIPLE SCLEROSIS.

Two mHealth studies have investigated the efficacy of videoconferencing among those with multiple sclerosis (Finlayson et al., 2011; Zissman et al., 2012). Both studies had randomised controlled designs and lasted between four weeks (Finlayson et al., 2011) and six months (Zissman et al., 2012). The intervention was preferred in both studies. Finlayson et al. (2011) study included 190 participants who were multiple sclerosis patients. In the intervention group, participants received a group fatigue management programme via teleconferencing for week weeks (once a week for 70 minutes). An occupational therapist led the calls with small groups (five to seven participants per group). The focus of the sessions was on developing self-management skills, interaction, and peer support. Usual care was provided to the control group for four weeks, after which they also received the intervention. It was found that the intervention group experienced less fatigue impact compared to the control group. This positive finding was maintained at six months.

Zissman et al. (2012) study included 40 multiple sclerosis patients. Participants in the intervention group were provided with information about medical problems, and answers to any medical questions, as well as support about multiple sclerosis for six months. Videoconferencing with nurses 24 hours a day, seven days a week was used to deliver information. Each intervention group participant could contact the nurses for free 30 minutes a week. This group also received usual care at a clinic. The control group received only usual care. Improvements in six multiple sclerosis symptoms (hands' dysfunction, feet weakness, walking impairment, pain/cramps, fatigue and dysesthesia) and higher health-related quality of life levels were shown for the intervention group compared to the control group.

Together, the above studies show that videoconferencing is a beneficial modality of intervention for patients with multiple sclerosis. Specifically, benefits were seen for both fatigue management programmes (Finlayson et al., 2011) and care management programmes (Zissman et al., 2012). Additionally, Zissman et al. (2012) found that there was a decrease in medical costs of 35% for 67% of the intervention group, which again suggests that videoconferencing is highly cost-effective. In all, it seems that videoconferencing should be used instead of usual care for multiple sclerosis patients.

PHYSICAL DISABILITIES.

Two mHealth studies have investigated the efficacy of videoconferencing among people with physical disabilities (Huijgen et al., 2008; Sanford et al., 2006). These studies provided telerehabilitation, which is when patients receive a remote rehabilitation programme (such as physical exercises) to do at home (Bairapareddy, Chandrasekaran, & Agarwal, 2018). Experts (such as nurses and physicians from care centres) follow these sessions online and in some cases also provide support by the telephone, through email and via videoconferencing (Kizony, Weiss, Harel, Feldman, Obuhov, Zeilig, & Shani, 2017). Both had randomised controlled trials and the study duration was between four weeks (Sanford et al., 2006) and two months (Huijgen et al., 2008). Findings were mixed. In one study, there was no difference in health outcomes between the intervention and control groups (Huijgen et al., 2008), whereas the health outcomes of the intervention group were improved relative to the control group the other study (Sanford et al., 2006).

Eighty-one patients with affected arm/hand function participated in the Huijgen et al. (2008) study. A portable unit with sensorised tools (a key, light bulb, book, jar, writing, checkers and keyboard) connected to the hospital server and also to two webcams (for videoconferencing and recording) was supplied to the intervention group. The participants were required to complete exercises for improving functional activity and communicate with therapists weekly via videoconferencing. At post-test, participants showed similar levels of either maintenance or improvement for the arm and hand functioning for the intervention and control groups. These results suggest that videoconferencing may not always be beneficial in this population.

However, the results of Huijgen et al. (2008) should be considered in the context of work by Sanford et al. (2006). Here, physically impaired participants who had been recently prescribed mobility devices received therapy via videoconferencing for four weeks (1 hour per week). Supporting participants in gaining self-efficacy for performing rehabilitation tasks as well as discussing adaptive strategies and exercises were the key aspects of the therapy sessions. The control group did not receive any therapy. It was found that the intervention group showed more self-efficacy for rehabilitation tasks than the control group. In summary, current evidence shows that videoconferencing may support health outcomes for those with physical impairments, but more studies are needed.

CONCLUSION.

In this review, studies about videoconferencing interventions for disabled populations are presented. The health topics of investigation included: mental health, cardiovascular disease, multiple sclerosis, and physical disability. Most of the evidence available (seven studies) was focused on mental health, four studies were focused on cardiovascular disease, and two studies each were available on multiple sclerosis and physical disabilities. Current evidence indicates that videoconferencing is appropriate for interventions to improve disabled population health. For instance, it has been shown that videoconferencing can lead to improvements in the self-efficacy for rehabilitation (Sanford et al., 2006), reductions in hospital visits for chronic respiratory failure patients (Vitacca et al., 2009), as well as reduction in symptoms such as less fatigue of multiple sclerosis patients (Finlayson et al., 2011) and depression symptom improvement in both chronic obstructive pulmonary disease patients (Gellis et al., 2014) and mental health patients (Moreno et al., 2012). It is also clear that mHealth and videoconferencing delivers cost-benefits over conventional means of healthcare that mean even no differences in health outcomes become meaningful in terms of provision.

Research studies have suggested that mHealth can support Deaf people's needs in healthcare by providing a culturally sensitive, simple, and cost-effective means of delivering health advice and diagnosis (Blaiser, Behl, Callow-Heusser, & White, 2013; Crowe, Jani, Jani, Jani, & Jani, 2016; Wilson, Guthmann, Embree, & Fraker, 2015; Wilson & Wells, 2009). One of the reasons mHealth has the potential to be so effective

is that such technologies can support Deaf people in making informed decisions about their healthcare by giving them control over how they wish to communicate (Young & Hunt, 2011). The fact that different mHealth options are available to use both remotely and in-person means that healthcare can be made accessible and tailored to the Deaf patients' needs. In what follows, then, I review the available literature on mHealth interventions for Deaf people with a focus on videoconferencing which is the primary modality of delivery.

1.3.2 VIDEOCONFERENCING HEALTH INTERVENTIONS FOR THE DEAF POPULATION.

INTRODUCTION.

To date, a review of the literature concerning how useful and effective mHealth-based interventions are for the Deaf population has not been conducted. Therefore, the main objective of this review is to synthesise literature available on mHealth interventions for Deaf people. This review will summarise issues relating to health topics, design and key results that can inform future mHealth research. Unlike in the previous sections, the Deaf population studies in this review will be categorised based on health outcomes (not populations). These outcomes include: mental health (depression awareness, management, and psychotherapy), substance abuse support, and language delays. These health issues are experienced by Deaf people to a greater extent than by the general population. For instance, on a global scale, 39-42% of the Deaf population experience depression and anxiety (Landsberger et al., 2014), compared to 10% of the general population (WHO, 2018). Substance use disorders are experienced by 26-51% of the Deaf population (Landsberger et al., 2014), compared to 36% of problem drug users in the general population (United Nations Office on Drugs and Crime, 2017) and 7.5% of the general population “engaged in heavy episodic drinking” (WHO, 2018). Around 3 in 1000 children are born with hearing loss, which can lead to language delays if not detected and treated in the first few months after birth (Smith, Bale, & White, 2005; Watkin, McCann, Law, Mullee, Petrou, Stevenson, Worsfold, Yuen, & Kennedy, 2007).

MENTAL HEALTH.

Two mHealth studies among Deaf people have targeted mental health outcomes. Depression awareness and management was the focus of one study (Wilson & Wells, 2009). Here, the intervention involved participants receiving a videoconference psychoeducational lecture about depression. The intervention group results were compared with a control group who read information from a lecture. Depression knowledge and mental health (depression and hopelessness) in the context of mental health services (secondary healthcare services) were the target outcomes. A mental health professional delivered the lecture and a sign language interpreter translated into sign language.

Fifty-five Deaf participants were randomly allocated to either an intervention or control group. After completing each of their tasks, the groups switched (intervention did the control group task and controls did the intervention group task). The recruitment involved posting adverts to where Deaf people meet in the local areas, emailing various college and university lists as well as publishing adverts in Deaf information outlets. After completing the tasks, all participants filled in a depression knowledge questionnaire and the intervention group rated the intervention satisfaction and cost-effectiveness. Depression and hopelessness were measured at baseline and post-test. It was found that all groups had a post-test increase in depression knowledge but there was no difference between intervention and control groups. It was also found that there was a larger significant reduction in depression for the intervention group compared to control group but that there was no significant group difference for hopelessness and no significant pre-post changes to intervention group satisfaction. Supporting other studies including participants with other disabilities, cost-effectiveness analyses showed that there would be savings of 55 hours/year for delivery via videoconferencing (versus face to face).

There are limitations to these findings. The small period of time for the intervention (one week) is one such limitation. There were also small participant numbers who responded to scales that have not been validated for the Deaf population. Evidence regarding increases in knowledge across both intervention and control groups

shows that the intervention is as good as the traditional method and that the mHealth technologies care more cost-effective.

A second study overcomes some of the limitations of Wilson and Wells (2009). Here, Crowe et al. (2016) conducted a three-year videoconferencing psychiatry intervention for Deaf participants in rural areas. Psychiatry sessions were supplied face-to-face to the control group. Coping abilities, mental illness symptoms, and satisfaction with the service were the target outcomes. Therapists fluent in sign language delivered the sessions. Twenty-four Deaf participants, diagnosed with a mood disorder (n=19), psychotic disorder (n=3) and anxiety disorder (n=2) were involved in this study. Participants were allocated to the intervention (n=11) or control group (n=13). Results indicated that there was no difference in coping abilities between the control and intervention groups before or after the treatment. However, there was a tendency for the coping to increase at post-test across both conditions, which suggests that using mHealth technology is no worse than face-to-face.

In terms of psychiatric symptom reduction (e.g., lower levels of depression, less likely to think about suicide, less likely to have racing thoughts and hear voices or have mood swings), a significant difference was found between the intervention and control groups. The symptom reduction was twice as large in the intervention group, compared to the control group. The preference for the mHealth intervention suggests that for at least one aspect of mental well-being, it is reasonable to suggest that technological interventions should be used over and above face-to-face treatments. Satisfaction with the services was also larger for the intervention group (100%) compared to the control group (81.82%). Similarly, 100% of the intervention group felt they received all the necessary services, compared to 90.9% of the control group. Hence, results show a preference for the intervention in terms of service satisfaction and symptom reduction. This study highlights the importance of cultural sensitivity in mHealth interventions for Deaf people, as improvements were shown from an intervention which took Deaf people's communication needs and views into account by using therapists fluent in sign language. A limitation of this study lies in the small numbers of participants, which means that it is not fully possible to generalise to the Deaf population.

Key lessons regarding mental health for Deaf populations from these studies are that the evidence is still limited in showing whether mHealth technologies support Deaf mental health. However, both studies show that videoconferencing is no worse and, in some cases, better than face-to-face support. Combined with evidence of the cost-effectiveness of videoconferencing over face-to-face support, these data are encouraging and support the role of mHealth in aiding mental health outcomes for Deaf people.

SUBSTANCE ABUSE DISORDERS.

One study examined the influence of videoconferencing on substance abuse disorders among Deaf people. Here, a culturally sensitive online rehab service intervention, which involved videoconference-based support in recovery was conducted (Wilson et al., 2015). The intervention was based on previous residential services that involved staff who were fluent in sign language and Deaf aware. In addition, the previous services utilised treatment procedures modified to account for language and cultural needs of every Deaf person. The control group was enrolled in residential substance abuse services. Mental health, well-being, and substance abuse outcomes in the context of the substance abuse treatment services (secondary healthcare services) were targeted by this intervention. Drug and alcohol counsellors and case managers who were fluent in sign language delivered the intervention. Deaf people with drug and alcohol issues took part in the study. Participants were recruited by the staff involved with the programme contacting various referral sources in the local area. There was an intervention group (n=8) and a control group (n=87). The participants were measured on life satisfaction, the likelihood of being diagnosed with substance abuse disorder, depression and self-esteem at baseline and post-test.

Results revealed that there was no difference between intervention and control groups for any of the measured outcomes. There were, however, significant improvements pre and post-test within the groups for life satisfaction, self-esteem and depression, and marginally significant reductions in the likelihood of being diagnosed with substance abuse disorder. It was also calculated that the online version of the intervention is cheaper (\$10,000) than traditional face-to-face services (between \$20,000-\$32,000). As there were improvements for both online and traditional services

and the online service was cheaper, the online service could be considered a more cost-effective modality given it was no worse than face-to-face service.

It is important to note that this study had a small number of participants in the intervention group (n=8). Hence, key lessons about the efficacy of videoconferencing for Deaf people from this study should be interpreted in the context of these numbers. Nonetheless, this research did show some improvements from using substance abuse services (face-to-face and mHealth to the same extent) and highlight that cost savings can be made using mHealth.

DEAF CHILDREN'S LANGUAGE DELAYS.

One study looked at how mHealth technologies support the needs of Deaf children in a specialised early intervention (Blaiser et al., 2013). The intervention group received videoconference meetings for the child's language delay treatment and the control group participated in usual care. Language development of children with hearing loss in the context of early intervention programmes for Deaf children with language delays (secondary healthcare services) was the target outcome. Early Intervention Hearing Specialists delivered the intervention. Participants were families of Deaf and Hard of Hearing children. The families were recruited from the sample of all the families enrolled in the Utah Schools for the Deaf and Blind (USDB) Parent Infant Programme (PIP). Participants randomly allocated to either the intervention group (n=13 families) or control group (n=14 families). Parent engagement with the treatment of the families and children's language improvements were measured at pre and post-test.

Results at post-test indicated that children in the intervention group showed more expressive language relative to the control group and parents were more engaged in their children's development compared to the control group. In addition, cost-effectiveness analyses showed that if three to four visits were provided to each child every month, the cost savings for providing services to 15 families using videoconferencing instead of in-person services would be between \$56,280 and \$86,970 over a 24 months period. This said, there was no improvement in children's receptive language after the intervention, which suggests that the results do not

conclusively demonstrate a preference for using videoconferencing in the key outcome of interest (though there was no disbenefit either).

The key lesson about Deaf children's language delays is that there is a preference for using mHealth as opposed to face-to-face services. Another key lesson here is that, like in the other studies reviewed, mHealth interventions have large cost savings relative to traditional face-to-face provision.

CONCLUSION.

In this review, studies about mHealth technology interventions for Deaf people were discussed. The health topics were mental health, substance abuse disorders and language delays of Deaf children. In summary, the mHealth research is still in the developmental stages and the evidence that is available is only present for three health topics. The current evidence provides a number of key implications and directions for future research. As the literature stands, there is support for using mHealth, and videoconferencing in particular, as a means of improving health access and health outcomes among Deaf people. These effects appear especially heightened in studies that take into consideration Deaf people's needs and culture (with, for example, specifically trained sign language deliverers) – alluding to the critical role that health communication plays in elucidating outcomes. These benefits span the health outcomes reviewed here.

Perhaps most notably, the reviewed research showed that mHealth has substantial cost benefits over and above traditional face-to-face forms of treatment. In this context, the findings in all studies that the videoconferencing was no worse than traditional treatment are highly salient. That is, given comparable outcomes, there is an argument that videoconferencing should be considered a very useful means of improving the health of Deaf people that is both acceptable and cost-effective. Hence, researchers and policymakers should seek to develop and harness such tools moving forward. In developing these tools, it is essential that they are grounded in relevant theory and evidence. One theory that may have especial utility in the development of mHealth interventions for Deaf people is Self-Determination Theory. It is to this framework that I now turn.

CHAPTER 2: SELF-DETERMINATION THEORY

We have seen that mHealth interventions have the potential to be useful for improving the health of Deaf populations. However, a limitation of such past interventions is that they typically adopt a top-down approach, where health outcomes are brought about by scheduling and/or structuring new health communication opportunities via digital techniques. These opportunities include, for instance, increasing the amount, or nature, of healthcare communication, changing the modality within which healthcare communication is delivered, or training medical staff in the provision of various educational mHealth materials. One of the problems with top-down health interventions of this nature is that they are typically atheoretical. This can hamper intervention efficacy by overlooking key mediators that link strategies to enhance health outcomes with the establishment of positive health habits (Lonsdale, Rosenkranz, Peralta, Bennie, Fahey, & Lubans, 2013).

One key mediator between the intervention and sustained health behaviour is motivation. According to organismic theories of human motivation, such as Self-Determination Theory (SDT; Ryan & Deci, 2000), it should be no surprise that top-down interventions can be ineffective – especially in the long-term (Ryan, Patrick, Deci, & Williams, 2008). This is because they assume people are reactive, with the intervention designed to impose external structures which move or motivate people into health behaviour. In the short-term, this approach may yield better health outcomes, but it will ultimately fail to sustain adaptive changes once the reason for this behaviour – the intervention – is removed (Deci, Eghrari, Patrick, & Leone, 1994).

In contrast to top-down interventions, which assume motivation is developmentally acquired, SDT takes an organismic approach to motivation and assumes that people are proactive (rather than reactive). In so doing, SDT shifts

intervention focus from top-down (i.e., attempting to motivate behaviour) to bottom-up (i.e., creating opportunities for people to motivate themselves). Hence, within SDT, health behaviour is changed via the support of inherent motivational tendencies that reside within each individual. Research shows people are inherently oriented to be autonomous (the need to experience self-direction), competent (the need to feel effective), and related (the need to feel close to others) in social contexts (Deci & Ryan, 2000). When these inherent psychological needs are met, the behaviour is regulated by intrinsic (rather than extrinsic) motivation, which fosters sustained engagement to health behaviours. There is extensive empirical support for SDT, and the efficacy of SDT-based behaviour change interventions targeting autonomy, competence and relatedness (Ng, Ntoumanis, Thøgersen-Ntoumani, Deci, Ryan, Duda, & Williams, 2012).

This chapter, then, is dedicated to a review of SDT and to elucidate its relevance in Deaf health communication interventions. The first section of this chapter contains a background to SDT and the role played by different forms of motivation in Deaf healthcare access and communication. Next, grounded in SDT principles, I will introduce InterpreterNow, which is the mHealth intervention that forms the basis of this thesis. The chapter finishes with a summary of the thesis aims and an overview of the empirical chapters.

2.1 SELF-DETERMINATION THEORY

SDT is a theory of motivation with applications to health and healthcare settings (see Ryan et al., 2008). Whereas some alternative motivation theories articulate how beliefs, goals, and thought patterns determine behaviour (e.g., achievement goal theory or the theory of planned behaviour), SDT is distinctive as it highlights innate motivational resources (Reeve, 2012). The philosophic begging point to SDT is in its organismic-dialectic viewpoint that suggests people have several innate motivational resources each of which interact with the social context to stimulate optimal functioning (Deci & Ryan, 1985). Hence, people are oriented to integrate behaviour, through the realisation of these motivational resources, and thus are active (rather than passive) actors in affecting their own motivation. Such an organismic approach to motivation was

borne out of previous work in psychoanalytical (Freud, 1960), humanistic (Rogers, 1963) and developmental (Piaget, 1971) fields.

However, SDT extends these literatures in a salient way. Within SDT, tendencies to self-actualization and optimal functioning are activated by environments that support autonomy, competence, and relatedness. Likewise, people are vulnerable to control, incompetence and alienation, especially when the environment is frustrating of tendencies to integrate behaviour. In so doing, SDT offers valuable insight regarding how healthcare professionals might cultivate the motivational resources of autonomy, competence and relatedness to facilitate the integration of behaviour – and, in turn, uptake and adherence to better health behaviour (Deci et al., 1994).

To outline the idea of the internalisation or integration of behaviour, SDT stipulates the conditions under which people do, do not, or only partially embrace extrinsic motives (such as the need to clean teeth twice a day or have regular check-ups with their general practitioner) into their self-concept (Reeve, 2012). Here, SDT posits that people are disposed to internalise features of the environment so as to integrate extrinsic motivational cues such that they match underlying goals and values (for example, acknowledging the personal relevance of cleaning teeth regularly to being healthy). Put differently, people proactively strive to endorse, as personally meaningful, recognized norms, limits, rules and behaviours in the social context. To the degree by which the psychological needs (i.e., for autonomy, competence, and relatedness) are satisfied and, in turn, the behaviour is fully internalised (i.e., events in the environment are fully endorsed by the self), optimal psychological functioning and engagement to health behaviour is produced. By contrast, when the psychological needs are frustrated, and, in turn, behavioural integration does not occur or is partial, ill-being and non-engagement to health behaviours are likely.

As individuals possess variability in the extent to which behaviour is internalized, four forms of extrinsic motivation have been described within SDT that differ in their amount of self-determination. External regulation is the form of extrinsic motivation that is the least autonomous. This regulation acts as a motivational impetus bereft of behavioural internalisation and personal meaning. It survives, put simply, as means to an end. Someone would exhibit external regulation when they partake in health

behaviours such as teeth cleaning for reasons beyond oneself – for example, to attain a payment or avoid a punishment. Introjected regulation is a type of extrinsic motivation which has been only partially internalized and thus is similarly understood to be low in comparative autonomy. For introjected regulation, motivation emerges from internal contingencies. Behaviour is instigated as it bolsters self-worth and minimises self-conscious emotions (such as shame and guilt). Someone would possess an introjected regulation when they engage in health behaviours such as teeth cleaning because they would feel especially guilty if they didn't. Together, extrinsic and introjected regulations motivate people in the absence of personal commendation, and therefore are purported to be *controlled* forms of extrinsic motivation (Standage, Curran, & Rouse, 2018).

Turning to autonomous types of extrinsic motivation, identified regulation is a motivational impetus that cogitates activity valuation. In other words, while the external motive is not naturally stimulating, it nonetheless has sufficient personal meaning to be self-endorsed. When someone has an identified regulation, then, motivation comes from volition owing to the personal benefit of the activity. Someone would have an identified regulation when they engage in health behaviours such as teeth cleaning because they want to maintain good oral hygiene. Integrated regulation is the most autonomous type of extrinsic motivation. The regulation manifests as people come to identify with the benefits of health in such a way as to equate “engaging in health behaviour” with “I’m a healthy person”. Integrated regulation has a similar amount of self-determination to intrinsic motivation, but these forms of motivation differ because whereas intrinsic motivation acts as a spontaneous behavioural impetus emerging from implicit interest, identified regulation necessitates extensive reflection and self-awareness (Reeve, 2012). Someone would exhibit an identified regulation when they identify with a health behaviour or an activity. Together, identified and integrated forms of behavioural regulation possess perceived volition. Accordingly, they are understood to encapsulate *autonomous* forms of motivation (Standage et al., 2018).

2.2 THE EMPIRICAL BASIS OF SDT IN HEALTHCARE SETTINGS

2.2.1 SDT IN HEALTHCARE SETTINGS

MOTIVATION.

In line with SDT, autonomous motivation tends to be central to an individual's sense of self and has been shown to lead to adaptive health outcomes (Deci & Ryan, 1985; Ng et al., 2012). Conversely, controlled appears to contribute to negative consequences for well-being in health settings. For instance, autonomous motivation had been shown to encourage health-promoting behaviours, which may lead to positive health outcomes. Indeed, a meta-analysis of 184 datasets (Ng et al., 2012) showed that autonomous motivation leads to various positive health outcomes. Research studies have demonstrated that autonomous motivation leads to better outcomes in different treatment programmes such as those focused on substance abuse (Zeldman, Ryan, & Fiscella, 2004), tobacco dependence (Williams, Patrick, Niemiec, Ryan, Deci, & Lavoie, 2011), physical activity promotion (Fortier, Sweet, O'Sullivan, & Williams, 2007), dental hygiene (Halvari & Halvari, 2006; Halvari, Halvari, Bjornebekk, & Deci, 2010) and healthy eating (Coa & Patrick, 2016). Autonomously motivated individuals are more likely to engage in health-promoting behaviours, which may result in better mental and physical health outcomes. For instance, positive outcomes include: better self-esteem, eating regulation and diet quality of women (Guertin, Barbeau, Pelletier, & Martinelli, 2017), higher quality of life ratings for overweight teenagers (Fenner, Howie, Straker, & Hagger, 2016), higher fruit and vegetable intake (McSpadden, Patrick, Oh, Yaroch, Dwyer, & Nebeling, 2016), medication adherence of heart failure patients (Stamp, Dunbar, Clark, Reilly, Gary, Higgins, & Ryan, 2016), fewer depression symptoms in HIV patients (Shah, Majeed, Yoruk, Yang, Hilton, McMahon, Hall, Walck, Luque, & Ryan, 2016) and intentions of H1N1 flu patients to wear protective masks

(Chan, Mullan, Zhang, Chatzisarantis, & Hagger, 2015). Therefore, it is important to ensure that people who are accessing healthcare doing so for autonomous reasons.

BASIC PSYCHOLOGICAL NEED SATISFACTION AND FRUSTRATION.

Basic psychological needs are those innate motivation resources of autonomy, competence and relatedness (Ryan & Deci, 2000). Autonomy is the need to regulate and control one's choices and decisions. Competence is the need for understanding the reason behind one's actions and feeling achievement from completing tasks. Relatedness is the need to connect with other people (Deci & Ryan, 1985). When the needs are satisfied, patients are more likely to choose to look after their health based on their own free will and to find the behaviour important and meaningful or rewarding in terms of their inner goals (Deci & Ryan, 2000). When these needs are frustrated, the patient will adopt the behaviour suggested by the doctor (for instance, attempting to lose weight or trying new medications) but the reasons for which the patient takes part in the behaviour changes are due to feeling pressured by the doctor or because they feel that they should, as opposed to for intrinsic reasons (Deci et al., 1994).

Relatedness, for instance, will be satisfied when the doctor accepts the patient's perspective (Deci & Ryan, 1985, 2000). Competence will be satisfied when the doctor provides reasons for treatments and gives positive feedback when the patient follows prescribed guidelines and adheres to medication and treatment regimens (Deci & Ryan, 2000). Autonomy will be satisfied by the doctors allowing patients to make choices and communication in a neutral and accepting manner, as opposed to a forceful or controlling one (Deci et al., 1994). A research study showed how need satisfaction leads to autonomous motivation (Koponen, Simonsen, Laamanen, & Suominen, 2015). The findings of the study were that when the patients had a higher perceived competence of being able to achieve their self-care goals (i.e., need satisfaction), they became autonomously motivated. The autonomous motivation led to health behaviour change (better glycaemic control for patients with type 2 diabetes).

Other research has shown how need satisfaction and need frustration lead to divergent outcomes (Bartholomew, Ntoumanis, & Thogersen-Ntoumani, 2011; Chen, Vansteenkiste, Beyers, Boone, Deci, Kaap-Deeder, Duriez, Lens, Matos, Mouratidis, & Ryan, 2015). For instance, when needs are satisfied, students in Belgium and China scored high on subjective vitality, life satisfaction and self-esteem, and low on depression levels (Chen et al., 2015). Furthermore, Chen et al. (2015) found that need frustration contributed to students' ill-being (as indexed by more depression symptoms and lower levels of subjective vitality, life satisfaction and self-esteem). A study by Bartholomew et al. (2011) found similar results. Here, need satisfaction among athletes was positively associated with vitality and positive affect. By contrast, need frustration contributed to negative outcomes such as eating issues, burnout, negative affect, physical symptoms, and depression. Overall, research has shown that need satisfaction leads to autonomous motivation which results in positive health outcomes, whereas need frustration leads to controlled motivation which can promote negative health outcomes. According to the above evidence, it is important to foster an environment, which supports need satisfaction.

AUTONOMY SUPPORT.

Given psychological need satisfaction is influential in health behaviour, it follows that the supports for the psychological needs would also be. When the social environment supports basic need satisfaction, it helps to enable internalisation and may also improve wellbeing (Standage et al., 2018). The social environment will support basic psychological needs when competence support (structure) and relatedness support (involvement) in an autonomy-supportive as opposed to controlling manner (Standage et al., 2018).

According to SDT, autonomy-supportive behaviours are purported to support the psychological needs (Mageau & Vallerand, 2003). Autonomy support refers to the degree to which healthcare staff encourage patients to take initiative in their health behaviours, be active problem solvers and take a patient-based, rather than professional perspective (Black & Deci, 2000; Grolnick, 2002; Gurland & Grolnick, 2003; Mageau & Vallerand, 2003). Many researchers have defined the critical features of

autonomy support. Grolnick and Ryan (1989) and Reeve (2006), for example, highlight the salience of appreciating patient perspectives by acknowledging negative affect. Such a psychological component of autonomy support is tied to the idea of professional empathy (cf. Koestner et al., 1984). A further feature of autonomy support is the delivery of choice and joint-decision making (Marbell & Grolnick, 2013; Reeve, 2006) that are understood to expedite perceptions of autonomy. Lastly, Assor, Kaplan and Roth (2002) contend that a salient feature of autonomy support is to support patient independence by permitting them to express their thoughts and opinions. Together, these provisions permit patients the freedom to self-endorse healthcare advice and prescription and, therefore, cultivate their psychological needs.

More specifically, permitting patients the occasion to voice and act on their perspectives is likely to yield autonomy satisfaction. Likewise, conveying trust in patients' capacities to be self-directed in their health behaviours is likely to satisfy competence. Finally, taking interest in and valuing patient perspectives is likely to yield heightened relatedness. In order to be autonomy-supportive, then, a doctor should consider the perspective of the patient, explain treatments and reasons behind prescriptions, promote choices and encourage patients to make decisions (Deci & Ryan, 1985). By contrast, a doctor provides a controlling environment when they do not give rationales, do not let patients make choices or decisions and are not interested in understanding the view of the patients (Deci & Ryan, 2000).

Research has shown that autonomy support leads to autonomous motivation via basic need satisfaction, while controlling environments are related to controlled motivation via need frustration (Bartholomew et al., 2011; Edmunds, Ntoumanis, & Duda, 2007; Reeve, 2012; Standage, Duda, & Ntoumanis, 2003, 2005; Williams, 2002). Autonomous motivation has been shown to lead to maintained health behaviours due to need satisfaction based on autonomy-supportive perceptions of the environment (Hagger, Chatzisarantis, Barkoukis, Wang, & Baranowski, 2005; Hagger, Chatzisarantis, Culverhouse, & Biddle, 2003). For instance, in a physical activity promoting study (Hagger & Chatzisarantis, 2007), it was found that when the environment was autonomy-supportive, students reported stronger intentions to exercise and exercised more frequently. Additionally, students were autonomously motivated to exercise if the environment was autonomy-supportive.

Within the biomedical ethics domain, the autonomy of patients is considered a valuable outcome of health interventions (Beauchamp & Childress, 2001). Therefore, in patient-centred care, one of the important ways of supporting the patient for the physician to provide an environment which makes the patient feel more autonomous. A meta-analysis of SDT health interventions (Ng et al., 2012) provided clear support for patient-centred care approaches (Street et al., 2009). SDT is a patient-centred theory as the concepts of autonomy-supportive healthcare climate, psychological need satisfaction and autonomous motivation are based on the point of view of the patient.

2.2.2 THE MOTIVATION OF THE DEAF POPULATION IN HEALTHCARE SETTINGS.

As we have seen, Deaf people experience issues with access, communication, and motivation in healthcare (for instance, Emond et al., 2015a, 2015b; Iezzoni et al., 2004; Kritzinger et al., 2014; McKee et al., 2011). In some ways, these issues might be described as motivational. That is, Deaf people appear to report many controlling and need frustrating experiences as opposed to autonomy-supportive ones (see Emond et al., 2015a, 2015b; Kritzinger et al., 2014; Reeves & Kokoruwe, 2005; Ringham, 2012). To date, SDT interventions have not been conducted on Deaf people's motivation in the healthcare domain. However, Deaf people are likely to experience motivational issues which can be viewed within the SDT framework. In particular, need frustration experiences are common among this population and these may be influential in understanding health inequities.

COMPETENCE FRUSTRATION.

There are many examples of controlling environments in the healthcare experiences of Deaf people. For instance, the environment could be said to be controlling when Deaf people have little perceived support for their health issues, treatments or rationales for the reasons behind them. There is much data to support these ideas in terms of competence frustration. For example, Deaf people generally experience a lack of health information provision and have a weak understanding of health issues. The 2011 Census for England and Wales showed that 65% of British Sign Language users are unable to understand English (British Sign Language

Broadcasting Trust, 2016). Additionally, research suggests that Deaf people in the UK have an average reading level of an 8 to 9-year-old child (Sterne, 2009). The Deaf population also have limited health knowledge. For instance, research studies show that 40% of Deaf participants did not know heart attack symptoms, 60% did not know any symptoms of stroke and also that the participants could only identify 50% of the risk factors for cardiovascular disease (Margellos-Anast, Estarziau, & Kaufman, 2006). Additionally, certain English words such as “cholesterol” do not have signs available in British Sign Language (Patel et al., 2011), which means that many Deaf people will not be able to understand written health materials. Lastly, lip-reading leads to Deaf people understanding of only around 40% of spoken words (Ebert & Heckerling, 1995; Lieu, Sadler, Fullerton, & Stohlmann, 2007; Steinberg et al., 2006). However, although accessing information by lip-reading and from written notes is hard for Deaf people, many Deaf people report having to use these methods of communication in healthcare settings (Steinberg et al., 2006).

Shortage of information at an appropriate level for Deaf people was highlighted by research which showed that most health emergency materials were written using language above the recommended reading levels (8 to 9 year old child level for Deaf people; Neuhauser, Ivey, Huang, Engelman, Tseng, Dahrouge, Gurung, & Kealey, 2013). Additionally, it was shown that there is a lack of preventative health information available in sign language (Bisol, Sperb, Brewer, Kato, & Shor-Posner, 2008; Napier & Kidd, 2013). In general, Deaf people do not access information incidentally (such as from the radio, TV or written information on billboards) to the same extent as hearing people (Pollard, Dean, O'Hearn, & Haynes, 2009). Another reason that Deaf people often do not understand health treatments is due to a lack of British Sign Language interpreters. In the UK there is one fully qualified British Sign Language interpreter available for every 275 Deaf people (Royal National Institute for Deaf, 2004). A research study showed that around 40% of Deaf people were able to access a British Sign Language interpreter in healthcare settings (Hocker, Letzel, & Munster, 2012), whereas in another study 39% of Deaf patients were unable to access British Sign Language interpreters (Henning, Krägeloh, Sameshima, Shepherd, Shepherd, & Billington, 2011). A study reported that 70% of Deaf participants had not attended a GP surgery recently although they needed to do so as there was no British Sign Language interpreter available (Emond et al., 2015a, 2015b). Deaf patients also reported that it is particularly

difficult to access a British Sign Language interpreter for healthcare appointments at short notice and in emergencies (Smeijers & Pfau, 2009). However, Deaf people may still have problems even when British Sign Language interpreters are available. This may be because the British Sign Language interpreters are unqualified (Harrington & Turner, 2001; Lane, 1992) or because certain patients do not feel comfortable asking private medical questions when a British Sign Language interpreter is present (Arulogun, Titiloye, Afolabi, Oyewole, & Nwaorgu, 2013; Middleton et al., 2010).

When British Sign Language interpreters are not accessible or Deaf people would prefer not to use British Sign Language interpreters, supportive technology might be used to gain access to healthcare. However, supportive technology can be problematic for certain Deaf people. For instance, teletypewriter (TTY) involves written communication (and therefore misunderstanding due to Deaf people's issues with vocabulary and English grammar) and due to healthcare staff not knowing how to use TTY (Steinberg et al., 2006). Relay services can also be difficult to use in certain situations such as when a doctor's surgery has an automated appointment system which requires entering numbers on the keypad – because it takes too long for the British Sign Language interpreter to explain to the Deaf person what to type (Steinberg et al., 2006). Additionally, a study found that many GP surgeries require the patients to call on the telephone to make appointments or ask the GP questions, which is not possible for Deaf people (Smeijers & Pfau, 2009).

Poor communication was stated as a reason for not using healthcare service for 36% of Deaf participants (Emond et al., 2015a). Communication in healthcare settings suffers when British Sign Language interpreters are not available for healthcare appointments. In that situation, Deaf people may have to bring hearing family members who can sign to appointments or use suboptimal communication methods. The issues surrounding using family members to interpret are misunderstanding, the family members talking to the healthcare staff but not to the Deaf patient and being overprotective (Harrington & Turner, 2001; Kritzinger et al., 2014; Lane, 1992; Steinberg et al., 2006). The evidence above highlights how the Deaf people's competence need can be frustrated in healthcare settings due to low health knowledge, understanding, lack of British Sign Language interpreters and poor communicated.

RELATEDNESS FRUSTRATION.

Another way in which Deaf people perceive healthcare to be suboptimal is when healthcare professionals make little attempt to or are unable to acknowledge patient perspectives due to lack of Deaf awareness and/or inappropriate attitudes (Emond et al., 2015a; Naseribooriabadi, Sadoughi, & Sheikhtaheri, 2017). This is likely to impact on levels of related and, more specifically, relatedness frustration. For instance, in terms of Deaf awareness, a study showed that health staff did not know how to best communicate with Deaf patients (Ubido et al., 2002). Other research also highlights healthcare staff's lack of Deaf awareness (Harmer, 1999; Iezzoni, O'Day, Killeen, & Harker, 2004; Meador & Zazove, 2005; Munoz-Baell & Ruiz, 2000; Steinberg, Sullivan, & Loew, 1998). Similarly, healthcare professionals can sometimes hold implicit biases against Deaf people such as viewing Deaf patients as not being confident or independent and having a non-questioning attitude (Kritzing et al., 2014). The lack of understanding and respect between Deaf people and healthcare professionals may hinder the building of relationships and frustrate relatedness. Accordingly, this may be another factor that helps us to understand the perceived poor healthcare received by members of the Deaf community.

AUTONOMY FRUSTRATION.

As with competence and relatedness, there is also evidence that healthcare settings are autonomy frustrating for Deaf people. Indeed, the healthcare environment is commonly experienced as controlling, with Deaf people reporting manifold incidences of patronising language and coercive behaviour that prompt them to accept views or treatments, as opposed to allowing them to partake in these healthcare decisions (Emond et al., 2015a, 2015b; MacKenzie & Smith, 2009; Reeves, Hogan, & Rafferty, 2002; Scheier, 2009; Steinberg, Wiggins, Barmada, & Sullivan, 2002; Steinberg et al., 2006). In particular, autonomy is likely frustrated when Deaf people communicate in healthcare settings in the absence of British Sign Language interpreters (Emond et al., 2015a, 2015b; Middleton et al., 2010; Reeves et al., 2002). In those situations, the communication between Deaf people and healthcare staff is often suboptimal. The suboptimal communication methods are lip-reading, spoken English and writing. The overwhelmingly preferred method of communication for Deaf people is British Sign

Language. Evidence suggests that although most (50-80%) of Deaf patients want to communicate with healthcare professionals in British Sign Language but only 30% do so (Emond et al., 2015a; Feldman & Gum, 2007; Middleton et al., 2010). In fact, writing was the most used method of communicating with Deaf patients (46% of appointments) in healthcare, although none of the Deaf patients prefer communication by this method (Ebert & Heckerling, 1995; Emond et al., 2015a). Additionally, researchers found that 23% of Deaf people communicated with healthcare professionals using spoken English together with lip-reading although none to communicate in this manner (Emond et al., 2015a). Only 11% of Deaf people would prefer to only lip-read in appointments (Middleton et al., 2010). Therefore, research has clearly demonstrated that Deaf people would prefer to communicate in British Sign Language as opposed to lip-reading, spoken English or writing. However, Deaf people's communication preferences are still not being met in healthcare. As such, Deaf people's autonomy is commonly frustrated.

HEALTH OUTCOMES.

According to SDT if the patients' basic psychological needs are supported via the provision of autonomy-supportive environment, motivation will be more likely to be autonomous (i.e., conducted for internal reasons) and health behaviour will more likely be initiated and maintained (Williams, Deci, & Ryan, 1998). If behaviour change is maintained, this will potentially lead to better health outcomes. Conversely, it has been shown that controlling environments lead to basic need frustration, resulting in controlled motivation (Chen et al., 2015). The outcomes of controlled motivation are behaviours that are conducted for external reasons, which are less likely to be maintained and more likely to lead to worse health outcomes (Chen et al., 2015; Haerens, Aelterman, Vansteenkiste, Soenens, & van Petegem, 2015; Oliver, Markland, Hardy, & Petherick, 2008).

For Deaf populations, it has been shown that if healthcare access and communication is poor, Deaf people are more likely to experience worse preventative care than hearing people (Barnett, 2002), visit the Emergency Department more frequently (McKee et al., 2011), as well as having higher rates of obesity and pre-diabetes (Barnett et al., 2011). Deaf people also report limited knowledge surrounding health issues, which may be the result of poor healthcare access and communication.

For instance, Deaf people were shown to be unaware of their legal rights in healthcare settings (Steinberg et al., 2006). Additionally, Deaf people have reported lower levels of illness and treatment knowledge for HIV/AIDS, cardiovascular disease, cancer and preventative measures. For HIV/AIDS, Deaf people from 52 countries stated that they thought HIV/AIDS did not affect Deaf people (Haualand & Allen, 2009). In terms of cardiovascular disease knowledge, 39% of Deaf participants were not aware that they should call 911 if cardiovascular symptoms were experienced, 40% did know any of the symptoms of a heart attack and 60% did not know any stroke symptoms (Margellos-Anast et al., 2006). In Deaf cancer knowledge research studies, Deaf people did not know what the purpose of cancer screenings, mammograms or pap smears was or why medical and surgical cancer interventions were necessary (Orsi et al., 2007; Steinberg et al., 2002). Preventative healthcare knowledge was also poor for Deaf people, who were less likely than hearing people to believe that preventative measures (such as smoking less, healthy diet, regular exercising, and physical exams) were useful for maintaining good health (Tamaskar, Malia, Stern, Gorenflo, Meador, & Zazove, 2000). Different research studies highlight how low levels of healthcare access and poor communication in healthcare settings can lead to negative views, emotions, and physical outcomes, as well as limited knowledge of treatments and illnesses of Deaf patients. Therefore, research has shown how Deaf people often experience the “dark” side of motivation (Haerens et al., 2015) in healthcare, which is the pathway from controlling environments to need frustration to controlled motivation, lower behaviour change maintenance and worse outcomes.

However, there are ways in which Deaf people could have more positive healthcare experiences. Better outcomes could be achieved if the healthcare environments are more autonomy-supportive, resulting in need satisfaction which leads to autonomous motivation and behaviour change maintenance. Deaf healthcare issues are grouped around health access and communication. If Deaf people are to experience health equity they should be provided with more qualified and experienced British Sign Language interpreters, allowed to make communication method choices, encouraged to make informed choices and decisions by being provided with appropriate levels of healthcare information for their communication needs and health literacy as well as more sources of information from different communication modes. Also, Deaf people could have a more positive experience if they were able to forge emotional connections

with doctors (which would be more possible if healthcare staff made efforts to raise their own Deaf awareness, which would allow them to understand Deaf needs and views). Lastly, if Deaf people are provided with appropriate technological support (based on British Sign Language English and not audio technology like telephones), they would be more likely to use it for healthcare needs, reducing access issues as well as supporting the Deaf people by making them feel more competent and autonomous during healthcare experiences. SDT, then, is a highly useful framework for understanding and explaining healthcare issues, concerns, and best practice in the Deaf population.

2.2.3 THE CAPABILITY OF MHEALTH INTERVENTIONS TO AFFECT HEALTHCARE MOTIVATION.

MHEALTH AND MOTIVATIONAL CONCEPTS FROM SDT.

Returning to mHealth interventions, it is likely that SDT also helps us to understand how and why mHealth may be especially useful to the Deaf population. Given the communication issues and need frustration experiences detailed above, videoconferencing may be an especially beneficial application of mHealth for health communication and access of Deaf people, as well as having the potential to positively affect motivation during healthcare interactions. Videoconferencing could allow Deaf people the use of functions a telephone provides for hearing people (making appointments and conducting brief appointments by phone), as well as being able to communicate during appointments with the doctor via a British Sign Language interpreter. The outcome of better understanding and confidence might be Deaf people becoming more autonomously motivated to attend further appointments and to look after their health.

With regard to SDT, using videoconferencing may help to satisfy the basic psychological needs. For instance, competence satisfaction could occur due to Deaf people getting a better understanding of their health issues and easier access to health knowledge at an appropriate level (when videoconferencing meetings involve interactions between British Sign Language interpreters, Deaf people and healthcare

staff). Understanding what is going on during healthcare appointments may allow Deaf people to follow prescribed treatments with a higher level of accuracy, resulting in the Deaf people feeling less frustrated and confused as well as in better health outcomes. Additionally, some Deaf people are likely to learn how to use new technology (tablets and videoconferencing software) which may make them feel more competent in another aspect of their lives.

Autonomy is likely to be satisfied if the patients feel more confident in terms of treatment decision-making due to understanding what the possible options are and due to being able to communicate with the healthcare staff on the same level of understanding and knowledge as hearing people. This could lead to the patients being more autonomously motivated as they are able to make choices about their decisions which feel more personal and important to them. If choices about health are made for personal reasons, Deaf people are more likely to have more maintained behaviour changes, which is likely to lead to better health outcomes. Additionally, the Deaf person's autonomy could be satisfied from being able to communicate in their preferred manner (with a British Sign Language interpreter), as well as having communication options (as Deaf people can choose when to communicate by videoconferencing and when to communicate by other methods).

Finally, relatedness is likely to be satisfied when Deaf people feel more connected to the healthcare staff. This might be the case because using videoconferencing with a hearing British Sign Language interpreter and the Deaf person could help the healthcare staff to appreciate Deaf people's needs and points of view better and act more compassionately towards Deaf people. In turn, for the Deaf person, if the barrier of mistrust and frustration from misunderstanding is removed by a videoconferencing intervention, the Deaf people might be more likely to form a more equal relationship with their doctor. If the relationship between the doctor and patients is stronger, this could lead to more autonomous motivation for positive behaviour change due to more compassion of healthcare staff and Deaf people towards each other. This may, in turn, lead to better health outcomes. In summary, then, videoconferencing could provide a very useful modality for healthcare professionals to create an autonomy-supportive environment via the satisfaction of basic psychological needs.

2.3 INTERPRETERNOW INTERVENTION

2.3.1 WHAT IS INTERPRETERNOW?

InterpreterNow is a mHealth intervention that was developed in response to a large cohort survey conducted by Emond et al. (2015a, 2015b) and described in detail in chapter one. It is a Video Remote Interpreting Service, which provides a way of connecting the hearing and Deaf populations via commonly used videoconferencing technology. The Deaf person can communicate with a sign language interpreter on the screen of their device, who then translates from sign language to spoken English for the hearing healthcare professional. Highly trained remote sign language interpreters are available in daytime working hours. The interaction can take place live (the Deaf person contacts the remote sign language interpreter during a health appointment, for instance) or through remote means (where the British Sign Language interpreter translates for the Deaf person during a phone conversation with a hearing person).

The InterpreterNow mobile application can be used across different platforms (mobile phones, tablets and computers). Also, Deaf people can decide how and when to communicate about their healthcare. This intervention aims to give Deaf people more access to health facilities via better and instant communication, improve understanding of health issues, as well as empowering Deaf people and making them feel more involved in their healthcare. The type of technology that is used for this intervention (videoconferencing application for mobiles, tablets and computers) is appropriate for Deaf people as is evidenced in the results of a survey which showed that Deaf people tend to use smartphones and personal computers more than other types of technology (Maiorana-Basas & Pagliaro, 2014).

2.3.2 INTERPRETERNOW AND MOTIVATION (SDT).

SDT provides a useful theoretical explanation of how and why videoconferencing interventions, such as InterpreterNow influence motivation and health behaviour change. This theory proposes that behavioural engagement and psychological wellness are enacted when people's basic psychological needs are fulfilled. InterpreterNow provides for support of the basic psychological needs. Indeed, the specific aim of the intervention is to increase patient autonomy through enhanced control of their healthcare both in terms of scheduling and communication. It is likely, too, that the relatedness of Deaf people would be increased due to better healthcare experiences and clearer communication with healthcare professionals. The competence and health literacy of Deaf people should also be supported by InterpreterNow, given its facilitation of clear and interpretable health guidance and diagnosis. In summary, then, this thesis is committed to testing the efficacy of a new mHealth technology, InterpreterNow, in bringing about enhanced health among members of the Deaf population. As a means of explaining these effects, based in the foregoing theory and evidence, it is anticipated that this intervention will yield adaptive outcomes via supporting the satisfaction of the basic psychological needs of autonomy, competence, and relatedness.

2.4 CHAPTER OVERVIEW AND THESIS AIMS

2.4.1 CROSS-SECTIONAL STUDY AND PILOT TRIAL SUMMARY.

CHAPTER 3.

The initial empirical study in this thesis is comprised of a cross-sectional data analysis. This chapter was written with the aim to expand on the existing literature and test SDT's mediation model of healthcare motivation in a Deaf sample. In line with extant research and SDT, we hypothesised that autonomy support from healthcare professionals would positively predict psychological need satisfaction and negatively predict psychological need frustration. In turn, psychological need satisfaction was expected to positively predict autonomous motivation for healthcare and negatively predict amotivation and controlled motivation for healthcare. Psychological need

frustration, on the other hand, was expected to positively predict controlled motivation for healthcare and negatively predict autonomous motivation for healthcare.

CHAPTER 4.

This thesis study was a proof of concept trial. As part of the trial, participants were given tablets with InterpreterNow and asked to use them for one year (April 2016-April 2017) in healthcare settings (e.g., GP surgery, opticians and dentists). The variables which were measured included: demographic information (date of birth, gender, postcode, ethnicity, personal deafness definition, age first became Deaf), current medication, medical history, preventative measures, healthcare access and experience, health markers (weight, BMI, waist circumference and blood pressure), health anxiety, autonomy support (from the doctor and from important others like friends or family members), need satisfaction and frustration, motivation, locus of control and health literacy. These outcomes were measured before participants were provided with the tablet and after one year of using InterpreterNow service in health settings.

Additionally, every time that the participants used InterpreterNow, they were asked to complete a questionnaire about usability (items about ease/quality of the connection, the frequency of disconnects, quality of interaction, changes to communication/healthcare experience, satisfaction with interaction outcome, and the likelihood of using InterpreterNow for next interaction). Participants were randomly allocated to the intervention group or the control group. The control group used healthcare services as they have always used them (usual care). At the end of the trial, when the intervention group participants returned the tablets, the control group participants received the tablet and underwent the same procedure as the intervention group.

2.4.2 QUALITATIVE STUDY SUMMARY.

CHAPTER 5.

The next study comprising this thesis aims sought to provide rich and detailed information about the InterpreterNow service use. The topics of interest were: whether the InterpreterNow service works, key benefits, limitations, and how to improve the service in the future. The study involved qualitative analyses of interviews with British Sign Language interpreters and healthcare professionals as well as Deaf people's focus groups. Five British Sign Language interpreters were interviewed in person. Seventeen Deaf people participated in focus groups. Lastly, six healthcare professionals were interviewed by telephone. All participants were asked about their views and experiences of using InterpreterNow service. The focus groups and interviews permitted an understanding of user experiences in rich narrative detail – including critical insight into how and why the trial worked (or did not work).

2.4.3 FEASIBILITY STUDY SUMMARY.

CHAPTER 6.

This empirical chapter (Study 4) was focused on the feasibility of the InterpreterNow trial. The key issues discussed were the acceptability of the intervention and demand. To find out about acceptability in the current study, different sources of information were used. Information examined was about the understanding of procedures of the intervention, acceptability of the intervention to participants, satisfaction with the intervention outcomes, as well as benefits and issues related to the intervention. Acceptability and suitability information was obtained from indicators of engagement with the intervention process. The intervention process measures were obtained from the feedback of project workers as well as the immediate and one year follow-up usability questionnaires completed by participants about their expectations and experiences of study participation and the intervention. Demand was evaluated through a cost evaluation and by scrutinising usage data. Additionally, cost savings from using online methods compared with face-to-face methods were calculated. Usage information was obtained from data collected by the InterpreterNow application developers on how much the intervention was used and for which healthcare services.

CHAPTER 3: CROSS-SECTIONAL DATA ANALYSIS

3.1 INTRODUCTION

The health of Deaf people is considered to be poorer than that of the general population (Emond et al., 2015b). Deaf health is poorer because Deaf people typically avoid formal healthcare settings due to negative experiences, such as not feeling empowered, motivated, involved or respected by medical staff and the healthcare system (e.g., Emond et al., 2015; Fellingner et al., 2012; Meador & Zazove, 2005). In a recent survey, Action for Hearing Loss (2012) showed that communication issues are especially problematic (e.g., GP not facing the patients, GP not speaking clearly and the GP not checking the patient's understanding). The Action on Hearing Loss (Ringham, 2012) survey additionally showed that communication problems resulted in to 28% of Deaf people being unclear about diagnosis, 26% being unclear about health advice, and 19% being confused about medication following GP appointments (Ringham, 2012). A way to improve the healthcare provision among Deaf people is to better understand and support their motivational needs. Guided by Self-Determination Theory, then, this study investigates a model of healthcare motivation among a sample of Deaf people.

3.1.1 SELF-DETERMINATION THEORY.

A theoretical framework of motivation which might offer insight into the contextual processes that lead to positive and negative health outcomes in the Deaf population is Self-Determination Theory (SDT; Deci & Ryan, 2000). SDT is focused on how behaviour is regulated and postulates a number of different motivational regulations (Ryan & Connell, 1989; Ryan & Deci, 2000). The first, intrinsic motivation, arises when people act out of enjoyment and interest without external reasons. Second, integrated regulation, is a regulation in which an individual has reflectively endorsed behaviours as

aligning with their own world views and lifestyle. Third, identified regulation, arises via understanding the personal value and purpose of a behaviour. Fourth, introjected regulation, is motivation to avoid guilt or to feel proud of an achievement. Fifth, external regulation, is when behaviours are controlled by external contingencies such as rewards (such as good grades or prizes) or avoiding punishment (such as detention or losing money). Finally, amotivation, is a state of not being motivated in any way.

The primary distinction between the types of motivation regulation is in how the activity has been internalized into one's self-concept (Reeve, 2012). Intrinsic, identified, and integrated regulations are understood to be fully internalized as they reflect activities that are socialized as concordant with pre-existing values and goals of the self. In turn, they are grouped as autonomous forms of motivation as they encapsulate behaviours that are freely chosen without contingency. As a result, autonomously motivated individuals do not feel compelled to do the activity but, rather, engage out the sense of identity and enjoyment that leads to greater health behaviour adherence and well-being. Introjected and external regulations, on the other hand, are only partially internalized (introjection) or non-internalized (external regulation) in one's concept of the self. In turn, they are grouped as controlled forms of motivation because they encapsulate compulsive and rigid behaviour to serve an end other than the activity itself. Accordingly, controlled individuals feel compelled to engage out of a need to self-validate, garner social approval, and receive external reinforcements through participation which leads to poorer health behaviour adherence and greater ill-being.

Research supports the benefits of autonomous motives for health behaviours and well-being in healthcare settings. Autonomous motivation contributes positively to weight loss (Williams, Grow, Freedman, Ryan, & Deci, 1996), diabetes self-management (Williams, Freedman, & Deci, 1998; Williams et al., 2004), alcohol treatment programme engagement (Ryan, Plant, & O'Malley, 1995), fewer depression symptoms (Zuroff, Koestner, Moskowitz, McBride, Marshal, & Bagby, 2007), oral health behaviours (Halvari & Halvari, 2006), healthy eating (Pelletier & Dion, 2007), exercise planning for patients with heart disease (D'Angelo, Reid, & Pelletier, 2007), increased physical activity (Bagoien & Halvari, 2005), smoking cessation (Williams, McGregor, Sharp, Levesque, Kouides, Ryan, & Deci, 2006) and medication adherence (Williams, McGregor, Zeldman, Freedman, & Deci, 2004). It is also linked to positive psychological

factors such as having self-efficacy about maintaining healthy behaviours (Guertin, Rocchi, Pelletier, Emond, & Lalonde, 2015), self-esteem, positive affect and health-related quality of life (Standage & Gillison, 2007).

Also, in line with SDT, research shows that controlled motivation is maladaptive in terms of health behaviour and well-being. For instance, controlled motivation has been shown to result in treatment non-adherence (Williams, 2002; Williams et al., 1998), unhealthy eating (Guertin et al., 2017; Pelletier, Dion, D'Angelo, & Reid, 2004), lower levels of conducting health behaviours (Hagger, Hardcastle, Mallet, Pal, & Chatzisarantis, 2014), low maintenance of healthy eating (Stadler, Oettingen, & Gollwitzer, 2010) and poor alcohol treatment response (Ryan et al., 1995). It also correlates with higher adherence to negative social norms and attitudes about binge drinking (Hagger, Lonsdale, Hein, Koka, Lintunen, Pasi, Lindwall, Rudolfsson, & Chatzisarantis, 2012), and more depression symptoms (Rouse, Ntoumanis, Duda, Jolly, & Williams, 2011). Overall, autonomous motivation is linked to adaptive healthcare outcomes, whereas controlled motivation contributes to more negative outcomes.

NEED SATISFACTION AND NEED FRUSTRATION.

The basis for internalisation is the satisfaction of the basic psychological needs for autonomy, competence and relatedness (Deci & Ryan, 2000; Williams et al., 1998). Autonomy is “the experience of behaviour as volitional and reflectively self-endorsed” (Niemic & Ryan, 2009; p. 135). For instance, when patients are autonomous then they are willing to actively engage in trying to understand and participate in the health decision-making process. Relatedness reflects perceptions that one is valued and belongs within close groups (Deci & Ryan, 2000; Vansteenkiste, Ryan, & Deci, 2008). For instance, when a patient feels that their doctor respects and understands their needs and cares for their well-being, their relatedness need would be satisfied. Competence refers to feeling effective in terms of achieving goals and functioning at full capacity (Deci & Ryan, 2000; Vansteenkiste et al., 2008). For example, a patient might feel competent if they believe in their capacity to adhere to a treatment regimen.

Research has shown that when the psychological needs are satisfied, autonomous motivation and positive health outcomes typically follow (Edmunds et al.,

2007; Halvari et al., 2010). Psychological need satisfaction leads to more flossing and reduction in dental plaque (Halvari et al., 2010), greater subjective vitality and well-being of athletes (Adie, Duda, & Ntoumanis, 2008; Felton & Jowett, 2013), higher levels of exercise for participants of an online exercise programme (Weman-Josefsson, Lindwall, & Ivarsson, 2015), self-efficacy for overcoming exercise barriers, commitment to exercise and intention to continue exercising of overweight/obese people (Edmunds et al., 2007), greater well-being for nursing home residents (Kasser & Ryan, 1999) and dieting behaviour maintenance (Hagger, Chatzisarantis, & Harris, 2006).

Alongside psychological need satisfaction, research has begun to examine the antecedents of partial internalization and non-internalization, namely psychological need frustration (Deci & Ryan, 2000). Unlike a lack of psychological need satisfaction, psychological need frustration occurs when one feels acutely rejected or excluded in terms of social contexts (relatedness frustration), feels that they are unable to achieve goals fully (competence frustration) and feels patronised and excluded from decision making (autonomy frustration). Research shows that when the psychological needs are frustrated, controlled motivation and ill-being are the results. There is little research on psychological need frustration in healthcare settings, but research in other life spheres is suggestive. For instance, research has shown a link between need frustration and motivation (Krijgsman, Vansteenkiste, van Tartwijk, Maes, Borghuots, Cardon, Mainhard, & Haerens, 2017). In this study from the education domain (n=409), students' motivation and need satisfaction/frustration were measured during lessons which were graded or not graded. Psychological need frustration was negatively correlated with intrinsic motivation and positively correlated with external regulation. It is likely that external regulation (controlled motivation) from need frustration leads to negative health outcomes. Examples of negative outcomes due to the effect of need frustration on controlled motivation include: more binge eating and depression in the adolescent population (Koop-Deeder, Vansteenkiste, Soenens, Verstuyf, Boone, & Smets, 2014; Verstuyf, Vansteenkiste, Soenens, Boone, & Mouratidis, 2013), as well as burnout, disaffection, and negative affect in athletes (e.g., Balaguer, Gonzalez, Fabra, Castillo, Merce, & Duda, 2012; Bartholomew, Ntoumanis, Ryan, Bosch, & Thogersen-Ntoumani, 2011; Curran, Hill, Ntoumanis, Hall, & Jowett, 2016). Additionally, it was found that the need frustration of students results in depression, low self-esteem (Chen et al., 2015;

Nishimura & Suzuki, 2016), as well as higher somatization and anxiety (Cordeiro, Paixao, Lens, Lacante, & Luyckx, 2016).

AUTONOMY-SUPPORTIVE HEALTHCARE CLIMATE.

According to SDT, autonomy-supportive behaviours of healthcare professionals are purported to support the psychological needs of patients (Mageau & Vallerand, 2003). According to Reeve (2006), there are five key behaviours that are characteristic of autonomy support. First, autonomy-supportive professionals attempt to nurture patients' inner resources by instructing in such a way that supports their interests, sense of enjoyment, and preference for volition. Secondly, autonomy-supportive professionals rely on informational, non-controlling language, which flexibly relays messages to patients with information-rich, competence-affirming statements that describe why they are doing well or making progress. Third, autonomy-supportive professionals communicate value and provide meaningful rationales such that patients are aware of the use, importance or otherwise unapparent personal relevance of healthcare recommendations. Fourth, autonomy-supportive healthcare professionals acknowledge and accept negative affect to counter the motivational problem that they often encounter when they negotiate conflicts between what patients want to do, and what they need them to do. Fifth, autonomy-supportive professionals are patient, giving patients enough time to make decisions and actively listening.

Providing patients with the opportunity to voice and act on their ideas is likely to afford satisfaction of the need for autonomy. Similarly, conveying trust in patient's abilities to be self-directed in their behaviours is likely to satisfy competence. Likewise, taking interest in and respecting patient perspectives is likely to facilitate relatedness. Research supports these ideas. For example, autonomy support from the healthcare staff at a hospital was linked to patient need satisfaction which led to autonomous motivation for weight gain in anorexia nervosa patients (Koop-Deeder et al., 2014). It was also found that perceived autonomy support from physicians and nurses increased basic need satisfaction of haemodialysis patients, which then led to higher health-related quality of life ratings (Chen, Chang, Tsai, & Hou, 2018). This pathway has been shown in studies on diabetes self-management (Koponen et al., 2015; Williams, Lynch, & Glasgow, 2007; Williams, Patrick, Niemiec, Williams, Divine, Lafata, Heisler, Tunceli,

& Pladevall, 2009; Williams et al., 2004), physical activity adoption counselling (Fortier et al., 2007), weight loss (Silva, Markland, Vieira, Coutinho, Carraca, Palmeira, Minderico, Matos, Sardinha, & Teixeira, 2010), smoking abstinence (Williams, Niemiec, Patrick, Ryan, & Deci, 2009) and mental health (Jochems, Mulder, Duivenvoorden, van der Feltz-Cornelis, & van Dam, 2014; Zuroff, Koestner, Moskowitz, McBride, & Bagby, 2012).

SDT IN DEAF POPULATIONS.

A healthcare population neglected in existing SDT research is Deaf people. Here, SDT may have utility in explaining the motivational processes that yield sustainable motivation for healthcare because Deaf people are typically controlled or amotivated when it comes to seeking health advice and support (Emond et al., 2015a, 2015b; Fellingner et al., 2012; Royal National Institute for the Deaf, 2004). The reason for the amotivation may be that Deaf people do not tend to feel that their physicians are creating an autonomy-supportive environment. For instance, Deaf patients are often dissatisfied with treatment and communication in healthcare settings (Barnett, Koul, & Copolla, 2012; Steinberg et al., 2006; Witte & Kuzel, 2000). Medical practitioners were reported to have the opinion that Deaf patients needed more time and effort than hearing patients and to be more likely to provide services with a range of other issues (chronic illness, mobility, cognitive or psychiatric) than hearing people (Bachman, Vedrane, Drainoni, Tobias, & Maisels, 2006; Ebert & Heckerling, 1995). Also, medical staff have been shown to act in a patronising as opposed to an empathetic or supportive manner towards Deaf patients if treatment was attempted (MacKenzie & Smith, 2009). Other issues that were experienced by Deaf people included disagreements about the communication and access needs of Deaf people between the Deaf people and healthcare staff, Deaf people's worries about not understanding treatment regimens and correct medication dosage, poor Deaf awareness of healthcare staff, not enough British Sign Language interpreters available, problems during physical procedures and examinations and the inability of Deaf patients to communicate by telephone (Iezzoni et al., 2004; Middleton et al., 2010; Reeves, Kokoruwe, Dobbins, & Newton, 2004).

The low autonomy-supportive environment may result in Deaf people's basic psychological needs being frustrated. For instance, Deaf people may feel that their

autonomy is not supported due to the patronising and controlling attitudes of healthcare staff and not having access to their preferred communication methods (Emond et al., 2015a, 2015b). Patients may experience the frustration of the competence need when they do not understand the treatment prescribed by the doctor (Ubido et al., 2002) or take the wrong medication dosage (Iezzoni et al., 2004). Lastly, relatedness may be frustrated if patients feel that the healthcare staff are not supportive, that healthcare providers “discounted and disbelieved” Deaf people, rushed through appointments and lacked Deaf awareness (Nemon, 1980; Ubido et al., 2002). The basic psychological need frustration could lead to lower quality motivation, which may then result in Deaf people using healthcare service less than hearing people, being less likely to receive preventative measures such as pap smears or mammograms, more likely to take wrong medication doses and having less knowledge about illnesses and related risk behaviours (Royal National Institute for the Deaf, 2004; Tamaskar et al., 2000; Woodroffe, Gorenflo, Meador, & Zazove, 1998). Additionally, Deaf health has been reported to be worse than that of the general population (Brown & Cornes, 2014; Emond et al., 2015a, 2015b).

Whilst the SDT process model has been tested for a variety of populations, no attempts have been made to identify whether SDT constructs can be used to explain the motivation for Deaf people’s health behaviours and outcomes. The Deaf people’s lack of motivation, as well as negative behaviours and health outcomes, seem to be related to the negative impact of a low autonomy-supportive environment created by healthcare providers, as was shown above. Therefore, the present research aims to identify the SDT constructs and the links between them in the Deaf population.

3.1.2 STUDY AIMS.

Deaf people are understood to suffer from communication and motivational difficulties in healthcare settings (Emond et al., 2015a, 2015b). The aim of this study, then, is to expand on the existing literature and test SDT’s mediation model of healthcare motivation in a Deaf sample. In line with extant research and SDT, we hypothesised that autonomy support from healthcare professionals would positively predict basic psychological need satisfaction and negatively predict basic psychological need frustration. In turn, basic psychological need satisfaction was expected to

The same sample of Deaf people was analysed throughout the thesis. This is the case because this vulnerable population was difficult to recruit. In more sparse areas (such as Cumbria), there were far less Deaf people who were available to recruit. Also, some Deaf people could not participate as they had an additional learning disability or found it hard to understand British English and it was not possible to be certain that they had understood the details of the study. In terms of intervention delivery, many deaf people forgot or got confused about using the tablet and the mobile application and got discouraged from using InterpreterNow very quickly, leading to participants withdrawing from the study. During data collection, some deaf people found the questionnaire pack hard to understand also. In terms of follow-up, after the initial study was completed, many of the participants were not motivated to return for follow-up questionnaires or interviews. Also, only four project workers were employed by the SignHealth charity for the purpose of supporting the InterpreterNow project. The project workers were responsible for recruiting participants, supporting the participants with the questionnaires, explaining the reasons for the study to the participants, training participants to use the tablet and InterpreterNow and supporting participants during the intervention. The high workload for the project workers (particularly during the testing phase) was another reason for how many participants were recruited. That is, the project workers supported participants as much as they could (based on their contracted hours and availability).

3.2.2 PROCEDURE.

A questionnaire pack including the Treatment Self-Regulation Questionnaire, the Healthcare Climate Questionnaire and the Basic Psychological Need Satisfaction and Frustration Scale was administered after approval from the local university ethics committee. The participants were required to sign a consent form to verify the participants' understanding of the right to withdraw and of the trial purpose. The questionnaire pack was given to participants before they participated in the trial. Participants were supported by project workers who communicated in sign language at level 3 (or higher) and also participants were shown British Sign Language video recordings for some of the questionnaires. The questionnaire pack took up to an hour to complete.

3.2.3 MEASURES.

HEALTHCARE CLIMATE.

Autonomy support was assessed through the previously validated short form HCCQ (Williams et al., 1996). The interpersonal climate of the healthcare professionals that the Deaf participants might be involved with was analysed by asking the participants to rate six statements (e.g., “My physician encourages me to ask questions.”). Each item was responded to using a seven-point Likert-type scale (strongly disagree=1; strongly agree=7). HCCQ has shown good internal consistency (.82) in health research (Williams et al., 1996).

BASIC PSYCHOLOGICAL NEEDS.

The 24-item Basic Psychological Need Satisfaction and Frustration Scale (Chen et al., 2015) was used to assess the satisfaction and frustration of the basic psychological needs of autonomy, competence and relatedness. There are six subscales within the overall scale – three scales about need satisfaction and three scales about need frustration. Each need frustration and satisfaction subscale are assessed by four items scored on a five-point Likert scale ranging from 1 (*Not true at all*) to 5 (*Completely true*). In the original study (Chen et al., 2015) internal consistency is adequate, with Cronbach’s alphas between .73 and .89 for satisfaction subscales and between .64 and .86 for frustration subscales.

AUTONOMOUS AND CONTROLLED MOTIVATION.

The Treatment Self-Regulation Questionnaire (Levesque, Williams, Elliot, Pickering, Bodenhamer, & Finley, 2007) was used to assess different forms of motivation (autonomous, controlled and amotivation). This scale has been used with varying stems such as “behaving in a healthy way” (Williams et al., 1996) or “The reason I follow my diet and exercise regularly is that” (Williams et al., 1998) or “The reason I take my medications as prescribed and check my glucose regularly is that” (Williams et al., 2004). For this study, the stem was “The reason I would engage in my healthcare is that”. The stem was followed by items representing autonomous

motivation (e.g., “Because I personally believe it is the best thing for my health.”) And controlled motivation (e.g., “Because others would be upset with me if I did not.”). Participants are asked to respond to items on a seven-point Likert-type scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). The internal consistency of each subscale was acceptable, with most Cronbach’s alphas being over .73 (Levesque et al., 2007).

3.2.4 ANALYSIS METHODOLOGY.

PATH ANALYSIS.

Path analysis was employed to assess the hypothesised model using IBM AMOS (Arbuckle, 2008). One exogenous variable (Autonomy Support), the mediator variables (Psychological Need Satisfaction and Frustration), and the two endogenous variables (Autonomous and Controlled Motivation) were represented using measured variables. This approach is similar to work that has attempted to test these relationships in other domains (e.g., Alvarez, Balaguer, Castillo, & Duda, 2009; Gagne, 2003; Hagger et al., 2003). This method was considered the most suitable due to the small sample size and the necessity of a minimum case-to-parameter ratio for coefficient stability (5:1; Kline, 1998). Conventional criteria were used to adjudicate the fit of the hypothesised model to the observed data. Adequate fit was deemed sufficient when: TLI and CFI > .90, SRMR & RMSEA < .10, $20 \chi^2/DF < 3$ (Bentler & Hu, 1995), whereas Hu and Bentler’s (1999) criteria were used as evidence of good fit: TLI and CFI > .95, RMSEA < .06, SRMR < .08. In a separate analysis, indirect effects with bias-corrected and accelerated bootstrap (1000 resamples) confidence intervals were calculated to assess the effect size and statistical significance of any mediation evidenced (MacKinnon, Lockwood, & Williams, 2004; Shrout & Bolger, 2002).

3.3 RESULTS

3.3.1 DESCRIPTIVE STATISTICS AND RELATIONSHIPS AMONG STUDY VARIABLES.

Prior to running the main analysis, the data were screened for missing values. There were 72 complete cases and 27 cases with incomplete data. For those with incomplete data, the percentage of missing data was between 1% and 100% (range 1-96). The probability of the pattern of missing values diverging from randomness was greater than .05 (MCAR $\chi^2=3854.859$, $DF=4233$, $p > .05$), thus data missing completely at random (MCAR) was inferred. Due to the low sample size and high amount of incomplete data, the items with over 50% missing data were removed ($n=9$). Then, the remaining missing items were estimated by using the full information maximum likelihood estimation (FIML). This resulting in a final sample of 90 (M age=56.26 years, $SD=2.12$). These data were approximately normal at the univariate and multivariate levels (skewness was between and kurtosis were between -1.96 and +1.96).

Table 1 (descriptive statistics and bivariate correlations) shows that participants perceived their healthcare professionals to be providing a high level of autonomy support. In our sample, autonomous motivation scores were higher than controlled motivation scores. Need frustration and satisfaction scores were moderate. Bivariate correlations between the latent variables were in accordance with the theoretical postulates. Need satisfaction and need frustration were positively associated with each other. Need frustration was positively associated with controlled motivation. Controlled and autonomous motivations were positively associated with each other.

Table 1. *Descriptive statistics and bivariate correlations for study variables (n=90).*

	M	SD	1	2	3	4	5
1. Autonomy Support	4.37	1.49					
2. Need satisfaction	3.10	.49	-.05				
3. Need frustration	3.09	.50	.32	.55**			
4. Autonomous Motivation	5.80	1.16	.10	-.18	-.16		
5. Controlled Motivation	4.79	1.15	.05	-.13	.03	.13	

Note: Significant effects * $p < .05$ level ** $p < .01$ level

3.3.2 PATH ANALYSIS FINDINGS.

Figure 2. *Results of path analysis. Note: Dashed lines indicate a non-significant effect; un-dashed lines indicate a significant effect. * $p < .05$, ** $p < .01$.*

3.4 DISCUSSION

The present study examined relationships from healthcare professional autonomy support to the autonomous and controlled motivation for healthcare via basic psychological need satisfaction and psychological need frustration in a sample of Deaf adults. Results provided little support for the hypothesised associations in this population. Of note, only a positive relationship between psychological need frustration and controlled motivation emerged in the analyses. All other paths were non-significant. For the Deaf population, then, it appears that controlled motivation for healthcare is increased they perceived that their psychological needs are frustrated.

3.4.1 SDT MODEL OF HEALTHCARE MOTIVATION IN DEAF PEOPLE.

As we have seen, the current findings largely do not concord with extant theory and research in populations other than Deaf people. In particular, the current findings suggest that autonomy support does not appear to have an impact on Deaf people's basic psychological needs. This result may be an artefact of the low sample size (more below) or it may be a population-specific effect particular to the Deaf community. Perhaps Deaf people are especially vulnerable to a lack of healthcare information and expertise (Emond et al., 2015b) and therefore competence, rather than autonomy, is the focal need to target in healthcare interactions. Here, structure may be required to build competence before Deaf people have confidence in their abilities to use autonomy granted by healthcare professionals for their own healthcare needs (cf. Curran, Hill, & Niemiec, 2013). More research is needed to test this possibility.

Other findings are also different from previous research (Ng et al., 2012). Notably, the pathway from psychological need satisfaction to autonomous motivation was not found in this study. Again, this may be due to the low sample size but there is also the possibility that this, too, is an effect specific to Deaf people. As can be seen in

the descriptive section, the variance in psychological need satisfaction was very small (i.e., under half a unit on a 7-point scale). This suggests that Deaf people feel commensurate amounts of psychological need satisfaction that are below levels seen in most other populations (e.g., Assor, Kaplan, Kanat-Maymon, & Roth, 2005; Haerens et al., 2015; Rouse et al., 2011). Given the homogeneity of perceived need satisfaction, relationships may be difficult to detect in small samples and this may explain the lack of findings here. More work, though, is needed to better understand this effect.

Finally, it was found in this study that psychological need frustration positively predicted controlled healthcare motivation. This finding is in line with extant research in other health domains (e.g., Bartholomew et al., 2011; Chen et al., 2015; Krijgsman et al., 2017). Therefore, it appears that although psychological need satisfaction did not predict autonomous healthcare motivation, psychological need frustration nevertheless carries negative effects. Here, controlled motivation for healthcare is likely when Deaf people feel controlled, incompetent, and rejected in the health domain and therefore appear to require support for these frustrated needs if and when they occur. We did not test the role of controlling environments on need frustration in this study, but controlling behaviours are known to frustrate the needs (e.g., Bartholomew et al., 2011; Curran et al., 2016; Krijgsman et al., 2017). Hence, mitigating these behaviours should be a goal of future interventions.

It is possible that the reason that the SDT constructs in the model were not strongly supported in baseline data is that the measurement instruments are not fit-for-purpose. For instance, the motivational measures have not been validated with a Deaf sample, meaning that it is unclear whether Deaf people were able to understand the questionnaires. In order to ascertain with more certainty whether Deaf people experience motivation in the same way as other populations, it is necessary to conduct a validation study of the questionnaire measures with this sample. As part of this validation study, researchers should ensure that Deaf participants are provided with BSL interpretation of the questions. Also, in the validation study, the wording of the questions should be simplified as some Deaf people do not understand conceptual words or do not know the meaning of medical terms due to low health literacy and the nature of BSL (Patel et al., 2011; Barnett & Pollard, 2009). Extensive pilot work with different Deaf people should have been conducted on the motivation questionnaires before using them in the baseline

study to ensure Deaf people understood the questions. In addition, the autonomy support questionnaire was brief whereas other questionnaires were too long. Therefore, length of questionnaires would be another factor which should be considered in measure validation. Lastly, it is possible that Deaf motivation is actually affected by different factors compared to general population motivation. For instance, perhaps the important other support is more important for Deaf people's motivation than healthcare autonomy support. This might be the case because a lot of Deaf people tend to have strong links within the Deaf community (Emond et al., 2015a, 2015b).

3.4.2 STRENGTHS AND LIMITATIONS.

This is the first study to apply and test an SDT model to the motivation of Deaf people in healthcare settings. The findings show limited support for the framework. Before we interpret these findings as a refutation of the theory, it is important to be aware of the studies limitations. We did not measure controlling behaviours, and these may be more proximal indicators of healthcare professional behaviour than autonomy support. Indeed, Emond et al. (2015a, 2015b) found that Deaf people consistently feel controlled in healthcare scenarios and relying on low scores of autonomy support may not pick these behaviours up (Bartholomew et al., 2011).

Due to the hard-to-reach nature of this population, our sample size was limited in this study at only 99 participants. This necessarily reduces power to detect effects in the population when they exist (i.e., Type II error). Although certain vulnerable populations like Deaf people may be referred to as hard-to-reach in literature, this term is largely inaccurate and unfair. In fact, methodology has been developed specifically for recruiting hard-to-reach people, such as chain referred methods (using several recruitment approaches and relying on previous participants' social networks), using indigenous field workers (field workers who are themselves from the sample under consideration), as well as relying on gatekeepers for recruitment, forming participant steering groups, targeted-based sampling, time-location sampling and conventional cluster sampling (Platt, Wall, Rhodes, Judd, Hickman, Johnstone, Renton, Bobrova, & Sarang, 2006; Kennan, Fives, & Canavan, 2011; Dowrick, Gask, Edwards, Aseem, Bower, Burroughs, Catlin, Chew-Graham, Clarke, Gabbay, Gowers, Hibbert, Kovandzic, Lamb, Lovell, Rogers, Lloyd-Williams, Waheed, & the AMP Group; Shaghaghi, Bhopal, & Sheikh, 2011). There is

ample evidence to support the view that using appropriate research methodology can lead to better recruitment and supportive experiences for vulnerable participants (Shaghghi et al., 2011; Kennan et al., 2011; Platt et al., 2006). Another important factor that may lead to better recruitment of vulnerable or hidden populations is the knowledge of the specific characteristics of the participants (Shaghghi et al., 2011). Furthermore, according to Freimuth & Mettger (1990), the reason that researchers may hold the view that certain groups are hard to reach, is that the researchers are frustrated by attempting to recruit people who are different to themselves and also due to failures of interventions to change the negative health behaviours of such vulnerable groups. Researchers may also carry discriminatory views, such as hard-to-reach participant groups are fatalistic, that they do not have high level information processing skills, and that they experience limited access to information from a variety of communication channels and distrust health institutions (Freimuth & Mettger, 1990). In order to overcome such prejudicial views, vulnerable participants should be viewed in a new way (Freimuth & Mettger, 1990). For instance, blame should be shifted to society (not the person), differences (instead of deficits) should be emphasized and patient-centred communication styles should be used by researchers during recruitment and the intervention (Freimuth & Mettger, 1990).

Therefore, reframing the way that vulnerable groups are viewed and communicated with, understanding the specific needs and characteristics of vulnerable groups as well as using appropriate recruitment methods is likely to lead to more positive recruitment experiences for researchers and more supportive experiences of research and engagement for vulnerable group members. Future follow-up work on this sample should attempt to use the above recommendations in order to not unfairly label the sample and also ensure more Deaf friendly recruitment.

Another limitation is that there was quite a large amount of missing data in this sample. The reasons for this related to Deaf participants' communication. For instance, not all Deaf people have a high enough level of literacy to complete written questionnaires (Pollard & Barnett, 2009). To overcome this issue, British Sign Language translation was provided by sign language fluent support workers and through British Sign Language videos. However, certain words are difficult to translate coherently into British Sign Language (Patel et al., 2011). Whilst some of the SDT questionnaires have been translated into other languages, translation and validation of such questionnaires

was beyond the scope of the current project. Future work should, however, aim to make the research more Deaf friendly by using questionnaires translated into sign language.

3.4.3 CONCLUSION.

This study has provided limited support for an SDT model of healthcare motivation in Deaf people. Whilst most relationships were not significant, the relationship between psychological need frustration and controlled motivation is suggestive of the potential ill effects of controlled environments in healthcare settings among this population. The fact that other relationships in the model were not significant may be due to one or a combination of Deaf specific effects, low participant numbers, lack of available validated questionnaires for Deaf populations, and missing data. In short, this study is suggestive – especially in the case of psychological need frustration and its effects. Here it speaks to the need to create more empowering climates for Deaf people that attempt to overcome controlling scenarios that create the perception of control and coercion. Accordingly, in the next chapter, I describe and test an intervention – InterpreterNow – committed to breaking down barriers that create controlling scenarios in healthcare settings by permitting Deaf people more control over their healthcare communication.

CHAPTER 4: RANDOMISED CONTROLLED TRIAL OF THE INTERPRETERNOW SERVICE

4.1 INTRODUCTION

There is a small but significant portion of the UK population who are Deaf. According to the most comprehensive estimates, nine hundred thousand people are severely or profoundly Deaf and 11 million people experience some degree of hearing loss in the UK (Ringham, 2012). As we have seen, Deaf people face many issues in terms of health access, which can result in negative healthcare experiences, as well as having detrimental consequences on Deaf health. The present research aims to improve Deaf health outcomes by introducing a timely mobile technology intervention, namely InterpreterNow. Deaf people in the UK are more likely to have hypertension, obesity, asthma and depression than hearing people (Emond et al., 2015b). In addition, Deaf people often have lower health literacy levels which means that Deaf people might not know when they are ill, might not know their family medical history, and are reluctant to seek out advice or information about their health (Emond et al., 2015a, 2015b). Deaf people also report difficulties accessing healthcare due to a lack of high-quality Deaf interpreters, not feeling motivated or empowered about their health, low Deaf awareness of health professionals, not feeling in control of their own healthcare and wanting to communicate in sign language but being unable to. This study aimed to investigate whether providing Deaf people with access to remote British Sign Language interpreters via InterpreterNow – a videoconferencing mobile application – could support Deaf people’s motivation towards positive health behaviours, leading to an increase in health knowledge, and help to improve the experiences of Deaf people within the healthcare setting.

4.1.1 DEAF HEALTH AND THE NEED FOR INTERVENTION.

BARRIERS TO HEALTHCARE.

Communication between Deaf people and health professionals is a prominent barrier to healthcare access for Deaf people. Action on Hearing Loss conducted a survey to identify whether Deaf people have the same access to healthcare services as

hearing people and to find out about Deaf people's healthcare experiences (Ringham, 2012). Six hundred and seven Deaf people were asked to report on their GP appointment experiences. Results indicated that, after the appointments, 28% of Deaf people were unclear about the diagnosis, 26% were unclear about health advice and 19% were also unclear about medication. The Deaf participants indicated that the central reasons for the communication problems were that the GP did not face the patients, that the GP did not speak clearly, and that the GP did not check the patient's understanding. Therefore, poor communication appears to result in misunderstanding that might provide some explanation for the inequity in health between the Deaf populations compared to the general population that I documented in the first chapter.

TRADITIONAL HEALTH INTERVENTIONS FOR DEAF PEOPLE.

Several Deaf health interventions have been employed to in an attempt to tackle some of the issues related to Deaf health inequity (e.g., Barnett et al., 2014; Choe et al., 2009; Engelberg, Nakaji, Harry, Wang, Kennedy, Pan, Sanchez, & Sadler, 2017; Folkins, Sadler, Ko, Branz, Marsh, & Bovee, 2005; Garnefski & Kraaij, 2011; Harry et al., 2012; Jensen et al., 2013; Kaskowitz et al., 2006; Patel et al., 2011; Sacks et al., 2013; Taegtmeier et al., 2009; Yao et al., 2012; Zazove et al., 2012). In the main, as described in Chapter 1, these interventions were effective in bringing about improvements in health outcomes for Deaf people such as knowledge increase, changes in attitudes, and symptom alleviation. To summarise, intervention studies have shown knowledge increases about symptoms and health risks of HIV, testicular and prostate cancer, smoking, cervical and ovarian cancer, skin cancer and heart disease (Berman, Guthmann, Crespi, & Liu, 2011; Choe et al., 2009; Folkins et al., 2005; Harry et al., 2012; Jensen et al., 2013; Patel et al., 2011; Taegtmeier et al., 2009), as well as anti-smoking attitude changes (Berman et al., 2011). Health interventions for Deaf people have also been successful at decreasing smoking (Berman et al., 2011), increasing weight loss (Barnett et al., 2014), and reducing depression and anxiety (Barnett et al., 2014; Folkins et al., 2005; Garnefski & Kraaij, 2011).

Yet the effectiveness of traditional health interventions are limited in that many have failed to consider the specific needs of Deaf people (see Jensen et al., 2013; Patel et al., 2011). Deaf people struggle in face-to-face interventions that do not employ

British Sign Language interpreters (remote or in person) due to limited levels of verbal vocabulary knowledge in the Deaf population (Pollard & Barnett, 2009). In addition, sign language itself has no signs for certain medical terms (e.g., “cholesterol” in Patel et al., 2011) making it difficult for hearing people to effectively communicate medical information to Deaf people. Therefore, it is often difficult to explain medical terminology and even harder to support health behaviour change via knowledge exchange. Finally, Deaf people may not be as aware as hearing participants of risk factors for illnesses such as heart disease (Patel et al., 2011) and HIV/AIDS (Heuttel & Rothstein, 2001). Therefore, traditional (face-to-face non-technological) health interventions that rely on using speech and writing to communicate are not always appropriate for Deaf people. This is primarily because Deaf people are unable to comprehend auditory information. In terms of written English, Deaf people’s access is often limited because sign language greatly differs from English (it has no written form and, the syntax and grammar are unlike English; van Staden, Badenhorst, & Ridge, 2009).

TECHNOLOGY FOR DEAF PEOPLE.

Given these limitations, certain technologies that support Deaf communication may provide a way of overcoming the problems related to traditional (face-to-face non-technological) interventions. Mobile health (mHealth) is an especially important technology in this regard, defined by WHO (Kay et al., 2011) as “medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices.” (p.6). mHealth has the potential to provide Deaf people with more control and autonomy as they are able to access health information and therefore make informed decisions about how and when to utilise their healthcare. mHealth interventions can also help to overcome issues of non-British Sign Language based interventions, as they provide opportunities for Deaf people to communicate using sign language or to use technological methods such as texting or writing emails instead of trying to lip-read. The use of mHealth makes certain tasks related to health promotion much easier due to higher processing power (such as information dissemination) and introduces new options (such as mobile applications for recording own health targets). mHealth technology can also help Deaf people in terms of providing shortcuts such as using automated booking systems to make healthcare appointments.

However, mHealth interventions may not be appropriate for all situations or for every Deaf person. For instance, Thoren and colleagues (2013) found that older participants with hearing loss (75-96 years old) were less likely to use the internet than younger participants with hearing loss (25-64 years old; Thoren et al., 2013). Maiorana-Basas and Pagliaro (2014) similarly found that younger Deaf people prefer to use mobile phones and iPads, whereas older Deaf people prefer computers. It is noteworthy, though, that Deaf people do seem to largely benefit from new technologies. A study by Power and Power (2004), reported that across Deaf people of all ages, having the opportunity to use mobile texting reduced stigma, improved communication with hearing and Deaf people alike and led to “spontaneous, unmediated, and private access to businesses, services” (p. 8).

INTERPRETERNOW.

InterpreterNow is a mHealth intervention that may provide a solution to a variety of issues relating to Deaf people’s health. The intervention is a mobile application developed subsequent to a large survey with Deaf people about their health-related issues (Emond et al., 2015). In this large survey, Deaf people indicated that contacting the GP or health centre was often difficult, that very little contact was made with the GP online or by mobile texts, that most Deaf people found receptionists unhelpful and that Deaf people often had to lip-read in health appointments. The issues that the survey revealed were related to worse health outcomes (Deaf people were found to be more likely to be obese and have higher levels of depression and hypertension than hearing people) but also to motivation, negative health experiences, lack of access to healthcare and sign language interpreters, as well as views of Deaf people about the hearing culture. To tackle these complex issues, the InterpreterNow mobile application was created. This mobile application works as a communication tool, whereby Deaf people can use online video calls (akin to Skype or facetime) to communicate with sign language interpreters in real time. The sign language interpreters are fully qualified and registered and available from 8am – midnight during weekdays and 8am – 8pm at the weekend. The large amount of control over communication options facilitated by InterpreterNow is provided as a response to Deaf people noting that they were often not able to communicate in their preferred way during healthcare appointments (Emond et al., 2015). The purpose of the mobile application is to directly address the variety of

communication issues raised by Deaf people in the Emond et al. (2015) survey. The aim of this research is to identify whether using this videoconferencing mobile application, which provides access to British Sign Language interpreters online, improves Deaf people's health knowledge, access, motivation and experiences in healthcare settings.

MECHANISMS OF CHANGE: INTERPRETERNOW AND SDT.

As we saw in the previous chapter, theoretical frameworks can be used to explain the mechanisms through which interventions may facilitate engagement in healthcare. SDT is such a theoretical framework that might be especially useful in the context of InterpreterNow. SDT is a meta-theory concerned with the tendencies of humans to seek the satisfaction of three innate basic psychological needs. To recap, these are the needs for autonomy, competence, and relatedness. Need satisfaction occurs when an autonomy-supportive environment is provided by healthcare professionals. An example of an autonomy healthcare environment is when the doctor acts in nurturing and supportive ways and is accepting of patient views (Jang, Kim, & Reeve, 2016). Conversely, controlling environments lead to need frustration, such as when doctors pressure patients to behave in prescribed ways and do not answer questions or allow for opinions other than their own (Jang et al., 2016).

Motivation for healthcare is directly affected by psychological need frustration or satisfaction. Need satisfaction leads to autonomous motivation, whereas need frustration leads to controlled motivation or amotivation. It has been shown that autonomous motivation leads to persistence, adherence and better health (e.g., Pelletier, Fortier, Vallerand, & Briere, 2001; Pelletier et al., 2004; Ryan, Rigby, & King, 1993). Conversely, controlled motivation results in treatment non-adherence (Williams, 2002; Williams et al., 1998), worsening of depression symptoms (Rouse et al., 2011) and negative health attitudes (Hagger et al., 2012). Therefore, in order to improve health-related outcomes, autonomous motivation is critical and should be maintained through need satisfaction from autonomy-supportive environments. We saw from the last study that, by contrast, when psychological needs are frustrated, controlled motivation that creates compromised health outcomes is yielded.

According to Patrick and Williams (2012), SDT is applicable for explaining health-based motivation because patient autonomy is fundamental to health and well-being. Autonomy is seen as a priority outcome in health ethics, as it can lead to social justice and welfare improvements. It was found that the core themes defining patient-centred care (i.e., autonomy-supportive care) were “patient participation and involvement, the relationship between the patient and the healthcare professional, and the context where care is delivered” (Kitson, Marshall, Bassett, & Zeitz, 2012; p.1). These themes intricately align to concepts proposed by SDT such as autonomy (patient participation and involvement), relatedness (the relationship between the patient and the healthcare professional) and the importance of the environment (context where care is delivered).

The review of Ng et al. (2012) further supports the view that SDT is relevant to understanding healthcare motivation. Ng et al. (2012) conducted a review of 184 SDT studies in healthcare settings. They showed that interventions, where healthcare staff were taught to behave in an autonomy-supportive manner led to improved adherence, motivation and health (e.g., for smoking in Niemiec, Ryan, Deci, & Williams, (2009)). Need satisfaction and autonomous motivation were also related to more flossing, visiting the dentist, life satisfaction, positive affect, reduction in weight and doing more exercise (Edmunds et al., 2007; Halvari et al., 2010; Silva et al., 2010). In relation to this thesis, SDT is especially useful in the context of Deaf health because Deaf people’s psychological needs are frequently thwarted (by healthcare professionals during healthcare appointments, for instance), which may explain why Deaf people report dissatisfaction with healthcare interactions (Emond et al., 2015). In this context, InterpreterNow may help to reduce the nature and frequency of need frustrating interactions and increase perceptions of need satisfaction. This is because InterpreterNow provides the opportunity for Deaf people to express their views and opinions via a trained translator (autonomy), to better understand and receive information regarding their health and healthcare needs (competence), and to interact more meaningfully and with a sense of understanding with the healthcare professional (relatedness).

4.1.2 PRESENT RESEARCH.

The current study, then, investigates the effect that InterpreterNow has on the motivation, access, and communication experiences of Deaf people in healthcare settings using a one year randomised controlled trial. The participants' views of healthcare communication, access and motivation were measured before and after the InterpreterNow trial. This study extends and improves on previous research by using rigorous methodology, a long timescale and by using Deaf friendly methodology.

In most Deaf health intervention studies, non-randomised controlled designs were used (Jensen et al., 2013; Sacks et al., 2013; Shabaik et al., 2010; Taegtmeyer et al., 2009; Wilson et al., 2015; Yao et al., 2012). This can lead to a lack of generability of the sample to the overall population as well as to the results occurring due to confounding variables. For this reason, the InterpreterNow trial uses more rigorous methodology (a waitlist randomised controlled trial). The control group were put into a waitlist and received access to InterpreterNow after the intervention group has finished the trial. This means that more Deaf people who need access to British Sign Language interpreters will be able to use InterpreterNow. Previous studies have also used short timescales (e.g., Blaiser et al., 2013; Garnefski & Kraaij, 2011; Wilson & Wells, 2009) which means that there might not be enough time to see all the possible changes that occur during the intervention. Therefore, the present study was conducted over one year to allow Deaf people enough time to use InterpreterNow for different healthcare appointments.

In this trial, Deaf needs were considered during the creation of the mobile application, which was informed by surveys on Deaf health (Emond et al., 2015). Additionally, Deaf staff on the data collection team and steering committees ensured that the insights from Deaf people were available to the hearing researchers. This is important because Deaf people are not always permitted to make their own decisions and Deaf needs are not satisfied in healthcare interactions (Emond et al., 2015). Moreover, the InterpreterNow trial provides Deaf people with different communication options by presenting all information in both written English and British Sign Language video format through the recruitment and intervention phases. The Deaf participants could choose how they communicated using the InterpreterNow mobile application

(remotely and in-situ). Additionally, this trial will be used to test Deaf health motivational changes by using SDT concepts. The trial will, therefore, extend the literature on SDT to the Deaf population by showing whether a higher autonomy-supportive environment due to a better relationship and understanding between doctors and Deaf patients can lead to improved Deaf need satisfaction and higher quality motivations for better health behaviours.

Lastly, this trial provides an insight into the use of videoconferencing for improving Deaf healthcare experiences. This extends on the Deaf videoconferencing intervention literature (Blaiser et al., 2013; Crowe et al., 2016; Wilson & Wells, 2009; Wilson et al., 2015) by attempting to investigate the use of videoconferencing to improve access to healthcare using more rigorous methodology than has been employed previously. In all, the present study provides an RCT test of a videoconferencing tool – InterpreterNow - committed to enhancing the health and healthcare experiences of Deaf people. It was anticipated that Deaf participants randomised to receive access to the InterpreterNow tool, relative to those in the control group, would report greater increases in health literacy, quality of health communication, autonomy support, autonomous motivation, and psychological need satisfaction. We also expected this group to show greater decreases in health anxiety, controlled motivation and psychological need frustration.

4.2 METHODS

4.2.1 PARTICIPANTS.

Ninety-nine participants (n=99) were recruited across four regions in the United Kingdom over a six-month period and randomly allocated to the intervention (n=52) or control (n=47) group (Table 2). Participants were based in Merseyside (n=29), Cumbria (n=30), Worcester (n=37) and Greater Manchester (n=3). There were no significant differences across all demographic variables (i.e., based on allocation or location). The mean age of all trial participants was 54.5 years (range=19 to 76). Participants were predominantly female (59%) and White British (only one person self-identified as Asian). Most participants self-identified as Deaf (n=96), three participants self-identified as Hard of Hearing and one participant as Deafened. Sixty-two participants had Deafness onset

at birth, whereas 29 became Deaf between birth and 3 years of age, and seven after 3 years of age.

DEMOGRAPHIC DATA.

Table 2. *Demographic profile of participants.*

Characteristic	Intervention (n=52)	Control (n=47)
Age in years, M (SD)	54.8 (12.6)	54.3, (13.0)
% Female	56	62
<u>Ethnicity (n, %)</u>		
White	51 (98)	47 (100)
Asian	1 (2)	0
<u>Region (n, %)</u>		
Worcestershire	20 (38)	18 (38)
Merseyside	15 (29)	13 (28)
Cumbria	15 (29)	15 (32)
Greater Manchester	2 (3.8)	1
<u>Hearing status (n, %)</u>		
Deaf	49 (94.2)	46 (98)
Hard of Hearing	2 (3.4)	1 (2)
Deafened	1 (2.4)	0
<u>Onset of Deafness (n, %)</u>		
At birth	34 (65)	28(60)
0 to 3 years old	13(35)	16(34)
3 to 6 years old	3(6)	1(2)
6 years or older	1(2)	2(4)

HEALTH MARKERS.

Mean scores for weight, waist circumference and body mass index (BMI) can be found in Table 3. The waist circumference definition varies by gender (NICE, 2006). For men, waist circumference is considered low if it is of less than 94 cm, for women low is less than 80 cm. High waist circumference is from 94 to 102 cm for men and from 80 to 88cm for women. Very high waist circumference is over 102 cm in men and over 88 cm in women. Mean scores indicate that the waist circumference was very high for both male and female participants.

Body mass index ranges are underweight (below 18.5), normal (19.5 to 24), overweight (25 to 29) and obese (30 or higher) (Centres for Disease Control and Prevention, 2018). Obesity is subdivided into Class 1 (31 to 34), Class 2 (35 to 39) and Class 3 (40 or higher). Mean BMI scores indicate that male participants are classified as Class 1 obese and women classified as overweight.

Table 3. *Mean (SD) for weight, waist circumference and BMI by gender across condition.*

Health markers	Intervention (n=47)		Control (n=47)		Total (n=94)	
	Female (n=27)	Male (n=20)	Female (n=28)	Male (n=19)	Female (n=55)	Male (n=39)
Weight	82.54 (19.73)	84.22 (18.11)	82.42 (14.04)	82.55 (13.48)	82.48 (16.91)	83.40 (15.83)
Waist circumference	102.74 (12.85)	106.93 (13.38)	104.12 (10.77)	101.78 (11.26)	103.45 (11.75)	104.42 (12.51)
BMI	29.78 (5.37)	31.81 (5.51)	29.63 (4.42)	30.13 (5.48)	29.70 (4.87)	30.99 (5.49)

HEALTH RISK CRITERIA.

OBESITY.

The risks related to obesity according to UK guideline (NICE, 2006) for study participants is shown in Table 5. The majority of participants were classified as either at high (24%) or very high (46%) risk of obesity-related diseases. Only 13% were classified as having no risk of obesity-related diseases.

Table 4. *Obesity-related health risks.*

BMI classification	Waist circumference		
	Low	High	Very High
Normal Weight (18.5 to less than 25 kg/m²)	No increased risk	No increased risk	Increased risk
Overweight (25 to less than 30 kg/m²)	No increased risk	Increased risk	High risk
Obesity I (30 to less than 35 kg/m²)	Increased risk	High risk	Very high risk
Obesity II (35 to less than 40 kg/m²)	Very high risk	Very high risk	Very high risk
Obesity III (40 kg/m² Or more)	Very high risk	Very high risk	Very high risk

Table 5. *Health risks related to obesity (n, %).*

Criteria	Intervention (n=39)	Control (n=41)	Total (n=80)
No increased risk	6 (15)	4 (10)	10 (13)
Increased risk	9 (23)	5 (12)	14 (18)
High risk	8 (21)	11 (27)	19 (24)
Very high risk	16 (41)	21 (51)	37 (46)

BLOOD PRESSURE.

According to the criteria established by the UK charity Blood Pressure UK (<http://www.bloodpressureuk.org/bloodpressureandyou/Thebasics/Bloodpressurechart>), the majority of participants were categorised as having pre-high (35%) or high blood pressure (47%) with only 19% categorised as having ideal blood pressure (see Table 6). None of the participants had low blood pressure.

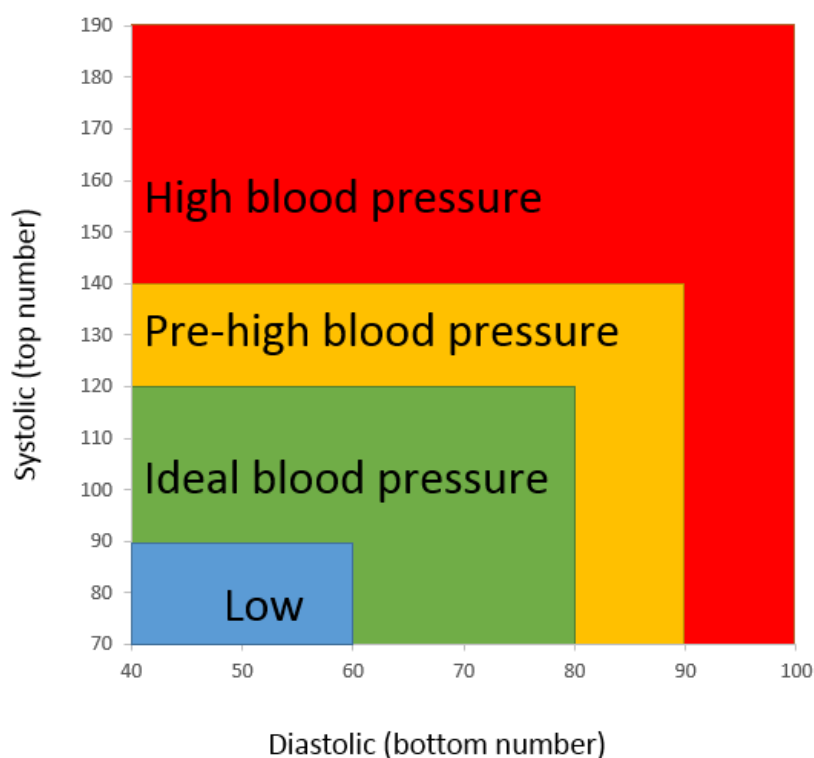


Figure 3. *Blood pressure chart for adults (adapted from www.bloodpressureuk.org).*

Table 6. *Blood pressure criteria (n, %).*

Criteria	Intervention (n=41)	Control (n=40)	Total (n=81)
Low	0	0	0
Ideal	8 (20)	7 (18)	15 (19)
Pre-high	12 (29)	16 (40)	28 (35)
High	21 (51)	17 (42)	38 (47)

CURRENT MEDICATIONS.

The most common medication taken was aspirin (n=11) and the least common medications were warfarin (n=3) and clopidogrel (n=3) (see Table 7). In the present study, 66 % of the participants stated that they always received the correct medication from their doctor, with 16% stating that they sometimes receive the wrong prescription. In 35% of cases, the participants claimed that they had the wrong prescription due to communication problems.

Table 7. *Current medications taken by the participants (total n=99, the values below are for participants who stated that they are taking the medications).*

Medications	Intervention (n, %)	Control (n, %)	Total (n, %)
Aspirin	4 (4)	7 (7)	11 (11)
Clopidogrel	2 (2)	1 (1)	3 (3)
Beta-blocker	2 (2)	2 (2)	4 (4)
Warfarin	2 (2)	1 (1)	3 (3)
Other medications	14 (14)	23 (23)	37 (37)

Note: Other medications: zapain, codeine phosphate, loratadine, metformin, ramipril, perindopril, paracetamol, levothyroxine, amlodipine, crestor, lansoprazole, atorvastatin, fexofenadine, simvastatin, cosmocol, metabet, zicron, tramadol, thyroxine.

MEDICAL HISTORY.

The most common illness the respondents experienced was hypertension (n=21) and the least common was schizophrenia (n=1) and chronic obstructive pulmonary disease (n=1) (see Table 8). The medical history of participants in the present study was similar to that reported in a previous large-scale survey in the Deaf population (SignHealth, 2014).

Table 8. *Medical history for participants who had the illnesses (total n=99).*

Illnesses	Intervention (n, %)	Control (n, %)	Total (n, %)
Angina	3 (3)	0	3 (3)
Heart Failure	2 (2)	3 (3)	5 (5)
Raised Blood Pressure (hypertension)	11 (11)	10 (10)	21 (21)
Diabetes	7 (7)	4 (4)	11 (11)
Chronic kidney Disease	2 (2)	0	2 (2)
Chronic Obstructive Pulmonary Disease (COPD)	0	1 (1)	1 (1)
Asthma	10 (10)	9 (9)	19 (19)
Epilepsy	1 (1)	1 (1)	2 (2)
Underactive thyroid	5 (5)	6 (6)	11 (11)
Depression	11 (11)	9 (9)	20 (20)
Schizophrenia	0	1 (1)	1 (1)
Bipolar disorder	4 (4)	0	4 (4)
Atrial fibrillation	1 (1)	1 (1)	2 (2)
Arthritis	13 (13)	7 (7)	20 (20)
Other illnesses	10 (10)	7 (7)	17 (17)

Note: Other illnesses: B12 deficiency, multinodular thyroid (full removal of the gland), overactive thyroid, panic attacks, stroke, stress, glaucoma, retina pigmentosa, macular degeneration, IBS, B52 iron, stent, Meniere's disease, balance vertigo.

PREVENTATIVE MEASURES.

Information about preventative measures is a useful indicator of both healthcare access and of the Deaf people taking responsibility for looking after their health. The most common preventative measure was getting a blood test (n=65) and the least common was the prostate exam (n=10) (see Table 9).

Table 9. *Preventative measures for participants who said they had the tests (n=99).*

Measure	Intervention (n, %)	Control (n, %)	Total (n, %)
Flu vaccine	20 (20)	22 (22)	42 (42)
Blood test	36 (36)	29 (29)	65 (65)
Pap smear	7 (7)	8 (8)	15 (15)
Prostate examination	7 (7)	3 (3)	10 (10)
Mammogram	8 (8)	5 (5)	14 (14)
Any other procedures	3 (3)	7 (7)	10 (10)

Note: Other procedures include audiology, bowel cancer screening, glucose (eye test), irregular blood pressure check, liver scan, heart scan, CAT scan, trigger finger operation, steroid injection in the back.

4.2.2 PROCEDURE.

Participants whose preferred method of communication is British Sign Language were recruited from four regions of the United Kingdom. Each region (Merseyside, Greater Manchester, Cumbria and Worcestershire) had a British Sign Language-fluent project worker that managed the recruitment and data collection. The project workers received standardised training about how to collect, manage and store data. Ethical approval was obtained from the University of Bath Ethical Review board (EP 14/15). Project workers visited local Deaf clubs and organisations to deliver information about the study at advertised group sessions. Individuals interested in participating in the study were provided with a Participant Information Sheet (PIS; Text form and British Sign Language). Once the information had been received, participants were given 24 hours to consider if they would like to participate in the study. No sooner than 24 hours later, the project worker contacted individuals who had demonstrated an interest in participating in the study.

All participants who agreed to participate in the study attended a face-to-face baseline data collection. Before commencing the baseline data collection, participants were requested to confirm that they had read the PIS and had had an opportunity for any questions to be answered. Subsequently, participants provided written informed

consent. All participants who provided informed consent were asked to complete a baseline data collection. Participants were then randomly allocated to either the intervention group or the waitlist control group (Kim & Shin, 2014). Random allocation was achieved by using a random number generator website (<https://www.randomizer.org/>). The input for the website was the number of groups (2), how many numbers per set and number range (1=intervention, 2=control). The output was a list of digits (ones and twos) which were provided in a random order. Then the researcher allocated participants to the designated group based on the list. The group assignment was revealed to the participant after the completion of the baseline questionnaire.

4.2.3 INTERVENTION.

Participants who had been randomly allocated to receive the intervention were immediately provided with a tablet (Samsung Galaxy Tab4) containing the InterpreterNow app. Intervention participants were trained (for 30 – 45 minutes) in how to use the InterpreterNow application and given information regarding the terms of use and the situations in which the service could be used. Remote interpreters via InterpreterNow were available from 8am – midnight during weekdays and 8am – 8pm at the weekend. The InterpreterNow service was available for use for any health-related interaction including but not limited to GP surgeries, health centres, hospitals, walk-in centres, opticians and dentists. Access to InterpreterNow was provided for 12 months.

Participants allocated to the waitlist control group continued receiving standard healthcare provision without any additional intervention for 12 months (i.e., without receiving a tablet). After 12 months, waitlist control participants received a tablet and training with the same access to InterpreterNow for six months.

4.2.4 OUTCOMES.

At both the baseline and post-test data collections, participants were asked questions by the project worker about health information, healthcare communication and psychological factors (see Appendix 1 for psychometric instruments employed):

HEALTH INFORMATION.

Information about participants' health markers (weight, waist circumference and body mass index (BMI)), medications currently taken, medical history and preventative measures. This information was collected at baseline only. Information about health literacy was collected at pre and post-test. The health literacy questionnaire was the Rapid Estimate of Adult Literacy in Medicine (REALM) scale made up of 66 items (Davis, Long, Jackson, Mayeaux, George, Murphy, & Crouch, 1993; Pollard & Barnett, 2009). This scale includes 66 medical terms such as "impetigo", "colitis" and "smear". Participants are asked to circle any words which they knew the meaning of. This task has been previously validated with a Deaf sample (Pollard & Barnett, 2009). The internal consistency is high at a Cronbach's alpha of .98 (Dumenci, Matsuyama, Kuhn, Perera, & Siminoff, 2013).

HEALTHCARE COMMUNICATION.

Participants were asked about what communication methods are normally used and whether this is the preferred method. For example, participants were asked, "What method of communication do you most frequently use at each of the following centres (GP surgery, NHS hospital, Chemist, Opticians)?" Participants were provided with six different options to select from; British Sign Language Interpreter/British Sign Language no interpreter/Spoken English/Lip-Reading/Speaking and Signing/Written. This data was collected at pre and post-test.

PSYCHOLOGICAL FACTORS.

Autonomy support in healthcare climates and for important others, basic psychological needs, motivation (autonomous and controlled), health anxiety and health locus of control. This data was collected at pre and post-test. Healthcare autonomy support was assessed through the previously validated short form Healthcare Climate Questionnaire (HCCQ; Williams et al., 1996). The interpersonal climate of the healthcare professionals that the Deaf participants might be involved with was analysed by asking the participants to rate six statements (e.g., "My physician encourages me to ask questions."). Each item was responded to using a seven-point Likert-type scale

(strongly disagree=1; strongly agree=7). HCCQ has shown good internal consistency (.82) in health research (Williams et al., 1996).

Important other autonomy support was assessed by the Important Other Climate Questionnaire (IOCQ; Williams, Lynch, McGregor, Ryan, Sharp, & Deci, 2006). The perceptions of Deaf people about how autonomy-supportive their important others are was analysed by participants rating six statements (e.g., "I feel that my important others have provided me with choices and options about improving my health"). Each item was responded to using a seven-point Likert-type scale (strongly disagree=1; strongly agree=7). HCCQ has shown good internal consistency (.88) in health research (Williams et al., 2006).

The 24-item Basic Psychological Need Satisfaction and Frustration Scale (Chen et al., 2015) was used to assess satisfaction and frustration of the basic psychological needs of autonomy, competence and relatedness. There are six subscales within the overall scale – three scales about need satisfaction and three scales about need frustration. Each need frustration and satisfaction subscale is assessed by four items scored on a five-point Likert scale ranging from 1 (*Not true at all*) to 5 (*Completely true*). In the original study (Chen et al., 2015) internal consistency is adequate, with Cronbach's alphas between .73 and .89 for satisfaction subscales and between .64 and .86 for frustration subscales.

The Treatment Self-Regulation Questionnaire (Levesque et al., 2007) was used to assess different forms of motivation (autonomous, controlled and amotivation). This scale has been used with varying stems such as "behaving in a healthy way" (Williams et al., 1996) or "The reason I follow my diet and exercise regularly is that" (Williams et al., 1998) or "The reason I take my medications as prescribed and check my glucose regularly is that" (Williams et al., 2004). For this study, the stem was "The reason I would engage in my healthcare is that". The stem was followed by items representing autonomous motivation (e.g., "Because I personally believe it is the best thing for my health.") And controlled motivation (e.g., "Because others would be upset with me if I did not."). Participants are asked to respond to items on a seven-point Likert-type scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). The internal consistency of

each subscale was acceptable, with most Cronbach's alphas being over .73 (Levesque et al., 2007).

The Health Anxiety Inventory (Salkovskis, Rimes, Warwick, & Clark, 2002) is a questionnaire about preoccupation with illness. The internal consistency is .95 (Cronbach's alpha), which means that the scale is acceptable. There are 14 questions, with 4 statements each. All groups of 4 statements are scored 0, 1, 2 or 3 depending on the statement selected. For instance, participants might be asked to choose a statement out of four which applies to their feelings from the following:

- a. I do not worry about my health
- b. I occasionally worry about my health
- c. I spend much of my time worrying about my health
- d. I spend most of my time worrying about my health

The Multidimensional Health Locus of Control (Wallston, 2013) scale is about the extent to which participants feel that their health decisions are controlled by themselves, powerful others or chance. Scoring high on powerful others scale means that participants feel strongly that powerful others such as doctors, family or friends are in control of their healthcare decisions. Participants are asked to give a score from 1 ("Strongly Disagree") to 6 ("Strongly Agree") to 18 statements (e.g., "If I become sick, I have the power to make myself well again."). When this scale was validated for Deaf people, the internal consistency was acceptable for the Chance subscale (Cronbach's alpha=.71) and moderate for the Powerful Others subscale (Cronbach's alpha=.68) and the Internal subscale (Cronbach's alpha=.60) (Athale, Aldridge, Malcarne, Nakaji, Samady, & Sadler, 2010).

4.2.5 ANALYSIS METHODOLOGY.

DESCRIPTIVE APPROACH.

The health communication data (preferred versus current communication methods and communication methods used at healthcare services), as well as health literacy data, were summed into four groups: baseline intervention, baseline control,

post-test intervention, post-test control. Percentages were also obtained. The data were compared based on group frequency and percentage. Communication variables are nominal with no order within the categories. The health literacy variable is ordinal, as the different categories represent different levels of health literacy related to how many words Deaf people knew the meaning of.

BETWEEN-SUBJECTS ANALYSIS.

The participants were randomised into two groups – intervention and control. Therefore, the research design was a 2 x 2 Independent Groups Factorial Design. As such, a two-way ANCOVA was conducted to examine the difference in the outcomes across the groups. The dependent variables were continuous on a Likert scale. In this analysis, the Likert scale data were treated as interval. The dependent variables for this analysis were health anxiety, motivation factors (healthcare autonomy support, important others autonomy support, basic psychological need satisfaction and frustration and autonomous and controlled motivation) and health locus of control. The independent variables were dichotomous: time could only be baseline (1) or post-test (2), and the group could only be intervention (1) or control (2). The length of time InterpreterNow was used and the number of days the mobile application was used were controlled for by adding these variables as covariates. The outcomes of the analysis were the effect of time on dependent variables, the effect of group on dependent variables and the effect of the interaction of group and time on dependent variables.

4.3 RESULTS

4.3.1 HEALTH COMMUNICATION.

PREFERRED VERSUS CURRENTLY USED COMMUNICATION METHODS.

Deaf participants were asked about which method of communication was the most commonly used and preferred with healthcare professionals. The methods of communication were: British Sign Language with interpreter, British Sign Language no interpreter, Spoken English and Lip-reading, Speaking and Signing, and writing. The healthcare professionals were: GP surgery, hospital, chemist, optician and dentist. The

full breakdown by common and preferred communication methods for different healthcare services is in Appendix 2.

At baseline, 89% of the intervention group identified British Sign Language with interpreter as their preferred method of communication yet only 63% identified this method as their most commonly used method of communication. There appears to have been a slight increase in how many participants were able to use their preferred method of communication at post-test. After the intervention, 86% of participants stated that British Sign Language with interpreter was their preferred method, and 71% identified this as their most commonly used method. None of the respondents preferred writing things down as a method of communication with their health professionals yet 10% of Deaf participants reported having to write things down to communicate with healthcare professionals.

COMMUNICATION METHODS USED AT HEALTHCARE SERVICES.

Across all healthcare services, the predominant method of communication at baseline was in person although using a family member or friend was also a common method of communication at the hospital, dentist and GP surgery. Typetalk was not used very often except for at the opticians. At baseline, few participants reported using online methods of communication however at post-test, far more intervention participants reported using this method (see Appendix 3). For example, at baseline, only 10% of participants reported using online methods of communicating with their GP but this increased to 39% at post-test whereas no control participants reported using online communication. A similar shift in the use of online communication can be seen across all healthcare services for the intervention group. Fewer people were using typetalk and communicating in person, using the Deaf clubs and asking family members or friends to translate. There was no change in the number of Deaf people using text messaging over time. Most Deaf people didn't use letters or fax.

4.3.2 HEALTH ANXIETY INVENTORY.

The mean health anxiety scores indicate that Deaf participants' scores were lower than that of populations suffering from anxiety ($M=14.9$, $SD=6.2$; Salkovskis et al.,

2002). After controlling for length of time using the InterpreterNow application and number of days the application was used, analyses revealed that the effects of time and group on health anxiety scores were not significant. However, mean scores indicate that intervention participants demonstrated a decrease in health anxiety over time, whereas the control group showed an increase (see Table 10). The effect size (Hedges' $g = -.46$) was medium.

Table 10. *Time and group differences for Health Anxiety Inventory (means, SD).*

Intervention		Control	
Baseline (n=33)	Post-test (n=33)	Baseline (n=33)	Post-test (n=33)
12.49 (7.91)	9.98 (7.12)	12.67 (6.99)	13.55 (8.15)

4.3.3 HEALTH LITERACY.

At baseline, 18% of both the intervention and control groups understood 61 words or more from a list of 66 medical words which was provided in the REALM questionnaire. However, most participants (83% of the intervention group and 82% of the control group), earned scores that are comparable to “below ninth grade” level, which are indicative of low health literacy. At post-test in the intervention group, there was a reduction of participants with low health literacy (71%) whereas, at post-test in the control group, there was no change (82% of the sample had scores indicative of low health literacy; see Table 11).

Table 11. *Health literacy levels (n, %).*

Health literacy levels	Intervention		Control	
	Baseline (n=34)	Post-test (n=34)	Baseline (n=28)	Post-test (n=28)
0–18 (below 3rd)	4 (11)	3 (10)	4 (14)	6 (21)
19–44 (4th–6th)	7 (21)	9 (26)	11 (39)	12 (43)
45–60 (7th–8th)	17 (50)	12 (35)	8 (29)	5 (18)
61–66 (9th to high school)	6 (18)	10 (29)	5 (18)	5 (18)

4.3.4 PSYCHOLOGICAL FACTORS.

Psychological factors such as autonomy support provided by healthcare professionals, the influence of powerful others in the Deaf person’s lives and treatment motivations were compared for differences between intervention and control groups as well as time (baseline and post-test) (see Table 12). That is, we investigated whether the intervention group demonstrated greater changes in these variables compared to the control group, in expected directions, after having InterpreterNow for 12 months. The length of time using the InterpreterNow application and number of days InterpreterNow was used were also controlled for in analyses.

AUTONOMY SUPPORT FROM HEALTH PROFESSIONALS AND IMPORTANT OTHERS.

Results revealed a significant main effect of time for autonomy support provided by healthcare professionals. This result indicates that all participants perceived that their healthcare professionals were creating a more autonomy-supportive environment after one year. In addition, the main effect of condition (intervention or control) was significant, indicating that overall participants randomly allocated to the intervention group perceived their healthcare professionals to be more autonomy-supportive than those allocated to the control group. The effect size was medium (Hedges’ $g=.64$), suggesting that there was a meaningful difference between the two groups (see Table 12). However, the effect of the interaction between condition and time was not significant. These findings suggest that intervention participants felt that they were more

respected by healthcare staff, more supported and were offered choices about treatment after using InterpreterNow for 12 months.

Participants were also asked to rate the autonomy support provided by individuals they felt were important to them. The level of autonomy support perceived by both the intervention and control participants was greater for their important others (Intervention $M=5.45$, $SD=1.58$ & Control $M=5.06$, $SD=1.69$) compared to their health professionals (Intervention $M=4.68$, $SD=1.52$ & Control $M=4.13$, $SD=1.52$). However, no changes in the level of autonomy support provided by important others were observed over time or between groups. The effect size for perceived autonomy support of important others was small (Hedges' $g=.17$).

BASIC PSYCHOLOGICAL NEED SATISFACTION/FRUSTRATION.

Results revealed that both intervention and control participants perceived very similar levels of need satisfaction at baseline ($M=3.15$, $SD=.48$ v $M=3.09$, $SD=.48$) and post-test ($M=3.21$, $SD=.41$ v $M=3.22$, $SD=.56$) with very little change. The effect size was small (Hedges' $g=-.02$). A similar result was observed for need frustration with mean scores being very similar or slightly higher than that observed for need satisfaction, with a small effect size (Hedges' $g=-.11$). Therefore, the intervention did not increase perceptions of need satisfaction or decrease perceptions of need frustration. However, it is notable that these Deaf participants are experiencing as much need frustration as need satisfaction.

MOTIVATION TOWARDS TREATMENT.

Results indicate that there was a significant main effect of time between baseline and post-test ($p < .05$) but there was no significant effect of condition (intervention or control) nor a significant interaction for autonomous motivation. This means that over time, both groups felt more autonomously motivated towards their healthcare treatment. However, it is not possible to state that this increase was due to using the InterpreterNow application for one year as no differences were found between conditions. The effect size was small (Hedges' $g=.02$).

Results for controlled motivation revealed the main effect of time was significant. That is, controlled motivation decreased from baseline to post-test ($p < .05$). The effect size was small (Hedges' $g = .05$). However, the main effect of condition was not significant nor was the interaction between condition and time. This means that both groups experienced lower levels of controlled motivation towards their healthcare treatment at the end of the year. However, it is not possible to state that this decrease was due to using the InterpreterNow application as no differences were found between conditions (see Table 12).

Table 12. *Time and group differences for Self-Determination Theory factors.*

SDT factors	Intervention		Control	
	Baseline (n=31)	Post-test (n=31)	Baseline (n=31)	Post-test (n=31)
Healthcare Climate **	4.68 (1.52)	5.54 (1.10)	4.13 (1.52)	4.58 (1.80)
Important Other Climate	5.45 (1.58)	5.61 (1.87)	5.06 (1.69)	5.32 (1.72)
Psychologica I Need satisfaction	3.15 (.48)	3.21 (.41)	3.09 (.48)	3.22 (.56)
Psychologica I Need frustration	3.39 (.57)	3.18 (.39)	3.26 (.52)	3.23 (.51)
Autonomous motivation**	4.52 (.97)	5.65 (1.32)	4.19 (1.09)	5.63 (1.09)
Controlled motivation*	6.06 (.89)	4.68 (1.16)	5.92 (1.1)	4.62 (1.2)

Note: * Significant effects at $p < .001$, ** Significant effects at $p < .01$.

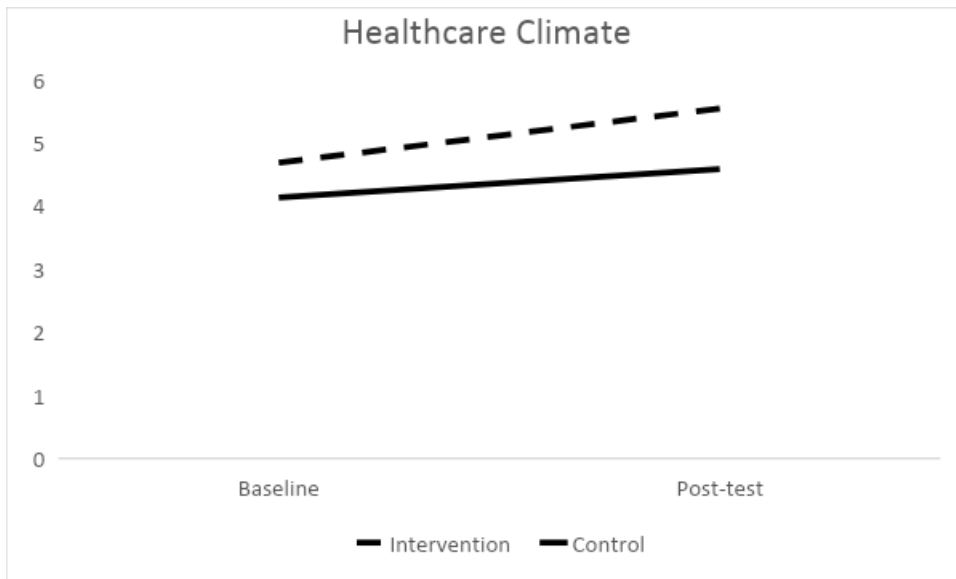


Figure 4. *Healthcare Climate (time and condition).*

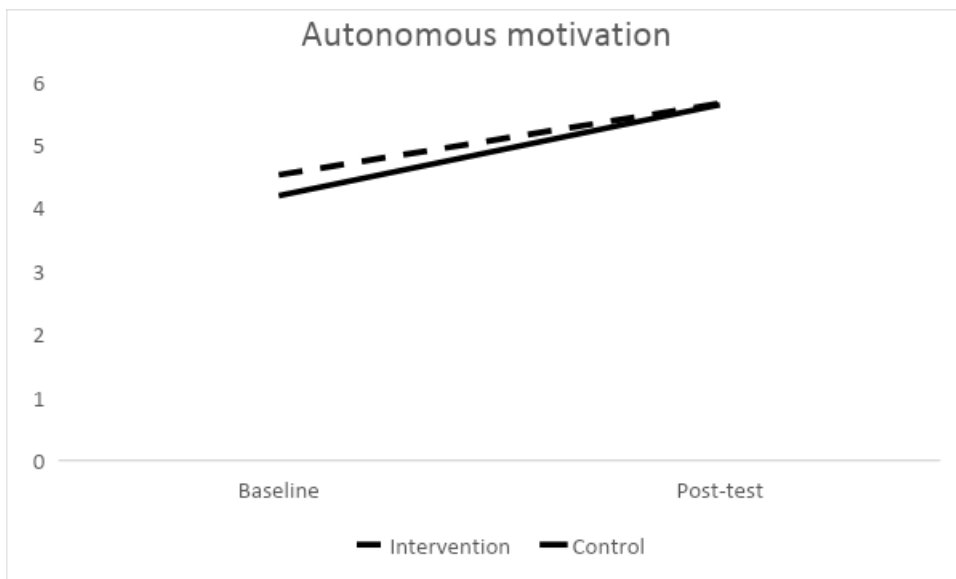


Figure 5. *Autonomous motivation (time and condition).*



Figure 6. *Controlled motivation (time and condition).*

HEALTH LOCUS OF CONTROL.

The main effects of time or group on health locus of control were not significant for any of the three subscales (see Table 13). Mean scores for internal health locus of control revealed a small non-significant increase over time in the intervention group. The effect size was small (Hedges' g).

Mean scores for powerful others health locus of control decreased over time and to a greater extent in the intervention but again this was not statistically significant. The effect size for powerful others was small (Hedges' $g=.02$). Finally, no changes were observed in the mean score for chance health locus of control, with a small effect size (Hedges' $g=-.2$).

Table 13. *Time and group differences for Health Locus of Control subscales.*

Health Locus of Control subscales	Intervention		Control	
	Baseline (n=31)	Post-test (n=31)	Baseline (n=31)	Post-test (n=31)
Internal	27.48 (6.66)	28.88 (6.45)	28.70 (4.23)	28.86 (5.99)
Powerful	28.72 (4.01)	24.3 (8.73)	26.03 (7.57)	24.14 (6.12)
Others				
Chance	25.77 (8.29)	26.12 (9.14)	26.90 (7.20)	27.80 (6.88)

*Note: ***Significant effects at $p < .05$.*

4.4 DISCUSSION

Using a rigorous RCT, the aim of the present study was to gain an understanding of the pre-post changes that occur following the introduction of a videoconferencing mobile application, InterpreterNow, for a sample of Deaf people. In summary, positive results on a number of variables in favour of the intervention were found. For instance, communication preferences were met and there was an improvement in health literacy when InterpreterNow was used. For the intervention group, the perception of autonomy support provided by healthcare professionals improved to a larger extent than in the control group. The main effect of group (intervention vs control) was significant, but the interaction between group and time was not (possibly due to low sample size, more below). Motivation changed significantly over time across both groups. There was a trend in the intervention group towards an autonomous motivation increase and controlled motivation decrease over time. As such, the present findings partially support previous research about the “positive” and “negative” pathways of motivation and suggest that InterpreterNow might be a vehicle for such pathways (Chen et al., 2015).

4.4.1 HEALTH COMMUNICATION, ANXIETY AND LITERACY.

Taking the outcomes studied in turn is informative in elucidating changes associated with InterpreterNow. In terms of health communication, in the intervention group, there was a small increase in the current use of the preferred communication method (British Sign Language) during appointments after using InterpreterNow. This

indicates that using InterpreterNow may help to increase the number of times Deaf people's communication preferences were being met, which is a highly salient change in this population (Emond et al., 2015). Further, at GP appointments, intervention participants used online methods (such as InterpreterNow) more at post-test compared to the control group. InterpreterNow appears to have provided Deaf people with a greater choice and allowed them to take control of their method of communication. Therefore, the InterpreterNow service provides an effective way to reduce communication issues experienced by Deaf people and increase use of preferred communication methods in healthcare settings (Emond et al., 2015a, 2015b; SignHealth, 2014). This finding is important as previous research has shown that Deaf people prefer to communicate in sign language in healthcare settings (Middleton et al., 2010) but that in many cases they have to communicate by other methods (lip-reading or written notes) (Steinberg et al., 2006). This can often result in patient frustration, miscommunication and misunderstanding of treatments (Ralston, Zazove, & Gorenflo, 1996; Scheier, 2009; Steinberg et al., 2006). Therefore, by increasing the access to British Sign Language communication, InterpreterNow could also have a positive effect on the health communication experiences and understanding of Deaf people.

This study, by contrast, indicated that there was no impact of InterpreterNow on Deaf people's levels of health anxiety. However, there was a trend for health anxiety to increase over time in the control group and to decrease for participants in the intervention group. It is possible that a longer period of time with access to InterpreterNow is needed to have an impact on health anxiety or a study with a larger sample size may provide the power to observe a significant effect. Either way, the role of a remote sign language interpreter service in helping reduce health anxiety warrants further exploration. Previous studies have shown that anxiety plays a role in Deaf experiences in healthcare settings, as Deaf people worry about getting wrong medication and not being understood (Ralston et al., 1996; Reeves & Kokoruwe, 2005; Steinberg et al., 2006). It is possible that anxiety about healthcare services would overlap with having health anxiety. Therefore, a reduction in health anxiety is an important outcome for the health of Deaf people. However, it should be noted that the health anxiety levels shown in the current sample were below the threshold for the health anxiety diagnosis. Therefore, our sample appeared not to experience this negative health outcome in a prominent way.

Turning to health literacy, Deaf people have been shown to have lower health literacy than the general population (Pollard & Barnett, 2009). This means that Deaf people might not know that they have certain illnesses, when they should visit the doctors' surgery and about treatments. Results from this study indicated that health literacy was improved by InterpreterNow use. The intervention group scores on the modified REALM task which are indicative of low health literacy ("below ninth grade" level) decreased from baseline to post-test. However, the control group showed no change. This suggests that using InterpreterNow might lead to a better understanding of health conditions, perhaps because Deaf people had better access and were empowered to ask questions.

Our results show a far higher percentage of Deaf people with low literacy levels than that observed by in previous research (Pollard & Barnett, 2009). The low literacy levels were at 32% (n=18), compared to 71% (n=24) at the intervention group post-test in the present study. The reason for this might be that 81% (n=46) of the participants in the Pollard and Barnett (2009) study had a university degree. In the present study, participants' education was not measured. Therefore, it is difficult to establish the reason that underpins the difference in health literacy across these two samples. Research on Deaf people's educational attainment level suggests that Deaf people may have lower education levels than the general population (British Sign Language Broadcasting Trust, 2016; Richardson, 2015; Richardson & Woodley, 2001). In the UK, 65% of British Sign Language users are unable to speak English well or at all (British Sign Language Broadcasting Trust, 2016). Therefore, future research on using InterpreterNow service with Deaf people should account for educational level. In summary, it appears that health communication and health literacy were improved when InterpreterNow was used but no effect on health anxiety was observed. Whilst the changes were small (and for health anxiety, not significant), they are suggestive of the potential of InterpreterNow for improving Deaf health communication.

4.4.2 PSYCHOLOGICAL FACTORS.

AUTONOMY SUPPORT FROM HEALTH PROFESSIONALS AND IMPORTANT OTHERS.

In the case of the psychological variables measured, the results showed some important findings. In particular, both the intervention group and the control group perceived the autonomy support of healthcare staff to have increased over time. Importantly, though, the participants who used InterpreterNow saw greater increases in autonomy support than the control group. The medium effect size indicated that this difference was practically meaningful. Using InterpreterNow appears to cultivate an autonomy-supportive environment in which the participants' views are accounted for, the participants feel confident in their choices and feel that they can ask questions and have input into their healthcare decision making. The observed changes in healthcare autonomy support are important because Deaf people have trouble communicating with hearing healthcare staff. As we have seen, many Deaf people don't trust healthcare staff, are more anxious during doctor appointments, are scared of getting wrong medications, and afraid of not being understood (Ralston et al., 1996; Reeves & Kokoruwe, 2005; Steinberg et al., 2006). Therefore, Deaf people are more likely to view healthcare staff as less autonomy-supportive. InterpreterNow then appears to help alleviate some of these issues by providing a way for Deaf people to understand more and feel more in control while communicating in their preferred manner.

No changes were observed over time or between groups for autonomy support provided by important others. This is perhaps unsurprising as the InterpreterNow service was designed to improve communication in healthcare settings. It is noteworthy, however, that the levels of important other autonomy support were generally higher than healthcare autonomy support. This could be because Deaf people often have a strong bond with other Deaf people which is probably stronger than with the hearing healthcare staff (Allen, Meyers, Sullivan, & Sullivan, 2002). Deaf people share a language, culture, traditions and common experiences and view themselves as having a different way of communication, not a disability (Graybill, Aggas, Dean, Demers, Finigan, & Pollard, 2010; Harmer, 1999; Johnston, 2004; Scheier, 2009; Terry, Lê, & Nguyen, 2016). It has been suggested that Deaf people have more self-esteem and a more positive view of themselves, as well as being protected from discrimination if they view themselves as a

member of the Deaf culture (Bat-Chava, 1993; Jambor & Elliott, 2005; Obrzut, Maddock, & Lee, 1999). Therefore, Deaf people have support from important others such as Deaf family or friends already, which is not affected by InterpreterNow, as those important others are likely to communicate in sign language already.

BASIC PSYCHOLOGICAL NEED SATISFACTION/FRUSTRATION.

Despite changes observed in both groups for perceived autonomy support from healthcare professionals, no changes were observed in the satisfaction and frustration of the basic psychological needs. This is curious given I found differences in favour of the intervention in terms of levels of autonomy support. It may be that the length of the study (12 months) was too short to detect effects on the psychological needs facilitated by changes in autonomy support. It would be interesting to see whether perceptions of need satisfaction and frustration change with a more sustained period of study. Beyond the group comparisons, mean psychological need scores indicate that participants had higher scores for need frustration than need satisfaction. This supports findings from Study 1 and suggests that Deaf people's health experiences may be negatively affected due to feeling autonomy, competence and relatedness frustration. Again, it would appear that Deaf people experience considerable need frustration, and this is very much in line with other data (e.g., Emond et al., 2015).

MOTIVATION TOWARDS TREATMENT.

Deaf participants' motivation changes over time but this change did not differ across treatment and control groups. Therefore, it appears that there are changes due to time that are not related to InterpreterNow. The reason that a slight increase in autonomous motivation and decrease in controlled motivation was found could be due to Deaf people being involved in a study which focuses on better healthcare experiences and access. This may have led to a shift towards a higher quality of motivation, where Deaf people were more influenced by internal factors (personal value) than by externally driven motivations and were taking more ownership and responsibility for their health.

The fact that Deaf people's autonomous motivation was increased while controlled motivation was decreased is supported by evidence. For instance, this has been shown in a physical activity promotion trial for women (Silva et al., 2010) and for undergraduate students (Nix, Ryan, Manly, & Deci, 1999). Increases in just autonomous motivation have also been shown in adults attempting to diet and reduce/quit smoking (Williams et al., 2002, 2004) and for patients involved in a methadone maintenance programme (Zeldman et al., 2004). The fact that Deaf sample outcomes for motivation follow that of other samples suggests that Deaf people may experience similar motivation patterns and so may be supported to increase in autonomous motivation using approaches from SDT literature. Autonomous motivation increase, and controlled motivation decrease have been shown to lead to positive outcomes such as more understanding (Grolnick & Ryan, 1987), greater psychotherapy involvement (Zuroff et al., 2007), improved well-being (Ryan et al., 1993) and healthier eating behaviours (Pelletier et al., 2004). Therefore, Deaf motivation changes due to InterpreterNow use (in intervention participants) and being involved in a trial focus on health promotion could also lead to positive health behaviours.

HEALTH LOCUS OF CONTROL.

Finally, this study shows that internal locus of control (the extent to which participants feel that their health decisions are controlled by themselves) increased non-significantly in the intervention group after using InterpreterNow for 12 months but that there was no change in the control group. A non-significant trend for powerful others locus of control (the extent to which patients feel that powerful others such as doctors, family or friends are in control of healthcare decisions) was also found. The trend was for a higher reduction of powerful others control perception in the intervention compared to the control group. The lack of change in perceptions of powerful others/internal control in the control group is supported by findings that Deaf people feel not responsible for their health and that the hearing staff are in control (e.g., Emond et al., 2015a, 2015b; Kritzinger et al., 2004). An explanation for the trends for change could be that Deaf people felt more in control of their health and communication options due to InterpreterNow use and therefore felt that doctors and family/friends (powerful others) had less control. Therefore, although the findings were not significant, the trends are following logical directions. Future research should aim to increase study power (by

increasing participant numbers and conducting the study over a longer timescale across multiple sites) to substantiate these trends.

4.4.3 STRENGTHS AND LIMITATIONS.

A key strength of the current study is that it is based on previous research with Deaf people which identified Deaf health communication and access issues (Emond et al., 2015a, 2015b). The InterpreterNow mobile application was then created with such issues in mind and in consultation with Deaf people. This study was also conducted in a naturalistic setting, in which Deaf people could decide for which healthcare services and at which time to use InterpreterNow. This study used project workers who were Deaf or Hard of Hearing, had a good level of British Sign Language (at least level 3) and were well-known to the Deaf participants they were working with. This means that Deaf people felt comfortable sharing issues about InterpreterNow trial with the project workers, as well as that project workers could translate the study materials to the participants to a high standard. Also, the fact that the project workers were Deaf or Hard of Hearing meant that they were likely to have experience of Deaf health access issues. Lastly, a positive aspect of this study is in the design, which was a randomised controlled trial. This design allows to measure treatment effects compared with control group whilst keeping other variables constant.

However, this study also has limitations. These include relatively small sample size, a lengthy package of questionnaires, and a lack of understanding of questionnaire items. The sample size was small due to the number of Deaf people located at study locations who could give consent (due to issues in understanding or learning disabilities of the other Deaf people), and who were willing to commit to two or three study data collections with long times (12 months) between them. The small sample size could lead to a loss of power, which may explain some of the non-significant findings. Another limitation is that the questionnaires were lengthy. This may have led to fatigue and boredom, resulting in a poor recall. Also, the questionnaire content may not have been fully comprehensible to the sample. This is likely as Deaf people have lower levels of health literacy than the general population (Pollard & Barnett, 2009). Additionally, the participants' may have not understood certain words as sign language uses a simpler vocabulary than English and does not include certain medical terms or concepts (Patel

et al., 2011). Video translated British Sign Language versions of certain questions were available. However, the longer and more conceptual questionnaires may have been difficult for project workers to understand and then explain to Deaf people. Only one questionnaire had been previously validated with the Deaf sample, whereas the rest had only been used with the hearing sample

Lastly, this study is limited in that the same baseline data was used for both the path analysis (Chapter 3) and the pre-post data analysis (Chapter 4). Such a methodology was employed for pragmatic reasons as recruitment across the multiple sites was a challenge (Worcester, Merseyside, Greater Manchester and Cumbria. In addition, it was not possible to find new participants for this study (Chapter 4) because of the time constraints and funding of the overall project. The gold standard approach would have been to make amendments to the measurement instruments used in the current study (Chapter 4) based on the previous study (Chapter 3) and to use different samples for the path analysis study and pre-post study. The improvements made following the path analysis would be to provide BSL translation, to make measures shorter and to ensure that Deaf people (and also project workers who are supporting them in filling in questionnaires) fully understand the conceptual words in the questions. This would ensure that the issues from the previous study (Chapter 3) would not be repeated in the current study (Chapter 4). In an ideal scenario, more charity locations would be involved in the project, ensuring that there are enough participants to have a separate sample for the path analysis study, then improve the measures based on lessons learnt from the path analysis study and recruit a new sample for the randomised controlled trial. In future studies, questionnaires should be fully available in the British Sign Language video format and should use more simple language to ensure that data quality is not affected by the Deaf people's lack of understanding.

4.4.4 CONCLUSION.

A waitlist randomised control trial was used to investigate whether using InterpreterNow would have an impact on healthcare access, health literacy, anxiety and Deaf people's motivation towards health compared to those that did not have access to InterpreterNow. Results revealed significant differences between intervention and control group over time for health communication, health literacy and autonomy support.

Findings also emphasise the appropriateness of InterpreterNow for improving the healthcare experience for Deaf people. For instance, using InterpreterNow led to an increase in the use of British Sign Language in health services (the preferred communication method), reductions in low health literacy and an increase in the perceptions of autonomy support provision of healthcare staff. These findings show that Deaf people can benefit in terms of using a remote British Sign Language interpreter service as it allows Deaf people a choice about their method of communication. InterpreterNow also helped to improve understanding during healthcare appointments and increased health knowledge. Increase in perceptions of autonomy support provided by healthcare professionals also indicates that the quality of communication can be improved when using a remote sign language interpreter service. Deaf people perceived that the healthcare staff were more supportive and allowed Deaf people to make their own decisions when InterpreterNow was used.

Following on from these quantitative changes in healthcare access, health literacy, anxiety and motivation it is important to understand the lived experiences of Deaf people using InterpreterNow. This is because such experiences yield rich narrative data on what Deaf people liked, didn't like, and found especially useful about InterpreterNow. This is important in developing and refining the tool and understanding the precise mechanisms of action – many of which are likely to have been overlooked when we measure changes using quantitative methods only (Creswell, 2008). In the next chapter, I provide an overview of empirical work that seeks to solicit qualitative data on InterpreterNow in an effort to build on the findings of study 2.

CHAPTER 5: QUALITATIVE INTERVIEWS AND FOCUS GROUPS

5.1 INTRODUCTION

In the UK, there are roughly 900,000 profoundly Deaf people (Ringham, 2012), many of whom experience inequality in healthcare settings. Deaf people have low health knowledge and often avoid health services (Steinberg et al., 2002). Key reasons behind the negative experiences of Deaf people are the attitudes of healthcare staff towards Deaf people and communication problems (for example, Emond et al., 2015a, 2015b; Iezzoni et al., 2004; Steinberg et al., 2002). Although this population experiences severe health communication and access problems, little research has been conducted to investigate the views of healthcare professionals, Deaf people and British Sign Language interpreters about experiences of Deaf people in healthcare settings. This chapter aims to address this gap in the literature by triangulating the views of Deaf people and of staff involved in Deaf healthcare (British Sign Language interpreters and healthcare professionals) who has been recruited to a healthcare intervention. The findings will provide a clearer understanding of the factors that might contribute to positive and negative Deaf experiences in healthcare settings. The participants were invited to provide views on their experiences during an mHealth application intervention, InterpreterNow. Focus group and interview questions were about experiences and effectiveness/appropriateness of healthcare interventions for Deaf people.

5.1.1 BACKGROUND AND KEY AIMS.

DEAF HEALTH AND COMMUNICATION ISSUES.

Deaf people have been shown to have worse health than the general population (Emond et al., 2015a, 2015b). For instance, Deaf people are more likely to experience higher rates of mental health issues, hypertension and high cholesterol (de Graaf & Bilj, 2002; Emond et al., 2015b; Fellingner et al., 2012). Deaf people also experience less access to healthcare than the general population, which can result in worse health outcomes, lower health literacy and limited understanding of health problems (Emond et

al., 2015b; Pollard & Barnett, 2009). Poor communication between Deaf people and healthcare professionals has been identified as a reason for poorer health care provision including not getting access to necessary treatment or medications (Emond et al., 2015a, b; Fellingner et al., 2012; Kuenburg et al., 2016; Ubido et al., 2002). Deaf people also report communication issues in healthcare settings such as their communication preferences being ignored, low levels of awareness of healthcare staff, healthcare staff not knowing any British Sign Language, and doctors being patronising and not supportive to Deaf people (Emond et al., 2015a; Kyle et al., 2005; Steinberg et al., 2002).

Additionally, there are issues related to British Sign Language interpreters such as doctors using teachers or family/friends although Deaf patients are less likely to disclose certain issues and family/friends might dominate the conversation and miss information due to lack of interpretation training (Hindley, 2005). Other issues around British Sign Language interpretation is that British Sign Language interpreters are often not available due to short notice of appointments or that healthcare staff think that patients do not need British Sign Language interpreters as the patients understand written English, which often is not the case as sign language and English are different (van Staden et al., 2009) and due to overall low health literacy of Deaf people (Pollard & Barnett, 2009).

This research highlights the need for innovative interventions that aim to improve both the health and health communication for the Deaf population. InterpreterNow is an example of an innovative online videoconferencing intervention that aimed to improve communication during Deaf-hearing interactions in healthcare settings by providing access to remote British Sign Language interpreters. Although intuitive benefits of providing Deaf people with access to online British Sign Language interpreters for any health care interaction can be identified (i.e., instant mobile access), little research has gathered the thoughts and opinions of those that might use such a service. Few qualitative studies have been conducted with Deaf people due to practical restraints. For instance, Deaf focus groups need to be smaller in size than those for hearing people, must include a British Sign Language interpreter and take more time complete.

The aim of this study is to address this gap in knowledge by triangulating the experiences of those that have used this remote sign language interpreter service during health care related interactions. Specifically, we gather the experiences of Deaf people, health professionals and British Sign Language interpreters employed to provide the online interpreting service.

PREVIOUS LITERATURE ON DEAF FOCUS GROUPS.

Focus groups have been identified as “an excellent method to elicit criticism, constructive suggestions and opinions of Deaf participants” (Kipp, Nguyen, Heloir, & Matthes, 2011; p.7). This is particularly poignant because Deaf participants are often excluded from larger quantitative studies. In comparison to quantitative studies, and when conducted in a Deaf friendly manner, focus groups can be easier for Deaf people to understand (as British Sign Language interpreters will tend to use simple terms and explain in detail) and may elicit better responses as British Sign Language is the preferred communication method for most Deaf people (Emond et al., 2015a, b). Previous qualitative studies were used for gathering opinions, for practical reasons and to assess interventions (e.g., Barnett & Franks, 1999; Jensen et al., 2013; Sadler, Gunsauls, Huang, Padden, Elion, Galey, Brauer, & Ko, 2001).

GATHERING OPINIONS.

Deaf focus group and interview studies have been used to gather Deaf population opinions on smoking habits (Barnett & Franks, 1999), healthcare experiences (Iezzoni et al., 2004; Steinberg et al., 2002, 2006; Terry et al., 2016) and Deaf health (Emond et al., 2015a, 2015b; ; Fellingner et al., 2012; Werngren-Elgström, Dehlin, & Ivarsson, 2003). Research on healthcare staff attitudes and Deaf health communication (Steinberg et al., 2002, 2006), found that during negative healthcare experiences Deaf people felt confused, frustrated, disrespected and mistrusting, as well as showing low knowledge of the value of tests and screenings, medication prescriptions and surgical interventions. In comparison, positive experiences included healthcare staff who focused on better communication, as well as opportunities for Deaf people to communicate in sign language (as British Sign Language interpreters/staff with sign language skills were present). Negative experiences were linked with

avoidance or lack of use of services, whereas positive experiences were linked to increased access to healthcare information/services.

The current study expands on the previous evidence from Steinberg et al. (2002, 2006) by including the views of British Sign Language interpreters. British Sign Language interpreters may have views in agreement with that of healthcare staff and Deaf people. Also, British Sign Language interpreters are likely to have views about particular interpretation-related issues such as where remote British Sign Language interpreters should be from (locality), whether British Sign Language interpreters should be known to the Deaf person or not, and about boundaries between Deaf people and British Sign Language interpreters. Therefore, this study aim is to provide evidence from an additional source.

PRACTICAL REASONS.

Studies have used interviews and focus groups for practical purposes such as a method of participant selection (Jensen et al., 2013), for adapting measurement tools (Barnett et al., 2011) and ascertaining best practice in British Sign Language interpreting in healthcare settings (CATIE Center, St Catherine's College, & NCIEC, 2007). The current study will attempt to gather practical information about the InterpreterNow trial from healthcare staff, British Sign Language interpreters and Deaf people. Practical information could be concerned with the connection, how easy it was to learn to use the tablet and the mobile application, how well healthcare staff accepted InterpreterNow in appointments, how easy InterpreterNow was to use for Deaf people, as well as suggestions of how to make InterpreterNow even easier to use in the future. Therefore, this study extends on previous research by conducting a qualitative study which gathers information about the use of a videoconferencing in healthcare settings.

ASSESSING INTERVENTIONS.

Qualitative research into the appropriateness/effectiveness of healthcare interventions has only been conducted in one non-technological study (Sadler et al., 2001). In this study, 123 Deaf and hard-of-hearing women participated in focus groups. There were five to 12 participants per focus group. The focus groups investigated how a

breast cancer education programme for hearing people could be adapted to be suitable for Deaf people. Results identified that Deaf people felt that they need more health knowledge. Also, results suggested that creating education programmes which account for Deaf communication and access needs would help to increase knowledge and compliance with screenings. Deaf people felt that the programme was useful which was indexed by the fact that they were likely to promote the programme to others and participate themselves. This study supports the current work as it provides an example of qualitative research about an intervention for Deaf people.

Sadler and colleagues (2001) highlighted problems for Deaf people during health interventions such as a lack of appropriate communication provision (sign language or lip-reading), too much information provided (both sign language and image-based information at the same time), as well as low health literacy of the Deaf community. These issues were used to change the programme. Deaf people were supported in terms of low health literacy and knowledge by providing more time for Deaf people to examine images and models. The accuracy of complex information understanding was ensured by including more visual models. Also, medical terms in big print were provided to support participants with low health literacy. Lastly, appropriate communication methods were used in this study (sign language).

Following the above changes, participants felt that the programme would be useful in the future and provided suggestions for improvement (such as introducing a train-the-trainer model for Deaf trainers and converting the programme into a sign language video). Therefore, this research showed that focus groups can be used with the Deaf population for assessing interventions. The study also showed that a variety of views can be obtained on topics such as recruitment to research programmes, low adherence of screenings and knowledge, as well as improvement suggestions. This study highlighted that Deaf people benefit from programmes which use preferred communication methods and are constructed with an awareness of Deaf culture.

The strength of this study was that 123 Deaf people were involved in the focus groups, which means that the data are more likely to represent population findings. Also, this study is beneficial as it focused not only on the views about the intervention but also on the suggestions for improvement (such as Deaf women would benefit from

programmes more if preferred methods of communication and learning styles were used). However, this study attempted to adapt a programme that was originally created for hearing people. This could be a problem as it may be hard to ensure Deaf needs are fully met as Deaf and hearing people may have differences in learning style/abilities due to the limited health literacy of Deaf people (Pollard & Barnett, 2009). Deaf people require simpler education materials and more time to understand them. Therefore, Deaf people would not be able to understand information which was initially presented to hearing people. However, an intervention made for just Deaf people, based on the opinions of Deaf samples, will be more likely to fully support Deaf needs.

The present study builds on Sadler et al. (2001) by showing the views of British Sign Language interpreters, healthcare staff and Deaf people for a videoconferencing intervention which was created and conducted in a Deaf friendly manner. The current study can explore whether having more sources of information about study appropriateness would lead to more variety in answers as well as strengthen the arguments of different groups. Also, this study will be an investigation into whether the participants would have more positive views about a Deaf friendly intervention with a preferable approach (videoconferencing) than those in Sadler et al. (2001). Lastly, insights of healthcare professionals and British Sign Language interpreters from the current study extend on the work of Sadler et al. (2001). British Sign Language interpreters' and healthcare professionals' opinions relate to the issues specific for that group (that Deaf people may not be aware of). Deaf people may speculate on these topics, whereas British Sign Language interpreters and healthcare professionals have primary experiences.

PRESENT STUDY JUSTIFICATIONS.

The present study employed focus groups to investigate the views of Deaf people about a health-related intervention (a mobile health application, InterpreterNow). This is similar to Sadler et al. (2001). The present research has adapted positive aspects of previous evidence (using focus groups to assess interventions, asking questions about experiences and suggestions for improvement). The positive aspects of previous studies were used to obtain Deaf people's views on how useful and appropriate a videoconferencing intervention, InterpreterNow was for improving Deaf

communication and access in healthcare settings. The present study also improved on the flaws on Sadler et al., (2001) study. The present study was also extended by conducting focus groups/interviews with British Sign Language interpreters and healthcare professionals, as well as Deaf participants. The purpose of using different groups is to understand topics from various aspects as well as to assess disagreements and agreements of the groups. Another improvement in the current research was that the intervention which was created specifically for Deaf people. This ensures that Deaf people's preferred communication method (British Sign Language) is used in delivery as well as accounting for that Deaf people's low knowledge and health literacy. The fact that this study is more Deaf friendly means that the intervention is potentially more appropriate for Deaf people's needs and that the views of participants will reflect that.

AIMS.

The key aim of the present study is to gain an understanding of the experiences of using a mHealth intervention, InterpreterNow. In particular, the aim is to understand intervention usefulness, effectiveness and appropriateness (Sadler et al., 2001) including both benefits and issues surrounding the use of the InterpreterNow service.

5.2 METHODS

5.2.1 MIXED METHODS DESIGN OF THE OVERALL THESIS

The current study used a "concurrent triangulation method design" (Creswell, Clark, Gutmann, & Hanson, 2003; p.162). This is a mixed methods design where different types of data was collected using both quantitative and qualitative methods. The mixed methods were employed to gain in-depth and thorough knowledge about the way that Deaf people use InterpreterNow and the factors that might influence health outcomes. Subsequently separate data analyses were conducted without mixing. In this instance, conducting a path analysis, feasibility evaluation and also an economic analysis. Such methods allow different sides of the problem to be elucidated including from a theoretical standpoint, reasons for outcomes, information from different groups, costings information and practical information about service use. For instance, there is a theoretical aspect in the path analysis and randomised controlled trial. In addition, the trial provides information

about changes before and after using the InterpreterNow app. Next, qualitative data provides rich information about why the changes in the trial occurred as well as barriers and facilitators of positive changes of using InterpreterNow. The questions in the interview guides were based around the outcomes of interest in the pre-post questionnaires. Also, the qualitative data provides different views from not just Deaf people but also healthcare practitioners, BSL interpreters and project workers, compared to just Deaf people in the trial. The economic evaluation provides information about costings that are useful for expanding the intervention to a national level or other locations. Finally, feasibility data was collected in order to provide practical information useful to charity stakeholders about service use and acceptability. Lastly, the data was integrated together into the same report for interpretation in the discussion section. The discussion combined findings from both qualitative and quantitative data in order to provide both a statistically valid as well as rich and detailed findings about why the rigorous quantitative changes in the data occurred.

In terms of types of evaluation, the present thesis includes both an outcome evaluation (randomised controlled trial) and a process evaluation (qualitative interviews and focus groups). Process evaluations help researchers to “identify interventions that are effective, and learn to improve those that are not” (Moore, Audrey, Barker, Bond, Bonell, Hardeman, Moore, O’Cathain, Tinati, Wight, & Baird, 2015, p.5). According the MRC process evaluation guidance document, randomised trials are a type of outcome evaluation yet by themselves may not be able to answer all the questions (e.g. applicability of intervention to different contexts or why the intervention failed) (Moore et al., 2015). Another reason that the MRC guidance recommends combining process and outcome evaluations is because the outcome evaluation helps to identify whether changes (such as a reduction in inequality) take place, whereas the process evaluation allows for a deeper understanding of how and why the changes occurred. According to Moore et al., (2015), the key components of process evaluation are: implementation (delivery processes), impact mechanisms (how the intervention and participants’ engagement with it lead to change) and context (external factors which affect intervention delivery and function).

There are different purposes for process evaluations based on the stage of the intervention (development, evaluation, and implementation). The present research study

is at a feasibility testing stage. In this case, the focus is on ascertaining whether the intervention layout is appropriate before scaling up. In addition, the current research aims to conduct process evaluation to understand whether the intervention is acceptable to deaf participants, BSL interpreters and healthcare staff.

In the present study (Chapter 5), interviews and focus groups were conducted to gather views about InterpreterNow service use. Qualitative interviews were conducted with British Sign Language interpreters and healthcare professionals. Seven focus groups were conducted with Deaf people who had participated in the intervention group for at least six months.

5.2.2 PARTICIPANTS.

Deaf participants (n=17; mean age=49.12, 64.7% female) from the InterpreterNow study sites (Worcestershire, Greater Manchester, Merseyside and Cumbria) were invited to participate in a group discussion about their experiences during the trial. All participants identified their hearing status as Deaf. Eleven participants were Deaf from birth and six participants became Deaf at 0 to 3 years old.

British Sign Language interpreters (n=5) who had provided interpretation during the trial were also interviewed. All British Sign Language interpreters were female. Opportunity sampling was used to recruit six healthcare professionals from healthcare services where InterpreterNow had been used. Four healthcare professionals were working as general professionals, one was a clinical psychiatrist and one worked as a consultant for elderly health. Four healthcare professionals were female and two were male.

5.2.3 PROCEDURE.

The semi-structured interview guides were compiled by two researchers (EK and PR). The questions varied slightly for Deaf people, healthcare professionals and British Sign Language interpreters. All interactions with Deaf people included one or two British Sign Language interpreters whose voices were recorded. The British Sign Language interpreters during those interactions provided additional written consent. Focus groups

and interviews were audio-recorded using Etekcity digital rechargeable dictaphone to allow audio files to be transcribed verbatim.

DEAF PEOPLE.

Project workers identified Deaf people who would be willing to participate in focus groups. Focus groups were conducted with participants who had been using the InterpreterNow service for at least six months. Six focus groups were conducted and included between two and five participants but on two occasions one participant was unable to attend (Mean n=3). For two focus groups, only one participant attended out of a total of two participants invited. Two British Sign Language interpreters were present for focus groups with three people and over, and a single British Sign Language interpreter was present for focus groups with two participants. Before the focus groups, the PhD researcher (EK) trained British Sign Language interpreters on consent, right to withdraw and asked them to read the focus group questions. The British Sign Language interpreters were asked to name the participants during the focus groups so that the PhD researcher (EK) could identify different participants for analysis. The Deaf participants signed consent forms after the PhD researcher (EK) explained the purpose of the focus groups, told the participants about their right to withdraw at any time and anonymity and answered any questions. British Sign Language interpreters signed the consent form at the bottom, indicating that they consented to their voices being recorded. The Deaf participants also provided demographic information about age, gender, ethnicity, Deaf status, their preferred method of communication and when they became Deaf.

During the focus groups, the researcher used a semi-structured guide. The interview guide was adapted based on a pilot focus group with seven Deaf people at one of the study locations (Worcestershire; see Appendix 14). The questions were open-ended and probing questions were used to elicit further detail from the participants. All focus groups were audio-recorded using an Etekcity digital rechargeable dictaphone. The purpose was to ask questions relating to the InterpreterNow service such as overall experiences in the trial, issues with InterpreterNow application and tablet, coverage, ease of use and improvement suggestions. The names of the participants were removed and replaced with

pseudonyms during the transcription of the recordings, so that it wasn't possible to identify individuals in the research report.

BRITISH SIGN LANGUAGE INTERPRETERS.

British Sign Language interpreters who had conducted remote interpretation during the trial were asked to participate in interviews. Five British Sign Language interpreters were interviewed one-on-one by the PhD researcher (EK) at the study sites. The British Sign Language interpreters were interviewed because there is a limited number of British Sign Language interpreters working on the InterpreterNow trial and based in different geographical locations across the UK.

Before the interviews were conducted, the purpose of the interview was explained, and British Sign Language interpreters were asked to sign consent forms to show agreement to participate. The British Sign Language interpreters' names were not used during interviews to ensure anonymity. The British Sign Language interpreters were asked questions from an interview guide (Appendix 14). Questions were about experiences during the InterpreterNow trial, using InterpreterNow for providing remote interpretation, coverage and improvement suggestions. There were also questions specific to the British Sign Language interpreter role such as issues related to interpretation delivery and the importance of having local British Sign Language interpreters. The responses were audio-recorded.

HEALTHCARE PROFESSIONALS.

Healthcare professionals who had been present when Deaf people had used the InterpreterNow application were invited by the PhD researcher (EK) to participate in interviews. The healthcare professionals participated after the trial had been running for seven months. Six healthcare professionals participated in telephone interviews and were reimbursed for their time with a £50 Amazon voucher. One-to-one telephone interviews were conducted due to healthcare professional time pressures. Also, healthcare professionals were a difficult group to recruit (due to work pressures), which is why they were reimbursed for their time. Healthcare professionals' interviews were shorter than the focus groups with Deaf people and interviews with British Sign

Language interpreters (approximately 20 – 30 mins each) to account for time issues experienced by healthcare professionals.

The healthcare professionals emailed the PhD researcher (EK) a signed scan of the signed consent form and gave verbal consent during the interviews. The interview guide (Appendix 14) contained questions about the service relating to their experience with InterpreterNow, issues, improvement suggestions, how Deaf people found using app/tablet. Some of the questions were more specific to healthcare professionals such as what the communication needs of healthcare professionals were during appointments with Deaf people. The interviews were audio recorded by putting the telephone on loudspeaker during interviews.

5.2.4 ANALYSIS METHODOLOGY.

Thematic analysis was used to scrutinise the data. The approach for the thematic analysis was inductive (data-driven), semantic (based on explicit content) and realist (report of reality as found in the data). This is the case as the process evaluation of the InterpreterNow service was focused on practical aspects such as experiences of using the mobile application and ease of use of the tablet. This type of thematic analysis allows to condense detailed raw text into a clear and brief format, establish links between research aims and findings from the data. This approach is highly efficient and straightforward to use. Also, thematic analysis is independent of theory, works with different research questions, can be used for different types of data and works for large datasets and can be used for both theory-driven and data-driven analyses.

Following familiarisation with the interview text, the questions from the interview guide were used to create themes. Also, unexpected themes emerged during familiarisation with the text. Coding was conducted based on the themes identified. This process was repeated three times (for focus group data from Deaf people, and interview data from British Sign Language interpreters and healthcare professionals). The data was analysed based on a coding frame developed by the PhD researcher (EK) specifically for this project. The coding frame development was guided by previous work (Berkowitz, 1997; Braun & Clarke, 2006; Clarke & Braun, 2014; Onwuegbuzie, Dickinson, Leech, & Zoran, 2009a, 2009b). The coding process followed that laid out by

Creswell and colleagues (see Figure 7 below) (Creswell & Clark, 2017; Creswell & Creswell, 2017; Creswell & Maietta, 2002; Creswell et al., 2003; Tashakkori & Creswell, 2007). After the initial themes were identified by the PhD researcher (EK), a second researcher reviewed the themes (PR) to ensure concordance. After this, the themes were given their final names. At the final stage, themes for all three groups were compared to each other, noting key similarities and differences.

Initial read through text data	Identify specific segments of information	Label segments to create categories	Reduce category redundancy and overlap	Create a model with most important categories
Many pages	Many text segments	30 – 40 categories	15 – 20 categories	3 – 8 categories

Figure 7. Coding process in thematic analysis (Adapted from Creswell & Maietta, 2002, Figure 9.4, p.266).

5.3 RESULTS

Analyses of the interviews and focus groups revealed four key themes across all groups: the benefits of using InterpreterNow, the purpose of the InterpreterNow service, the issues experienced when using InterpreterNow and suggestions to improve InterpreterNow (see Figure 8). The Deaf participants also discussed the topic of British Sign Language interpreters.

5.3.1 BENEFITS.

Deaf people (n=13) clearly indicated that there were benefits of using the InterpreterNow service for both Deaf people and healthcare professionals. Healthcare professionals (n=6) stated that a doctor and a nurse found the application and tablet acceptable to use in appointments, noting that the idea of bringing InterpreterNow to appointments was “fantastic” when the technology was working (according to project worker, CPW3). A key benefit of InterpreterNow for Deaf people was improved access to healthcare, especially for the older generation (n=10). See quote below highlighting the improved access.

“about the age as well with the older people, you know, we’re more at risk as far as our health is involved, so contacting the doctors, GPs that sort of thing, you know, it’s very, very useful.” (quote from a Deaf person, MR2)

Deaf people thought that having access to InterpreterNow gave them more knowledge about their health and gave them more independence (n=14). For example, one Deaf person (CR3) reported that because Deaf people could use InterpreterNow, they could easily contact the doctor themselves instead of going to the GP surgery or asking someone else to phone the doctor for them. Deaf people appreciated the fact that the application allowed them to communicate in their preferred language, British Sign Language (n=5). Lastly, Deaf people also indicated that they found it easy to understand how InterpreterNow works and how to use it (n=9). This is highlighted in the quote below.

“also, you get a letter saying, you’ve got this...an appointment, or whatever, it’s a wrong date or anything, then you can use it [InterpreterNow]...because obviously the service is only for ringing, so if you use InterpreterNow you can clarify you will be there, or change the appointment, or make an appointment.” (quote from a Deaf person, MR1)

Deaf people suggested that InterpreterNow was appropriate to use in a variety of situations including booking health appointments, during an appointment with an anaesthesiologist (before an operation), for booking hospital transport from home, in emergencies and also during GP appointments (n=10). Appointments during which InterpreterNow was identified to be acceptable to use were: at the diabetic clinic, the dentist, GP surgery and the hospital (see quote below).

“I was happy, and I was confident. It was a good positive. So, it’s perfect when I’m making appointments with the doctor directly. It’s fantastic. So, say I want to book a doctor’s [appointment] maybe tomorrow or next week Thursday, Friday and I’m in control of when the appointment is, and they say, they explain, obviously interpret for everything that I’m saying. So, thank you and goodbye and put the phone down. So that’s a fantastic experience. It’s perfect.” (quote from a Deaf person, WR4)

The British Sign Language interpreters' views were concordant with that of Deaf people. For instance, British Sign Language interpreters stated that the benefits for the health of the Deaf people were improved independence (by giving Deaf people ownership of their own life and autonomy as they don't have to ask family or friends to interpret, according to LSI3) (n=3). A further benefit was increased healthcare access (n=5). According to the British Sign Language interpreters, InterpreterNow made it easier to get an emergency appointment (CMI2), made the process of making appointments simpler (VCI1) and helped during health appointments if a face-to-face interpreter was not available (TSI5). British Sign Language interpreters also agreed that InterpreterNow was easy to use if the technology was functioning properly (n=4). The British Sign Language interpreters indicated the same appropriate situations for using InterpreterNow as Deaf people (n=5). The only difference between British Sign Language interpreters' and Deaf people's views was that British Sign Language interpreters highlighted more potential benefits to healthcare professionals such as improved communication, cost reductions and time savings (CMI2).

Healthcare professionals also indicated that Deaf people's access to healthcare and independence were improved by using InterpreterNow (n=5). In particular, healthcare professionals (GPs, DT4 and MJD2) noted that InterpreterNow could help to break down barriers for patients who are Deaf because it allows Deaf people to access the same services as hearing patients (for example, telephone consultations).

"for the [Deaf] patient, it's beneficial because they are able to access this service that we provide to our hearing patients which is telephone consultations. It's more convenient for them I assume because they don't have to actually get to the surgery and they can do this from their home and I would think it's more convenient for the interpreters because again they don't have to travel to the surgery and I would assume from that probably they're able to actually help more clients because they're not having to take into account any travelling time" (quote from a GP, MJD2)

Healthcare professionals provided more information about the benefits for healthcare professionals from InterpreterNow (improved communication, cost-effectiveness and time saving) (n=5). Communication was improved as the health professional (Consultant in Elderly Health, JCD3) could explain the details of the illness

to the Deaf person using InterpreterNow and because the British Sign Language interpreters could explain what emotions the healthcare professionals were trying to convey. Healthcare professionals (GP, AHD6) thought that InterpreterNow was cost-effective as it is cheaper than face-to-face British Sign Language interpreters. Time was saved in appointments as the Deaf patient could use the phone instead of going to the GP surgery in person (GP, MJD2). Time was also saved as the consultation could start straight away (GP, RMD5) and would only take the time that it was booked for, without overrunning (GP, AHD6). Using InterpreterNow is also faster than the doctor writing notes during appointments to communicate with the Deaf person (Consultant in Elderly Health, JCD3). Finally, healthcare professionals also suggested other ways in which it might be possible to use InterpreterNow including examinations, relaying blood test information, medication reviews, and blood pressure checks and for appointments when there's already an established treatment plan (GPs, AHD6 and MJD2).

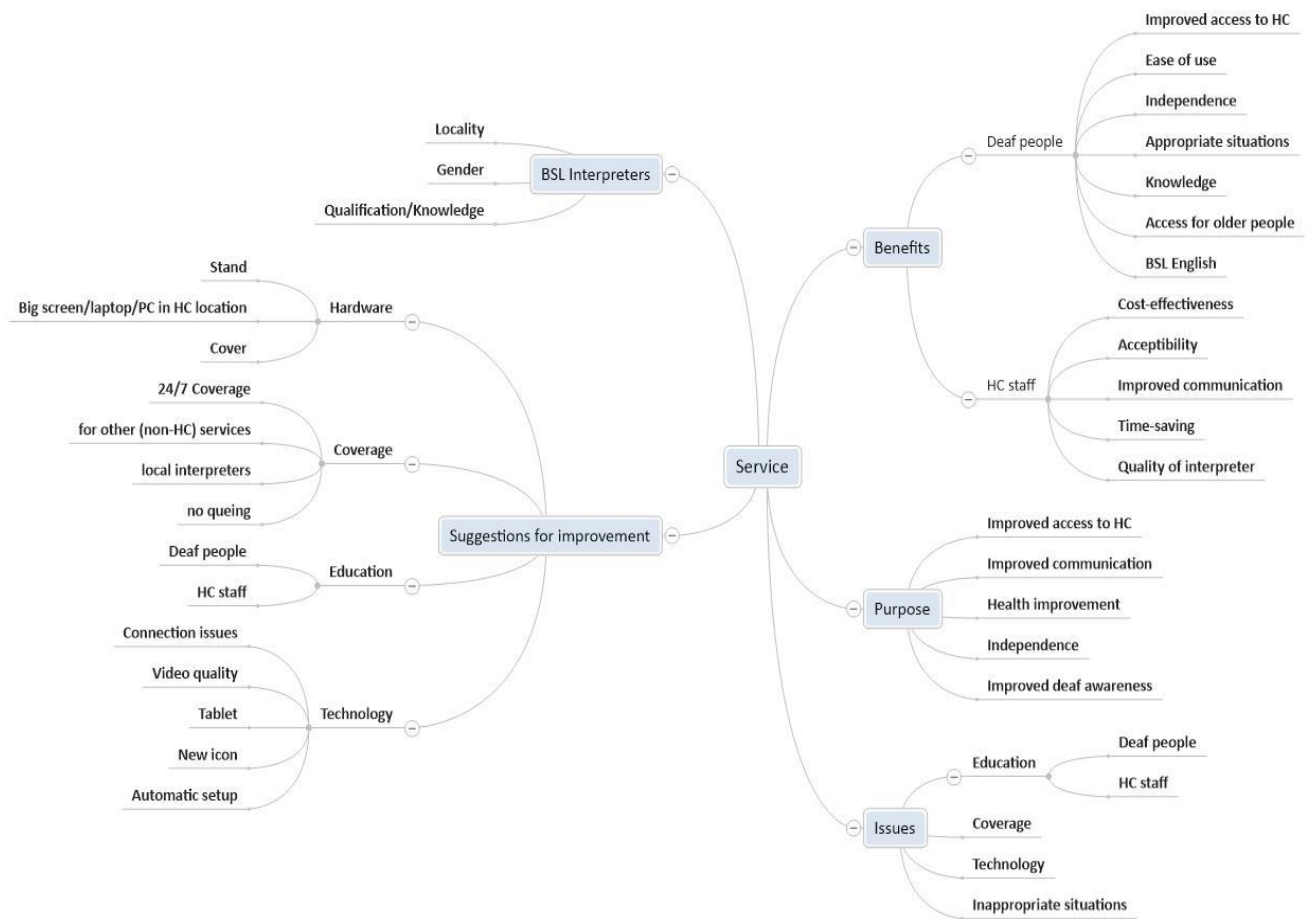


Figure 8. Visual representation of the themes.

5.3.2 PURPOSE.

According to Deaf people, the purposes of InterpreterNow are to support Deaf people's independence, improve Deaf awareness and healthcare access (n=12). Deaf people's independence is supported as they don't have to rely on their family for healthcare needs (n=7). Independence can also be improved by using a British Sign Language interpreter to communicate in British Sign Language with healthcare staff (n=8). The access to a British Sign Language interpreter makes it easier for Deaf people to understand what is being communicated during appointments and providing them with the ability to make informed health decisions (MR1, MR2, CR3, WR6). Deaf people (MR2 and MR3) stated that improvements in Deaf people's needs awareness could be due to the healthcare professionals getting experience with communicating with a Deaf person and British Sign Language interpreters when using InterpreterNow. Deaf people suggested that such exposure might help to spread the word about Deaf people's needs and might give healthcare professionals extra ideas about how to increase Deaf awareness within health settings (MR2 and MR3). Deaf people stated that InterpreterNow can help to improve access to healthcare by breaking down access barriers so that Deaf people have full communication and by providing a back-up for communicating during various healthcare appointments (MR2, WR1, WR4, CR6).

British Sign Language interpreters also noted that the key purposes of InterpreterNow were to improve healthcare access and the independence of Deaf people (n=5). In terms of access improvement, InterpreterNow can provide quick access to British Sign Language interpreters "on the go" (LSI3). InterpreterNow improved Deaf people's independence as it empowers them and ensures they don't have to rely on others for their healthcare needs (VCI1 and AJ14). In addition, British Sign Language interpreters (CMI2 and TSI5) stated that another purpose of InterpreterNow would be to improve health outcomes for Deaf people (see quote below). British Sign Language interpreters (CMI2, TSI5, VCI1 and AJ14) hoped that InterpreterNow use would support positive changes both to physical and mental health.

"[The purpose is] to explore ways of using this technology for health for Deaf people who would otherwise not have that access" (quote from a British Sign Language interpreter, TSI5)

Healthcare professionals (GPs, AHD6 and RMD5, and Consultant in Elderly Health, JCD3) also stated that the purpose of InterpreterNow was improved access to healthcare. Healthcare professionals were of the opinion that another key purpose is improving communication with Deaf people (GPs, DTD4 and AHD6, and Consultant in Elderly Health, JCD3). Healthcare professionals (n=6) consider that it is very important for Deaf people to express themselves in healthcare settings and to understand what the healthcare professional is talking about to get the correct diagnoses, tests and treatments. Below is a quote to illustrate the above paragraph:

“It’s the planning for her discharge, where she [the patient] was gonna go. Yeah, she understood the tests that we’d done and the illness that she’s got ...She’d been in for quite a few months but knowing each test that we’d done and why we’d done it and what the outcome was it was really helpful.” (quote from a healthcare professional (Consultant in Elderly Health, JCD3)

5.3.3 ISSUES.

The main issues relating to InterpreterNow were coverage, technology, education and inappropriate situations. British Sign Language interpreters (n=4) focused on education, technology and inappropriate situations. Deaf people (n=14) and healthcare professionals (n=4) placed greater emphasis on issues surrounding education and technology. Deaf people and healthcare professionals identified a variety of technology-related issues. The issues experienced included a poor internet connection, long InterpreterNow application loading time, text box not working, the screen freezing and/or being black, picture blurriness, the screen being too small, having the microphone at the back, connection issues and GP surgery not having any Wi-Fi. The influence of technology-related issues for some users was highlighted by one Deaf participant who stated that he tried to use the application once and didn’t use it again after that (see quote below):

“I took it to the doctors once. We put the Wi-Fi on, and the picture was very difficult to come up, and the picture for the interpreter was very difficult as well. She couldn’t see me. It was too dark. I could see her, but I couldn’t see her hands, very

blurry but she couldn't see me very well. So, we switched off and that was that. And I've never used it again." (quote from a Deaf person, CR5)

However, other Deaf people used the tablet constantly and after returning it, stated that they felt lost and that they could not be independent anymore (WR1, MR1 and MR2). This loss of independence is highlighted in the quote below:

"You know, I can use InterpreterNow and then...now it's gone it's like that independence has gone and I, you know, having to ask people to help me and it's like, "Please can I have the tablet back?" (quote from a Deaf person, MR1)

An education issue identified for Deaf people was the fact that some of the Deaf people were not sure how to use the tablet and the application (e.g., Deaf person wasn't aware that they were blocking the camera for the interpreter) (see quote below from a GP, MJD2).

"Well, she knew exactly where the camera was because she was holding up packets of medication right to the camera. The problem was that then obstructed the view of the camera for the interpreter to be able to communicate with her. Which I think is probably just more of an education thing for the patient."

Education issues were also identified by the healthcare professionals who felt that they were not provided with enough training and as a result, did not have knowledge about Deaf people's health and communication needs as well as about the availability of British Sign Language interpreters (Clinical Psychiatrist, ABD1 and GPs, MJD2 and AHD6). British Sign Language interpreters indicated that they felt that InterpreterNow is not appropriate for all situations (VCI1 and TSI5). For example, they felt that the service is not appropriate for group meetings (over two people in the room), for patients with significant illnesses, for detailed appointments about in-depth issues, if the appointment causes emotional stress, at the optician's (it's dark), after having laser treatment or at the dentist (nowhere to put tablet when getting a filling) (see quote below from British Sign Language interpreter, TSI5):

“[InterpreterNow inappropriate to use for] operations, for fillings in the dentist. Where can you put the camera, so you can see? ... Emotional appointments. So, if it was like it was simple like oh, I’ve got a bit of a cold, or I’ve got a cough or something...you know something on my skin, but if its in-depth information, some personal issues about your body and things, it’s not appropriate. I want a face-to-face interpreter to make sure there’s clarification and that it’s clear.”

In terms of availability, British Sign Language interpreters highlighted that remote interpreting was not available 24 hours a day, despite the fact that emergency situations can occur at any time (as can be seen in the quote below).

“That is a really big gap we've identified, that there needs to be some sort of national service online for out of hours cover so that when people are getting sent to the hospital, at the moment each area will have its own contract with whoever the provider is. “ (quote from British Sign Language interpreter, VCI1)

5.3.4 SUGGESTIONS FOR IMPROVEMENT.

All the participants felt that changes to hardware, education, coverage and technology would improve the InterpreterNow service. Healthcare professionals (Clinical Psychiatrist ABD1, GP MJD2 and Consultant in Elderly Health JCD3) and British Sign Language interpreters (VCI1 and CMI2) suggested that having a laptop or PC with a large screen and a faster internet connection at the surgery would improve the service. Also, it was suggested by Deaf people that the equipment (computer/laptop/tablet) for InterpreterNow should be set up before the appointment (see quote below from a Deaf participant, CR2).

“I think the important thing to remember is to make sure the [British Sign Language] interpreter can see you and that you do have a good Wi-Fi signal, so I think equipment should be set up before you arrive. It’s difficult when you go into a GP’s office or in surgery, you have to think about, is the room too light? Is the shadow coming in from the window? To set up your equipment, make sure it’s an appropriate room for a Deaf person to communicate there. “

The British Sign Language interpreters' (CMI2) and Deaf people's (MR5) suggestions for improving the education of Deaf people were to ensure that all Deaf people had the same training levels across different regions. Another suggestion from the above groups was to introduce short online training videos about InterpreterNow (BSL interpreter CMI2 and Deaf person, WR7). Screenshots of different application functions could also be included to remind Deaf people how to use InterpreterNow (BSL interpreter, CMI2). Healthcare professionals (Clinical Psychiatrist, ABD1) indicated that it would be useful to have advance warning of when InterpreterNow would be used in appointments and what kind of room setup would be most appropriate.

5.3.5 BRITISH SIGN LANGUAGE INTERPRETERS (ONLY FROM DEAF PEOPLE).

The key themes for Deaf people concerning the British Sign Language interpreters were locality, gender and qualification (n=10). When discussing locality, some Deaf people (MR2, CR7, WR5 and CR6) said that they prefer not to know their British Sign Language interpreters because they don't want to share private information with someone they know well (this can be seen in a quote from a Deaf person below, CR6). However, other Deaf people (MR4, WR1, WR4 and MR1) stated a preference for local British Sign Language interpreters who are known to the Deaf person and with whom an established relationship exists. This means the British Sign Language interpreter already knows about their health issues and the Deaf person won't get confused when non-local British Sign Language interpreters use different signs (from different regions).

"I sometimes prefer not to know the person... If it's in the private information I don't really feel like I want to tell somebody that I know quite well. It's quite embarrassing. I prefer strange people in that situation. But it's the trust as well. If you don't know them, you're not quite sure how confident you are in using them and how confidential they'll be, so I just find going to the doctor, I prefer to do that alone, face-to-face and it's fine."

In terms of British Sign Language interpreters' gender, some Deaf people said that they don't have a preference (CR6 and MR1). Others indicated that if they wanted to get a British Sign Language interpreter of a different gender to the one that had come

up on the InterpreterNow screen, then they'd be happy to ask for that or keep calling until a British Sign Language interpreter with the preferred gender was on duty (CR7, WR5, and MR2). Deaf people also said that the fact that British Sign Language interpreters are fully qualified reassures them (WR2, WR1 and WR6). If a British Sign Language interpreter is fully qualified then they will abide by a code of conduct, will have professional indemnity insurance and a current enhanced DBS certificate. Deaf people noted that these qualifications were particularly important when the appointment was for the Deaf person's child (WR1, WR2, WR3, WR4).

5.4 DISCUSSION

InterpreterNow is a technology-based intervention that aimed to improve communication during interactions between Deaf people and healthcare professionals via the provision of online remote British Sign Language interpreters. This study aimed to improve the understanding of the negative and positive experiences of Deaf people during a videoconferencing intervention in healthcare settings. Our findings suggest that Deaf people could benefit from a healthcare videoconferencing mobile application. However, it was also shown that InterpreterNow is not appropriate to use in all healthcare situations and for all Deaf people. Further, ways to improve the service were identified that should be implemented before InterpreterNow is used more widely. The benefits of using InterpreterNow included improvements in healthcare access, communication and independence for Deaf people as well as a reduction in costs and resources for the NHS. The issues raised by Deaf people, British Sign Language interpreters and healthcare staff were about technology (such as the lack of connection in certain areas), as well as education (for instance, lack of awareness of InterpreterNow shown by the doctors). It was also not possible to use InterpreterNow for certain situations such as physical examinations as well as those that involve little light (such as opticians) or a lot of movement.

5.4.1 BENEFITS.

The benefits identified by the healthcare staff, British Sign Language interpreters and Deaf people can be separated into themes. The themes are benefits to NHS,

benefits relating to Deaf experience, benefits related to healthcare access, and the reasons why InterpreterNow is appropriate.

In terms of NHS benefits, healthcare staff and British Sign Language interpreters noted possible time savings and cost savings that would reduce the burden on the NHS. For instance, using InterpreterNow use led to shorter appointment time, which means that it isn't necessary to give Deaf people double appointments. In addition, using InterpreterNow meant that British Sign Language interpreters could talk to more people online and that travel costs are reduced. The fact that cost reduction was identified as a benefit, could mean that in some cases, InterpreterNow use could help to reduce of the financial burden on NHS services.

A prominent theme identified by Deaf people and British Sign Language interpreters related to the experience of Deaf people when interacting with healthcare services. Different studies have shown that Deaf people don't feel responsible for their health, feel scared and confused during healthcare appointments or feel patronised by healthcare staff (Emond et al., 2015a, 2015b; Iezonni et al., 2000; Steinberg et al., 2002). In certain cases, InterpreterNow seemed to support Deaf people in overcoming such issues. Participants stated that InterpreterNow promoted independence as Deaf people don't have to rely on others to translate English into British Sign Language. This is due to Deaf people learning a new skill (using the mobile application). Another reason independence is promoted is because Deaf people have control over how they communicate and when. Deaf people and British Sign Language interpreters also suggested that InterpreterNow use increased feeling of confidence about being able to communicate clearly in appointments and ask questions about treatment. This confidence could be due to Deaf people understanding more information during appointments and being able to relate more to their health professional. Therefore, using a mobile application for health communication might lead to more understanding in healthcare appointments and to a more positive healthcare experience for Deaf people.

Different participant groups (healthcare professionals, Deaf people and British Sign Language interpreters) also noted that the InterpreterNow service provided greater access to healthcare for Deaf people. Using InterpreterNow gives Deaf people the same

access as hearing people to telephone appointments (something which wasn't previously available to Deaf people), as well as immediate access to healthcare during emergencies. The quality of access to healthcare with InterpreterNow might be better than using friends or family to interpret. This is the case as with InterpreterNow Deaf people can use a professionally trained British Sign Language interpreter, who knows the appropriate terminology as opposed to their friends or family (who might use their own versions of sign language). Better Deaf healthcare access could potentially lead to more understanding for Deaf people, increase in health knowledge and better health outcomes. Better healthcare access for Deaf people would support previous research (Emond et al., 2015a, Fellingner et al., 2012; Steinberg et al., 2002, 2006) which has highlighted the importance of communication in Deaf healthcare issues, as well as showing that positive healthcare experiences (which include opportunities for Deaf people to communicate in British Sign Language) are likely to lead to an increased access to information and service use. Therefore, the experiences of Deaf people indicate that InterpreterNow provides a service that can help to improve Deaf healthcare access.

Lastly, appropriate situations for InterpreterNow use were noted by Deaf participants, British Sign Language interpreters and healthcare professionals. It appears that InterpreterNow was most useful for brief telephone appointments, making appointments by telephone, emergencies and simple face-to-face appointments. InterpreterNow provides Deaf people with an option for how they wish to communicate with healthcare professionals. Deaf people are in control and can decide when they would prefer to use InterpreterNow or when they would prefer to communicate via lip-reading or have face-to-face interpretation. The fact that participants discussed the appropriate situations highlights the boundaries and remits of the use of InterpreterNow.

Results from this study indicate that Deaf participants were making choices and were able to pick the preferred appointment type for using InterpreterNow. In patient-centred approaches to healthcare, making personal choices about health can lead to confidence as well as better health outcomes (Street et al., 2009). Therefore, the fact that Deaf people were making choices when using InterpreterNow may also lead to improved confidence during healthcare communication and potential improvement in health. Also, it is important to know why certain situations were more appropriate and

acceptable. Deaf participants in this study found InterpreterNow most useful when using the service to make appointment bookings or have brief appointments from their home (as a hearing person would use a telephone), which provides them with the same communication access as hearing people. InterpreterNow was also useful as a backup option when the face-to-face British Sign Language interpreter was not available such as in emergency situations. This shows that InterpreterNow is a highly flexible option, which can be controlled by the Deaf person at their time of need. It is very important to be able to communicate in emergency situations when a Deaf person might feel scared and confused. InterpreterNow is able to fill this communication gap, whereas as previously Deaf people would have not had the opportunity to immediately communicate during health emergencies effectively.

5.4.2 ISSUES.

The participants (Deaf people, British Sign Language interpreters and healthcare professionals) identified a variety of issues of using InterpreterNow service. The key issues identified could be grouped as technology issues, educational issues, as well as issues related to individual differences in the Deaf populations as well as inappropriate appointments for using InterpreterNow.

The technology issues were about hardware, connection and software. Some Deaf people stated that the screen was dark or blurry, which could be related to connection issues. Other Deaf people's tablets did not work and had to be replaced. In future InterpreterNow trials, Deaf people would use the mobile application on their own devices instead of being provided with tablets. Deaf people are used to their own devices more than tablets so would be more comfortable when using them. Also, Deaf people have more control over their own devices. The tablets belong to the local charities involved in the trial so Deaf people had to return them at the end of the trial and if the tablet broke, the Deaf person had to give it to the project worker to be fixed.

The connection issues were related to low connectivity in certain areas of the country. This is useful information because it allows to identify where InterpreterNow does or does not work. Therefore, this shows areas where connectivity should be improved. Participants stated that when the session to cut out or the screen was blurry

due to connections issues, this led to misunderstanding (as British Sign Language interpreter could not be seen clearly) or embarrassment when the tablet did not work. This is important to consider, as the key aim of the intervention was to improve Deaf health experiences, as opposed to adding extra pressures and stress. Therefore, in the future, it is important to separate whether issues experienced were due to training or connectivity.

Educational issues were related to differences in the training provided by different project workers. Project workers were trained for the trial on ethics and research methods by the PhD researcher (EK) at the same time. Project workers trained Deaf people on how to use the tablet and how to use InterpreterNow at the four Deaf community locations of the trial (Worcester, Merseyside, Cumbria and Manchester). In the future, it is vital that training received by Deaf people is the same across different locations. This could be achieved by providing regular refresher courses to project workers. However, it should be noted that some Deaf people seemed to understand how to use the application during training but were nervous to use it in the healthcare appointments or simply put the tablet away and forgot how to use it. There were some educational videos and materials available but not all Deaf people found them useful. Therefore, further efforts are needed to gain a clear understanding of the training needs of Deaf people using InterpreterNow. Previous studies (for instance, Iezzoni et al., 2004; Pollard & Barnet, 2009; Sadler et al., 2001) have highlighted the importance of training for Deaf people due to lower levels of health literacy than hearing people. Also, previous interventions have provided too much information for Deaf people to comprehend (Sadler et al., 2001). Therefore, future training should account for literacy issues as well as presenting information in short sections.

Other education issues highlighted were related to the lack of Deaf awareness. Some healthcare staff did not accept InterpreterNow in appointments, as they thought that Deaf people would be happy to read health information or lip-read. When asked about Deaf awareness in the interviews of this study, certain healthcare professionals stated that they simply did not have the time to go on training. Some healthcare professionals were more aware than others of Deaf issues and needs. Current findings of health staff having low Deaf awareness confirms previous evidence (for instance, Harmer, 1999; Steinberg et al., 1998; Ubido et al., 2002). For instance, staff often don't

know the best methods of communicating with Deaf people and assume that Deaf patients lack independence (Kritzinger et al., 2014; Ubido et al., 2002). In the future, it would be important to offer training to healthcare staff about general Deaf awareness in addition to that related to the InterpreterNow service.

When discussing issues experienced with the InterpreterNow service, it became apparent that Deaf people have a variety of different communication and access needs. Some Deaf people have additional issues, such as learning difficulties which make it harder for them to understand how to use InterpreterNow. Also, some Deaf people (mostly prelingual, those who were Deaf from birth) spend most of their time within the Deaf community and do not relate well with hearing people and furthermore, are not interested in attempting to relate to hearing people (Allen et al., 2002; Harmer, 1999). Other Deaf people fear technological advances and change (mostly older Deaf people or people ingrained within the Deaf community) (Bat-Chav, 1993; Harmer, 1999). The differences in Deaf attitudes to technology have been previously highlighted (Maiorana-Basas & Pagliaro, 2014; Thoren et al., 2013) with older people less likely to use the internet and are more likely to use desktop computers. In contrast, younger Deaf people tend to use the internet more as well as mobile phones and iPads. However, certain groups of Deaf people are comfortable with technology and are likely to find InterpreterNow useful. These findings are in concordance with previous research (Power & Power, 2004) indicating that Deaf people find access to technology to be useful for communication and that the access helps to reduce stigma. Power and Power (2004) support current study findings that some Deaf people found the technology of InterpreterNow beneficial. The current findings highlight the importance of understanding why some people Deaf people found InterpreterNow fully appropriate and useful while others did not.

Closely linked to the differences in Deaf needs is the topic of when InterpreterNow should not be used. Views and opinion about when InterpreterNow is appropriate to use varied across our participants. Some Deaf people feel that in general, face-to-face British Sign Language interpreters should be used for more involved and personal appointments, whereas others felt that for personal appointments (such as sexual health appointments), it would be preferable to use online British Sign Language interpreters who are not known to the Deaf person. Further, some Deaf

participants felt that face-to-face British Sign Language interpreters should be used in appointments where a lot of movement is involved, such as physical examinations, opticians and dentists. In addition, it might be difficult to use InterpreterNow at the opticians when the examinations rooms are dark. Certain Deaf people found InterpreterNow unacceptable to use either because it was not working properly or because they forgot how to use it or because they were fearful of technology. It is also noteworthy that some participants did not get ill throughout the intervention and therefore lacked the opportunity to use the service. The discussion about inappropriate situations further highlights the individual differences in terms of Deaf health needs (Emond et al., 2015a, 2015b; Thoren et al., 2013).

5.4.3 IMPROVEMENT SUGGESTIONS.

Participants identified that improvements could be made to overcome problems they experienced with the technology, service availability and education. Technology improvements proposed were related to hardware and connection. Service availability was related to constant service provision, queues and British Sign Language interpreter locality. Education improvements were about setting up equipment before healthcare appointments, preparation for the health appointment, low awareness of healthcare staff and training for Deaf people. In terms of technology improvements, changes to hardware proposed including having a large screen (computer or laptop). Faster internet connection at healthcare services was proposed as an improvement for the connection issues.

One of the service availability improvement suggestions was about the constant provision of InterpreterNow. British Sign Language interpreters and Deaf people felt that the service should be available 24 hours a day, seven days a week without queues. Constant coverage would ensure that the service can be used in all emergencies (which was stated to be one of the key ways in which InterpreterNow is used).

Service availability could also be improved if queues were reduced. Sometimes, when the Deaf person attempted to get in touch with a British Sign Language interpreter via InterpreterNow during appointments, they were put in a queue if the British Sign Language interpreter was occupied at a different appointment. Deaf people felt

embarrassed at appointments or hung up if there were queues. No queuing could be achieved if there were more British Sign Language interpreters employed on the service.

Another service availability suggestion was that local British Sign Language interpreters should be used for InterpreterNow service. Some Deaf people preferred local British Sign Language interpreters because they knew them and felt more comfortable, as well as understanding their signs better. However, other Deaf people preferred non-local British Sign Language interpreters because they felt this allowed for more privacy about private medical conditions. Therefore, more research is necessary to understand whether local or non-local British Sign Language interpreters should be used for InterpreterNow.

An educational issue that could be improved on was that some Deaf people took a long time to set up the tablet and turn on and use InterpreterNow. This problem could be improved by the advance setting up of equipment for appointments. Advance set up of equipment would particularly help older Deaf people who may not be used to technology.

Another educational issue was that doctors were not aware of or prepared to use InterpreterNow. It was suggested by healthcare professionals that receiving a warning in advance of when InterpreterNow would be used would be helpful. This would improve healthcare professionals' awareness of InterpreterNow, as well as allowing healthcare professionals to prepare for appointments with a different way of communication.

It was also suggested by healthcare professionals that Deaf people's training differences were an education-related problem for adequate use of the InterpreterNow service. It was suggested that providing the same training for all Deaf people may support Deaf people's use of InterpreterNow. Another suggestion was to provide a variety of training options for the InterpreterNow service (e.g., both online and face-to-face). The choice of training options would support individual preferences and make Deaf people feel like their needs are important.

Therefore, technology, service availability and education improvements can be made to overcome service issues. Some of the proposed changes are simple (for

instance, providing online training), whereas other changes depend on many factors (i.e., provision of local British Sign Language interpreters is dependent on funding sources as well as interpreter availability). Overall, the changes are closely linked with issues about the service and provide ideas for future alterations.

5.4.4 STRENGTHS AND LIMITATIONS.

Results from this study have shed light on the improvements that can be made to help improve the InterpreterNow service based on the views and opinions of British Sign Language interpreters, Deaf people and healthcare professionals on how useful and acceptable InterpreterNow could be for Deaf health communication improvement.

This study contributes to the literature in terms of providing additional information that Deaf people might not be unaware of. Previous research about evaluating a Deaf health intervention was only focused on Deaf people (Sadler et al., 2001). In Sadler et al. (2001) the participants were Deaf people who provided information about their views on an educational programme. However, Deaf people do not have the primary viewpoint about issues and concerns of healthcare professionals and British Sign Language interpreters. The views of healthcare professionals and British Sign Language interpreters may provide extra information which is different from that provided by Deaf people as well as confirming some of the views of Deaf people. Another way in which this study contributes to literature is by analysing the views of an intervention which is Deaf friendly (as it was created based on a Deaf health study by Emond et al. (2015a,b) and as it uses Deaf friendly methods by providing British Sign Language interpreters and sign language fluent project workers). Sadler et al. (2001) adapted an educational intervention for hearing people whereas the present intervention was created following interviews with Deaf people (Emond et al., 2015a, b). Therefore, the current study builds on the previous issues of Sadler et al. (2001). Also, this study is testing the acceptability of a videoconferencing intervention. Videoconferencing is a Deaf friendly approach as it uses technology which is faster and also because contact can be made remotely, which allows Deaf people more flexibility in comparison to face-to-face interventions (Sadler et al., 2001).

The current study also draws on the strengths of previous research. In this study, British Sign Language interpreters with hearing interviewers were used to interview Deaf people which helps to ensure Deaf people feel comfortable and understand the questions (Crowe, 2003; Sadler et al., 2001; Young & Hunt, 2011). Another way that the current study focus groups were made appropriate to Deaf needs is by allowing more time for the Deaf focus groups and constraining the number of participants to a maximum of four per focus group (Bisol et al., 2008; Kipp et al., 2011).

In summary, the positive aspects of the current study are using Deaf friendly methods (an intervention designed for Deaf people specifically), provision of additional information from healthcare professionals and British Sign Language interpreters and the fact that a novel type of intervention (videoconferencing) is being scrutinised. Also, the current study was organised to ensure that it was conducted in a Deaf friendly manner based on the suggestions from previous research (e.g., Kipp et al., 2011; Young & Hunt, 2011). However, more detailed and accurate outcomes could be obtained with some improvement in terms of methodology. Despite the new knowledge obtained in the current study, the limitations need to be acknowledged. The key limitations of this study are about the subjectivity of qualitative data, levels of intervention exposure and issues related to Deaf needs.

Qualitative study outcomes are often subjective. During qualitative interviews or focus groups, the researchers' views could influence participants. In particular, Deaf people could be influenced by a hearing researcher, as evidence has shown that Deaf people are easily confused and can occasionally lack independence and confidence in communicating with hearing people (Emond et al., 2015a, 2015b; Kritzinger et al., 2014). In order to minimise this risk, British Sign Language interpreters were present during focus groups with Deaf people. The presence of British Sign Language interpreters is comforting as some of them are well known to the Deaf people. The presence of British Sign Language interpreter also allows for a better understanding as Deaf people can communicate in British Sign Language, which is preferable to Deaf people lip-reading from the hearing interpreter.

Another limitation was that there were only a small number of people involved in this study, which means that caution needs to be taken when extrapolating these

findings at a population level. In comparison, the work of Sadler et al. (2001) included a larger sample (n=123) from which it is possible to make stronger conclusions. A further reason that the findings are limited is that participants had different levels of InterpreterNow use. Some participants used InterpreterNow less due to not getting ill or forgetting to use it or preferring face-to-face communication. This means that the participants had different levels of experience and exposure to InterpreterNow service. Also, participants starting using InterpreterNow at different points in time. This was due to practical constraints related to the length of time it took to conduct a baseline questionnaire and to train participants on InterpreterNow and the tablet. For instance, participants who had only just started using InterpreterNow may have found it challenging and confusing at first but learned to use it over time and then became more confident. Additionally, data were collected at one-time point per group (British Sign Language interpreters, Deaf people and healthcare professionals). Future research could collect view and opinions as Deaf people progress through the intervention at regular intervals. Such longitudinal qualitative data would represent a novel addition to the literature and help shed light on changes in InterpreterNow use over time.

Lastly, the study was limited due to issues Deaf people experience in communicating with hearing people. Research with Deaf people requires certain adjustments to ensure that Deaf people understand what the research is about and what they are being asked by the hearing interviewer. Deaf people often do not understand English very well (especially if they grew up within the Deaf community) and can find lip-reading from a hearing person difficult (van Staden et al., 2009). Also, Deaf people may not understand complex English concepts or medical jargon as this does not exist in sign language and due to Deaf people's low health literacy (Patel et al., 2011; Pollard & Barnett, 2009). Support was provided in this study by using audio-recordings, British Sign Language interpreters and allowing more time for the focus groups. A pilot focus group was conducted to understand and learn how to effectively communicate with Deaf people (slowly, clearly, with a lot of eye contact, sometimes explaining concepts in different ways to ensure understanding). This initial pilot focus group also helped to establish appropriate questions and how to lead the focus group (i.e., when communicating with both Deaf people and British Sign Language interpreters). In addition, the interviewer (EK) was trained in how to conduct focus groups and qualitative interviews, and the semi-structured interview guide was refined

under guidance from researchers experienced in qualitative interviewing. These efforts helped overcome the issues Deaf people experience when communicating with hearing people (for example, Emond et al., 2015a, 2015b; Patel et al., 2011; Steinberg et al., 2002, 2006).

Future directions of research could include conducting one-to-one interviews with Deaf people with British Sign Language interpreters present. Video-recording could then be used to capture the facial expressions and hand gestures of Deaf people. Also, sign language fluent interviewers might be preferred as the Deaf person may feel more comfortable, ensuring in more openness. Also, more participants should be interviewed to ensure that more power can be given to the findings. Interviewing participants more regularly (for instance, every two months) would ensure that opinions are collected across different levels of exposure to the study. Lastly, if Deaf people who had particularly negative or positive experiences with the service were pre-selected, as opposed to interviewing people with a mixed range of opinions, the key benefits and issues would be easier to ascertain.

5.4.5 CONCLUSION.

Deaf people have various individual needs which affect their views on healthcare and how they used a mobile application in healthcare settings. This study shows the views of British Sign Language interpreters, Deaf people and healthcare professionals on the InterpreterNow use. The findings highlight the exact reasons why some participants used InterpreterNow, whilst others did not, how to improve InterpreterNow and to encourage more Deaf people to use it. The findings provide an indication of what Deaf people, health professionals and British Sign Language interpreters would like to see from the service in the future and how simple an online interpreting service is to use. Finally, this work also supports other studies on feasibility by indicating the circumstance in which a remote sign language interpreting service is an acceptable means of communication within healthcare settings.

This research provides insight into the key benefits of the intervention (such as increasing motivation and health understanding for Deaf people), most common/appropriate ways of using InterpreterNow (for short simple appointments and in emergencies), the issues (connectivity and hardware not working) as well as improvement suggestions (more Deaf awareness training, as well as fixing technological issues).

Different participants were also able to provide insights specific to their group. For instance, healthcare professionals were emphasising that InterpreterNow Service could save NHS resources and provide equality in treatment and care for Deaf people. Deaf people's views provided an understanding of how different Deaf people have varying experiences depending on their communication preferences, age and understanding of technology. Lastly, British Sign Language interpreters noted that there is an overall lack of British Sign Language interpreters as well as stating concerns about British Sign Language interpreter locality. Therefore, the information from non-Deaf participants can be used to provide additional information from a different viewpoint and also extend on the information provided by Deaf people.

In conclusion, the present study triangulates the views and opinions of healthcare professionals, British Sign Language interpreters and Deaf people to produce rich in-depth data about the use of a remote sign language interpreter service to improve communication for Deaf people. The qualitative findings provide an explanation about how Deaf people could benefit from InterpreterNow, what issues result in Deaf people not being able to use InterpreterNow as well as how InterpreterNow could be improved to be more acceptable and usable in the future. The data collected can be used to improve the InterpreterNow service as well as provide information on Deaf people's health and communication needs. Such data can contribute to Deaf research literature as well as give insight for government or healthcare providers involved in conducting process evaluations of mHealth interventions for Deaf people.

CHAPTER 6: FEASIBILITY

6.1 INTRODUCTION

Deaf people often experience doctor-centred communication in healthcare (Beck, Daughtridge, & Sloane, 2002). Doctor-centred communication tends to involve dominant physician behaviours, such as the doctors being disinterested in patient views, not encouraging patient questions and not sharing medical data (Beck et al., 2002). This communication style often results in the Deaf people feeling controlled, not respected, and patronised (Emond et al., 2015a, 2015b; Iezzoni et al., 2004; Steinberg et al., 2002). Such negative healthcare experiences may then lead to worse health outcomes as well as worse access for Deaf people (Emond et al., 2015a, 2015b; Patel et al., 2011). Videoconferencing services provide a potentially cost-effective method of improving the healthcare experiences of Deaf people by allowing communication using sign language (Emond et al., 2015a, 2015b).

Yet, the feasibility of a remote sign language interpreting service has not previously been established to identify whether such technological interventions are appropriate for the Deaf population. Other reasons for conducting this feasibility study were that healthcare staff have shown a lack of Deaf awareness in intervention literature (Alexander et al., 2012; Emond et al., 2015a, 2015b; Kuenburg et al., 2016) and that Deaf people have health communication needs that may be resolved by this intervention (Barnett et al., 2011; Middleton et al., 2010; Steinberg et al., 2002, 2006). Therefore, this chapter assesses the feasibility of a Deaf videoconferencing intervention (InterpreterNow) by examining Deaf people's and project workers' acceptability of the intervention, how much and for which services the intervention was used and the potential cost savings.

6.1.1 ACCEPTABILITY.

Deaf people experience a range of communication and access issues during healthcare interactions. These issues might be reduced by the use of mobile technologies such as videoconferencing and text messaging (Emond et al., 2015a,

2015b; Hacking, Lau, Haricharan, & Heap, 2016; Kyle et al., 2013). However, the Deaf population is not uniform and some groups (for example, the elderly compared to young and middle-aged Deaf people (Thoren et al., 2013) might not be used to mobile technology/videoconferencing and could find it difficult to participate in mHealth interventions. For instance, it was found that a group of 41 Deaf participants did not find a mobile text messaging intervention acceptable (Hacking et al., 2016). In fact, 29% of the participants did not feel that the intervention promoted connection with healthcare staff, 46% did not find the text messages entertaining and only 27% felt that text messages were the best way of information delivery for Deaf people. Austen and McGrath (2006) found that mental health staff did not have enough knowledge of videoconferencing health interventions for Deaf people and were concerned about whether videoconferencing would be appropriate for mental health appointments for Deaf participants (Austen & McGrath, 2006). The acceptability of videoconferencing for mental health treatment also depends on whether the patient had previous access to face-to-face therapy and on whether the remote therapist was fluent in sign language (Crowe, 2017; Crowe et al., 2016). Therefore, research suggests that mHealth interventions may not be acceptable in all circumstances.

It is important to note, however, that some mHealth interventions have been shown to be acceptable to Deaf people (Wilson & Wells, 2009). Wilson and Wells (2009) demonstrated that using videoconferencing to provide information about signs, symptoms and treatment of depression significantly increased Deaf people's knowledge of depression. Results indicated that mHealth can be acceptable for promoting health knowledge. However, further research is necessary to ascertain whether Deaf people find mHealth interventions fully acceptable and whether mHealth interventions can support improvements in outcomes such as communication improvements, health outcomes, motivation and health behaviour change. Therefore, it is important to investigate and establish the acceptability of mHealth interventions for the Deaf population. The purpose of this chapter is to ascertain whether InterpreterNow was usable and acceptable for promoting better healthcare experiences and improving health communication. Specifically, Deaf people and project workers provided views about intervention acceptability. The Deaf people and project workers were asked questions such as whether the technology works as it should, whether the mobile

application is easy to use and why certain Deaf people don't like using the mobile application.

6.1.2 DEMAND.

Deaf people have been shown to use technology such as mobile phone text messaging, telephone typewriters (TTY), voice/TTY relay services, fax, and email on a regular basis (Power, Power, & Horstmanshof, 2007). An online survey was conducted to understand the technology preferences of three hundred and five Deaf people (Power, Power, & Rehling, 2007). Results revealed that text messaging was the most frequently employed and (by 96% of Deaf people) used for social (keeping in touch) and instrumental (obtaining information and making appointments) purposes. Deaf people also stated that they would like better connectivity and more reliable assistive technology provision (such as relay services). On average, 19 to 26% of Deaf people use assistive technology such as TTY, text pagers, flashing alerting devices and relay services (Kaye, Yeager, & Reed, 2008). These findings suggest that Deaf people already use technology in their daily lives and so may be open to using technology in healthcare settings. The above evidence highlights that InterpreterNow could be an appropriate intervention as many Deaf people are competent at using mobile technology such as text messaging and relay services (which is how the current videoconferencing intervention is delivered). However, this study aims is to establish how often a videoconferencing intervention was used when free access was provided for 12 months. The study also aims to provide an insight into when videoconferencing is most employed and useful (for instance, during simple appointments).

6.1.4 AIMS.

The present study sought to answer the following research questions:

- Is the InterpreterNow service acceptable to Deaf people?
- What are the views of project workers on the acceptability of the InterpreterNow service?

- How much does it cost to run the InterpreterNow service? Does videoconferencing use lead to travel cost reductions? Does InterpreterNow use lead to reduced medical appointment length?
- How much and when was the InterpreterNow service used by Deaf people?

6.1.3 COST EVALUATION.

mHealth interventions can support cost savings for Deaf people, NHS and for providers of the intervention (Askvig, Liccini, & Bossert, 2015; Cason, Behl, & Ringwalt, 2012; Kelso, Fiechtl, Olsen, & Rule, 2009; McCarthy & Leigh, 2012). For example, travel costs can be reduced by providing an outpatient (instead of residential) service, and by decreasing the number of unnecessary appointments such as brief appointments or confirmation of medication prescriptions which hearing people usually receive over the telephone.

Previous evidence shows that travel costs were reduced by using videoconferencing as opposed to face-to-face services (Blaiser et al., 2013; Wilson & Wells, 2009). It was found during a health education intervention study that when a lecture on depression signs, symptoms and treatment was delivered to Deaf people through videoconferencing, this led to \$1,800 annual travel cost savings (Wilson & Wells, 2009). The calculations were based on one consultation per week for a year. Travel savings for participants were \$1, 208.81 and \$676 for mental health professionals. Travel cost savings have also been shown in a videoconferencing intervention study on child language delays (Blaiser et al., 2013). Blaiser and colleagues (2013) showed that a cost saving of \$77 per appointment could be made due to the removal of travel costs for the British Sign Language interpreter. Using videoconferencing instead of face-to-face services for three to four visits per child per month for 15 families, the savings were estimated to be \$56,280 to \$86,970 over a 24-month period. The present study aims to establish the cost-effectiveness of a remote sign language interpreter service for health care interactions compared to a face-to-face interpretation.

Costs have also been reduced by converting residential treatments programmes into outpatient services by videoconferencing delivery. For instance, Wilson et al. (2015) identified that using videoconferencing for providing a Deaf outpatient service instead of a residential substance abuse treatment programme would result in cost savings between \$10,000 and \$22,000. This shows that videoconferencing helps to save funds for long-term treatment. However, less evidence is available about the cost savings that can be made by using mHealth technologies during shorter healthcare interactions such as GP appointments, hospital visits, opticians and dentists. The present study therefore investigates the cost-savings that can be obtained from using InterpreterNow, a remote sign language interpreter service, for short healthcare interactions.

Deaf people tend to require double healthcare appointments (when an appointment for a Deaf person is booked for the time of two hearing person's appointments at eight to ten minutes each on average (Curtis & Netten, 2012) to allow more time for British Sign Language interpreters to translate between the doctor and the Deaf person. Deaf people also need longer appointments Deaf people have lower health literacy than hearing people and so need more time to understand the doctor's prescription (Emond et al., 2015a, b; Pollard & Barnett, 2009). It might be possible to use InterpreterNow to reduce appointment length, leading to cost savings.

Also, Deaf people cannot use the telephone. In comparison, hearing people receive test results, brief consultations and prescription changes over the phone. Deaf people need to go to the GP surgery for such brief interactions. It is proposed that InterpreterNow can be used to save costs and time by allowing Deaf people to communicate by telephone about healthcare issues with remote support from British Sign Language interpreters. The aim of the study then, is to ascertain whether appointment length will be reduced from using InterpreterNow for telephone functionality and during appointments.

6.2 METHODS

6.2.1 STUDY DESIGN.

The present study sought to investigate the acceptability, demand and costs of the InterpreterNow service when provided to Deaf people to use for 12 months in healthcare settings. In addition, a cost evaluation of the service was also conducted. Acceptability was analysed by scrutinising process data from usability questionnaire responses of Deaf people (immediately and at one year follow-up) as well as semi-structured interviews with project workers. Demand was ascertained by analysing usage data. The cost evaluation established the savings that could be made from using videoconferencing instead of face-to-face services and the costs of running InterpreterNow. Usage data was how much InterpreterNow was used by Deaf people and the services where InterpreterNow was used.

6.2.2 ACCEPTABILITY.

IMMEDIATE USABILITY QUESTIONNAIRE.

After each use of InterpreterNow, Deaf participants were asked to complete a brief questionnaire (see Table 14) relating to the usability of the InterpreterNow mobile application and quality of the interaction. For example, participants were asked to rate the quality of the connection with the interpreter, the quality of interaction with the health professional using InterpreterNow and whether using InterpreterNow improved their healthcare experience. Questions were rated on a scale from 1 to 5. Objective data was also captured regarding the frequency of connections with InterpreterNow and the length of call to the interpreter. There was also an open question which allowed the participants to provide feedback on InterpreterNow experience. This questionnaire was completed after 69 calls (17% of total calls).

Table 14. *Items used to measure usability post health interaction with InterpreterNow.*

Usability Questions
1. Ease of connection with the British Sign Language interpreter
2. Quality of connection with the British Sign Language interpreter
3. Frequency connection disconnects
4. Quality of interaction with the healthcare professional
5. Improvement in communication with InterpreterNow
6. Improvement in healthcare experience
7. Satisfaction with the outcome of interaction
8. How likely to use InterpreterNow for the next interaction

ONE YEAR FOLLOW-UP USABILITY QUESTIONNAIRE.

After one year of using InterpreterNow in healthcare settings, Deaf participants completed a Follow-Up questionnaire that included questions relating to usability. For instance, information collected included how often InterpreterNow was used over the 12 months to make appointments, to receive information, how often InterpreterNow was used overall, ratings of communication quality with healthcare services when using InterpreterNow and the likelihood of using InterpreterNow in the future. Only participants that had been allocated to the intervention group (n=40) responded to these questions.

PROJECT WORKER FEEDBACK.

Interviews were conducted with three project workers (based at local charities in Worcester, Cumbria and Merseyside) who trained Deaf participants on how to use InterpreterNow and tablets, supported participants for 12 months of using InterpreterNow and conducted baseline and follow-up assessments with participants. Interviews were conducted after six months from the trial start date. Each interview lasted between 1hr to 1hr 30 min. Written consent was provided by each project worker. Interviews were conducted at a service location in Birmingham, UK. Two project

workers are Deaf, so in two interviews, British Sign Language interpreters were used whose voices were recorded. The British Sign Language interpreters provided written consent for being recorded.

Interviews were audio-recorded to allow the data to be transcribed verbatim. The recordings were made using an Etekcity digital rechargeable dictaphone. During the interviews, the PhD researcher (EK) used a semi-structured interview guide. The questions were open-ended and probe questions were used to elicit further detail. The project workers views were obtained about training Deaf participants, the service, training materials and use of InterpreterNow.

ANALYSIS METHODOLOGY.

IMMEDIATE USABILITY QUESTIONNAIRE.

Percentages were obtained from questionnaire items relating to usability. Free text questions were analysed using thematic analysis. The approach for the thematic analysis was inductive (data-driven), semantic (based on explicit content) and realist (report of reality as found in the data). This approach was used because the participants were answering practical questions about their experience of a single InterpreterNow call. Following familiarisation with the interview text, a coding process was implemented based on themes both from the interview guide and unexpected emerging themes. The data was analysed based on a coding frame developed by the researcher specifically for this project based on and guided by previous work (Berkowitz, 1997; Braun & Clarke, 2006; Onwuegbuzie, Dickinson, Leech, & Zoran, 2009a, 2009b). The coding process followed that of Creswell and Maitetta (2002) (see Figure 7 above). After the initial themes were identified by the PhD researcher (EK), a second researcher reviewed the themes (PR) to ensure concordance. After this, the themes were given their final names.

PROJECT WORKER INTERVIEWS.

The approach for the thematic analysis the same as for the analysis of the immediate usability questionnaire. This is the case as the interviews were focused on practical aspects of the project workers' experiences during the InterpreterNow trial. The analysis method followed the same steps as for the immediate usability questionnaire: familiarisation, coding based on the interview guide themes and emerging themes, and then categories were reduced until a model with most important categories was created (from Creswell & Maietta, 2002).

6.2.3 DEMAND.

Usage information was collected by the InterpreterNow application developers on a monthly basis and presented in an Excel spreadsheet. Additional data about usage was also collected by the project workers during the 12 months of the InterpreterNow trial. Data collected included information about how many tablets were used, what services were called, call duration, call date, and types of calls. Using InterpreterNow, it is possible to make either Video Relay Service or Video Remote Interpreting calls. Video Relay Service allows Deaf and hearing people to communicate by telephone. Using the Video Relay Service, the Deaf person connects to the British Sign Language interpreter on InterpreterNow and asks the interpreter to call a phone number. The hearing person will hear the British Sign Language interpreter on the phone and the Deaf person will see the British Sign Language interpreter signing responses on the tablet screen. Video Relay Service is useful for making appointments and for finding out brief health information such as confirming prescriptions or blood test outcomes. Video Remote Interpreting allows the Deaf person and a hearing person to communicate face-to-face. The conversation is interpreted by a British Sign Language interpreter remotely via InterpreterNow. Video Remote Interpreting is suitable for healthcare appointments when a face-to-face British Sign Language interpreter is not available.

6.2.4 COST EVALUATION.

The InterpreterNow trial was implemented over a period from April 2016 to October 2017. A cost description analysis was completed for the whole trial. Additionally, comparisons were drawn between costs for online and face-to-face British Sign Language interpreting.

INTERVENTION COSTING METHODOLOGY.

A cost analysis was completed using data on programme expenditures to estimate the total cost of the InterpreterNow trial. Cost data was taken from the programme budget and InterpreterNow data. Costs were classified as start-up, implementation and evaluation/monitoring/research (Batura, Pulkki-Brännström, Agrawal, Bagra, Haghparast-Bidgoli, Bozzani, & Sinha, 2014; LeFevre, Shillcutt, Broomhead, Labrique, & Jones, 2017). In addition, costs were described as recurrent or capital (one-off costs). Recurrent costs were grouped as qualitative interviews and focus groups, technology-related fees and staff. Qualitative interviews and focus groups costs included payment for British Sign Language interpreter time for the evaluator. Technology-related fees were the setup and cost of running of InterpreterNow service at a healthcare service, cost of equipment (tablets) and for SIM cards for the tablets. Staff costs were for travel, staff salaries, recruitment, utilities, training and meetings. Staff were considered managers (of the local charity), project workers and British Sign Language interpreters. Both scale-up and trial project costs were calculated. All the costs were expressed in U.K. Pound Sterling (£). The cost analysis was conducted using Microsoft Excel 2013.

COMPARISON BETWEEN ONLINE INTERPRETING AND FACE-TO-FACE METHODS.

Typical costs for face-to-face British Sign Language interpreter service was provided by charity stakeholders. The costs of remote British Sign Language interpreters were obtained from the InterpreterNow service stakeholders. From this information, it was possible to calculate the total call times for InterpreterNow calls and the price per InterpreterNow call. This was then compared with the same number of face-to-face appointments (one call was taken as one appointment). The difference

between InterpreterNow call costs and comparable costs for face-to-face British Sign Language interpreter appointments was provided.

6.3 RESULTS

6.3.1 ACCEPTABILITY.

IMMEDIATE USABILITY QUESTIONNAIRE.

LIKERT ITEMS.

Most questionnaires completed after using InterpreterNow indicated that the call was to communicate with a receptionist or secretary (28 calls), followed by GPs (18 calls). Calls were also made about repeat prescriptions, to paediatrics and an audiologist (one call for each service). The participants indicated that they had communicated about health reviews/consultations (n=27), appointment bookings (n=18), clarifications (n=9) and baby check-ups (n=7). Participants indicated that most appointments or contacts were made through InterpreterNow (n=43, 62%), compared with a member of family or friend (n=12, 17%) or in person (n=8, 11.5%; See Appendix 4). In the GP patient survey (Morse, 2014), it was found that Deaf people in the UK book appointments by phone (66%), in person (41%), online (5%) and by fax (1%).

Responses were mostly positive in terms of contacting British Sign Language interpreters and making appointments, technical aspects (such as quality of the line or frequency of connection cutting out), improved communication, health experience and interaction outcome, as well as the likelihood of using InterpreterNow for future appointments. Most participants found making contact or making appointments with InterpreterNow “Very Easy” or “Easy” (n=45, 67%). Most participants stated they “Strongly agree” or “Agree” (n=47, 71%) that it was easy to connect to a British Sign Language interpreter. The quality of the connection line with the interpreter was rated as “Very Good” or “Good” by 58% of the participants (n=38). According to 64% of the participants, the connection “Never” cut-out (n=41). The quality of the interaction with a healthcare professional (healthcare professional) was rated as “Very Good” or “Good”

by 74% of the participants (n=45). Also, 66% (n=42) of the participants stated that communication with healthcare professional had improved due to using InterpreterNow. 73% (n=48) participants also indicated that their healthcare experience improved due to InterpreterNow. Lastly, 76% (n=46) of participants were “Very Satisfied” or “Satisfied” with the outcome of the interaction when using InterpreterNow. Finally, most participants (91%, n=57) stated that they would be “Very Likely” or “Likely” to use InterpreterNow in the future.

OPEN RESPONSE FEEDBACK.

Open response feedback was categorised into three themes: the purpose of InterpreterNow, key benefits, British Sign Language interpreters and concerns.

Purpose. The purpose of InterpreterNow for Deaf people was improved access to healthcare (n=5). A quote by one Deaf person who had used InterpreterNow at a GP appointment highlights this:

“Now can book physiotherapy, dentist, optician, hospital, carer, local GP practice. Perfect.” (W112)

Benefits. The key benefits were acceptability of the InterpreterNow for healthcare staff and for Deaf people (n=8), as well the fact that InterpreterNow was appropriate to use in a variety of situations such as making health appointments or using InterpreterNow during an appointment with the GP or in the audiology services (n=12). The comment below from a Deaf person indicates how the InterpreterNow mobile application is appropriate to use with a health consultant and is acceptable to this healthcare professional.

“This appointment with the consultant. He had never seen online interpreting and he was very impressed.”(C120)

British Sign Language Interpreters. Deaf participants (n=6) noted that the gender and qualifications of British Sign Language interpreters were important to consider when using InterpreterNow. Below is a quote from a Deaf person about the importance of

getting the preferred gender British Sign Language Interpreter for GP appointments about private issues.

“Very good, but there was a man, but luckily it's was not private.”(C119)

Concerns. Deaf participants had concerns about technology, education and inappropriate situations (n=10). The technology problems included blurry images, frozen screen, tablet not working properly, bad connection and sound issues. In terms of education, a Deaf person who had a baby check up with a consultant mentioned that the consultant didn't want to wait for InterpreterNow to connect as *“he didn't need an interpreter because I am not speaking a different language.”(C120).*

Another Deaf participant thought that InterpreterNow was not appropriate for face-to-face appointments:

“I would prefer to use InterpreterNow to book appointment. Not the real life during the appointment.”(W128)

Other Deaf people also mentioned that any appointments in which there was going to be a lot of movement or not enough room wouldn't be ideal for using InterpreterNow (for instance, the optician, the dentist, physiotherapy appointments and also operation theatres) (n=7). Below is a quote from a Deaf person about services and situations when it would be difficult to use InterpreterNow.

“Physiotherapy and dentist and optician. Close face-to-face, any appointments where there's movement ... also operation theatre, day at hospital.” (W112)

ONE YEAR FOLLOW-UP USABILITY QUESTIONNAIRE.

INTERPRETERNOW USE.

InterpreterNow was used the most at the GP surgery and the hospital (Table 15). At the GP surgery, 67% of participants used InterpreterNow at least once. InterpreterNow was used at least once by 32% of the participants at a hospital. At the GP surgery and hospital InterpreterNow was used to make an appointment or get information (see Table 16). More participants found the quality of the interaction to be good/very good (58.5%) as opposed to average/poor/very poor (42%; see Appendix 8).

Table 15. *Using InterpreterNow at healthcare services (n, %).*

Healthcare services	Number of times used				
	Never	Less than 5 times	5 to 9 times	10 to 15 times	16 times and over
GP	13 (33)	13 (33)	9 (23)	3 (8)	2 (5)
Hospital	27 (68)	7 (17)	6 (15)	0	0
Chemist	39 (98)	1 (2)	0	0	0
Opticians	38 (95)	2 (5)	0	0	0
Dentist	31 (77)	6 (15)	3 (8)	0	0

Table 16. *Using InterpreterNow to make an appointment or get information (n, %).*

Healthcare services	Number of times used				
	Never	Less than 5 times	5 to 9 times	10 to 15 times	16 times and over
GP	15 (38)	13 (33)	7 (18)	2 (5)	3 (8)
Hospital	23 (56)	14 (35)	3 (8)	0	0
Chemist	35 (88)	1 (2)	1 (3)	0	3 (8)
Opticians	34 (85)	6 (15)	0	0	0
Dentist	29 (73)	8 (20)	3 (8)	0	0

Deaf participants rated the quality of communication with GPs, consultants and nurses the highest. 69% of participants that used InterpreterNow with GP's rated the quality of communication as "Good" or "Very Good". Consultants were rated as providing "Good" or "Very Good" communication by 69% of the sample and nurses by 59% (after excluding "Doesn't apply" responses) (see Table 17).

Table 17. *Communication quality ratings when using InterpreterNow (n, %).*

Healthcare services	Quality Ratings				
	Very Good	Good	Neither	Poor	Very Poor
GP	4 (17)	12 (52)	2 (9)	2 (9)	3 (13)
Consultant	4 (31)	5 (38)	3 (23)	1 (8)	0
Nurse	4 (24)	6 (35)	5 (29)	1 (6)	1 (6)
Chemist	1 (11)	3 (33)	4 (44)	1 (11)	0
Opticians	0	2 (25)	5 (63)	1 (13)	0
Dentist	2 (17)	3 (25)	5 (42)	1 (8)	1 (8)
Receptionist	2 (15)	4 (31)	4 (31)	2 (15)	1 (8)

LIKELIHOOD OF USING HEALTHCARE SERVICES IN THE FUTURE.

After using InterpreterNow for one year between 28% (for Dentist) and 40% (for GP) of the participants stated that they would be "Very Likely" or "Likely" to use InterpreterNow in the future (see Table 18). The GP surgery was the service where InterpreterNow would be most likely to be used in the future (by 40% of the sample).

Table 18. *Likelihood of using InterpreterNow in the future (n, %).*

Healthcare services	Likelihood of future use				
	Very Likely	Likely	Unsure	Unlikely	Very Unlikely
GP	9 (23)	7 (17)	14 (35)	1 (2)	9 (23)
Hospital	7 (17)	8 (20)	16 (40)	0	9 (23)
Chemist	4 (10)	8 (20)	19 (47)	2 (5)	9 (23)
Opticians	3 (8)	9 (23)	17 (42)	2 (5)	9 (23)
Dentist	5 (13)	6 (15)	19 (47)	1 (2)	9 (23)

After using InterpreterNow for a year, it became easier for the intervention group to contact or book an appointment at the GP surgery. In the intervention group, 67% of participants thought that it was “Easy” or “Very Easy” to contact their GP compared to 33% of the control group. Contacting a hospital was also “Easy” or “Very Easy” for 42% of the intervention participants compared to only 20% of the control participants. At all other healthcare services, there was no difference in the ease of making contact (see Appendix 5).

Most participants across both the intervention and control group indicated that they are likely to use a GP service, a chemist, opticians, and dentist in the next 12 months (see Appendix 6). These perceptions remained stable across time, for example, 93% of the intervention group stated that they are likely to use a GP at baseline and this changed to 94% at post-test. Similar patterns of stability were observed across all the health services including hospital, chemist, opticians, and dentist indicating that the likelihood of using healthcare services was not influenced by the provision of InterpreterNow.

SATISFACTION WITH CARE AT HEALTHCARE SERVICES.

Between 59% and 85% of the participants stated that they were “Very Satisfied” or “Fairly satisfied” with the care they received at the healthcare services after the intervention was completed (at post-test). In the intervention group at post-test, most participants were “Very satisfied” or “Fairly satisfied” with care at the GP (78%), opticians (82%) and dentist (85%). For all services except the hospital, more participants were “Very satisfied” or “Fairly satisfied” in the intervention group than in the control group. Only at the hospital were more participants in the control group (66%) “Very satisfied” or “Fairly satisfied” with care received than the intervention group (63%) (see Appendix 7).

QUALITY OF COMMUNICATION.

Different services. At baseline, the quality of communication was rated as best at the GP with 75% of the intervention rating their GPs communication as “Good” or “Very Good”. For the intervention group, opticians were perceived to have the worst quality of communication with 26% rating the quality of communication as “Poor” or “Very Poor”. No changes in quality of communication were observed for the GP from pre to post however some changes were observed in other healthcare settings. For example, nurses were rated “Good” or “Very Good” at baseline by 50% of intervention participants and this rose to 65% at post-test. A similar pattern was seen for the chemist (36% to 51%) and the dentist (44% to 64%). In contrast, fewer positive changes were seen for the control group. For example, 70% of the control group participants rated the chemist quality of communication as “Good” or “Very Good” at baseline and 48% at post-test. The optician was rated as “Good” or “Very Good” by 45% at baseline compared to 48% at post-test. The one exception in the control group was for the nurse where the percentage of people rating the quality of communication as “Good” or “Very Good” increased by 14% (Appendix 8).

GP qualities at last appointment. Most participants indicated that their GP was “Good” or “Very Good” at all the behaviours rated at baseline. However, at post-test the percentage of intervention participants that rated the GP behaviours as “Good” or “Very

Good” increased. For example, 67% of intervention participants rated their GP as “Good” or “Very Good” at giving them enough time, this increased to 94% at post-test. For the control group, the percentage remained relatively stable (i.e., 51% to 58%). A similar pattern can be observed for the “Asking about your symptoms”, “Listening to you” and “Involving you about decisions in your care” items. That is, a greater increase in the frequency of intervention participants rated their GP qualities as “Good” or “Very Good” after the intervention compared to the control participants (see Appendix 9). Analyses of the interviews revealed three key themes across project worker views: training materials, the InterpreterNow service and lack of use (see Figure 9).

PROJECT WORKER FEEDBACK.



Figure 9. Visual representation of themes for project worker data.

TRAINING MATERIALS.

Project workers described their views and experiences concerning training materials. A prevalent theme was about using videos for training Deaf participants (WPW1, CPW3 and MPW2). One of the project workers said they had plans to make a video which summarises key aims of the Tablets4Health projects (WPW1). Another project worker had already made a YouTube video for participants, which was used “to show them what to do and how to get access to the text or if you couldn’t see something or there was a problem, so I was able to show them on a step by step guide. And go

into settings here it is, click this, tick this, do that, do the other so that they have that backup” (MPW2). In addition, another project worker (CPW3) mentioned that there are training videos already available for participants on the tablet. In terms of written training materials, one of the project workers mentioned that a sheet with instructions had been lost by one of the participants (WPW1).

Therefore, project workers appear to indicate that video is the preferred medium for training Deaf participants, as there are varied ways of using videos (for introducing the project (WPW1) and for reminding how to use different mobile application options (MPW2 and CPW3). Also, there are different ways in which videos can be presented – both on YouTube (MPW2) and within the tablet itself (CPW3). In comparison, the written instructions are easier to lose (WPW1), resulting in participants forgetting how to use the tablet or mobile application options (WPW1) and not using the tablet as much (WPW1, CPW3 and MPW2). The quote below highlights the usefulness of video training materials for raising the awareness of the Tablets4Health project at healthcare services (Project worker, WPW1).

“I plan to film myself doing a bit of a summary of tablets4health and what it is and so on and I plan to send the healthcare settings so that they were aware of it and then they reply to that to say whether they’re likely to go to one of their meetings to talk about the service and things like that with showing them the tablet and what have you. “

SERVICE.

Project workers explained their views about different aspects of the InterpreterNow trial with specific reference to technology and queueing. Within the technology subtheme, project workers noted issues with the tablets (CPW3 and WPW1) and connectivity to the internet (WPW1, CPW3 and MPW2). When discussing tablets, one of the project workers stated that before providing the participants with tablets for the first time, she checked the tablet was functioning correctly and that it was possible to contact the British Sign Language interpreter. The project worker wanted to make sure that the tablet was ready to use, which is highlighted in the quote below (MPW2).

“[I] set it [tablet] up so it was functioning as it should so I’m not going to experience a problem in front of the Deaf client that will then cause them to lose confidence. “

Project workers also mentioned connectivity. One project worker stated that at one healthcare service, there was no access to the internet or Wi-Fi, so it is impossible to use InterpreterNow there (CPW3). This project worker (CPW3) also explained how certain areas in Cumbria have very low levels of connectivity. This can be seen in the quote below.

“No. There are places- I mean, literally, you could be on one end of a street and have 4G and then be on the other end of the street and you don’t have 4G. So, I’ve got two participants in Whitehaven, that’s one hour and a half’s drive away from me, and both of them, their tablets work at home, on the Wi-Fi, obviously. When they get into the doctor’s surgery, even on the doctor’s surgery’s Wi-Fi, the video quality is so bad they can’t use it. So, you can say with one doctor’s surgery - “oh it must be the quality of the Wi-Fi and the bandwidth and whatever”, whatever that means but the other one as well. It’s weird. It’s almost like Whitehaven is this little dip in strength-You can feel as if Wi-Fi is not great in the... sorry, not Wi-Fi, the coverage. So, it feels as if coverage is not brilliant. In certain areas. That was Whitehaven. It’s on the coast. I’ve only got two participants there with tablets. So, it just seems so ironic that both of them can’t get the tablets to work at the doctors’ surgery. “

The connectivity issue was also prevalent in other locations. In Worcester, the project worker (WPW1) stated that they thought that the screen was blank because “*Wi-Fi wasn’t strong enough*”.

In addition, project workers highlighted problems with queueing within the service (i.e., when a British Sign Language interpreter was not available immediately, the Deaf person received a message in InterpreterNow that they were in a queue) (CPW3). The project worker mentioned their disappointment at the presence of queues. She felt that she had been “*lead to believe that there will be no queuing system, if an interpreter was busy, the call would be redirected to somebody else, so there was no queueing*

system". The project worker mentioned that Deaf participants also felt strongly about this problem.

In summary, the main issues with the service mentioned by the project workers were technology (when the tablet did not work and connection issues) and queueing (which caused Deaf people to feel embarrassed at appointments or hang up). Although project workers did their best to prepare the tablet in advance and overcome any issues (such as asking about whether the system would involve queueing at the start of the project (CPW3)), problems such as connectivity across all study location or queueing could not be avoided.

LACK OF USE.

Project workers noted a variety of reasons for why participants were not using InterpreterNow. The reasons included: forgetting to use the app, inflexibility of the service, participants not getting particularly ill during the trial, preference for face-to-face interpreters and lastly, general unacceptability of the service for the participants (CPW3, WPW1 and MPW2).

When discussing how participants forgot to use InterpreterNow, project workers all mentioned that participants "*just need reminding to use the tablet*" because the Deaf person has "*forgotten how to use it [tablet]*" (WPW1). Also, project workers stated that occasionally Deaf people did not realise that they could use the tablet in certain health-related situations (CPW3 and WPW1). This problem is highlighted in the quote below (WPW1).

"So, I see them at coffee morning every other week, so I am able to remind them and talk to them and say: "Have you used it lately?". And they say: "Oooh, I had a doctor's appointment two days ago and I went to reception and I never thought to bring the tablet!"

A project worker stated that one Deaf person found the service inflexible as she couldn't use it at certain times ("*the service isn't open after six and he was ill after six*") (MPW2). She [the Deaf person] wanted to use it for her son's evening hospital

appointment and for Weight Watchers/Slimming World appointments which are at 7 pm. Therefore, service availability is an issue that should be addressed in the future.

A project worker mentioned that some participants did not need to use the tablet as *“they just haven’t been ill”* (CPW3). Another reason that the Deaf participants were not using the InterpreterNow service was that the Deaf person preferred communicating with a British Sign Language interpreter face-to-face as opposed to online and that *“the tablet was put away because it didn’t work”* (WPW1).

The unacceptability of the service was another reason for Deaf people not using the service. Project workers stated that some participants *“don’t like”* (WPW1) the service due to feeling that they *“were issued tablets, but they’re sitting, looking at the tablet, and it’s almost as if they tablet’s saying, “You have to use me, you have to use me”, and they’re looking at the tablet, going, “Oh gosh, this is just putting so much pressure on me, I don’t want it, I’m gonna give it back.”* (CPW3). Other Deaf participants were not used to using technology such as mobile applications or tablets (CPW3). Lastly, project workers also stated that some participants just did not want to use the service for no clear reason. This is highlighted in the quote below (WPW1).

“The majority of them, when they got home stuck the tablet on the shelf and just carried on with life”

In summary, it would seem that project workers felt that participants were not using the service for a variety of reasons. Some of the barriers for InterpreterNow use can be overcome with more training (fears of technology or awareness of services with which InterpreterNow could be used). Other issues can be fixed by changing the service. For instance, more participants might use the service if the working hours were extended. However, certain reasons for not using InterpreterNow were more individual such as preferring face-to-face interpreters or participants not needing to use the service as they were not ill. This highlights the different preferences of the Deaf population, which should be accounted for when attempting to introduce a new intervention.

6.3.2 DEMAND.

OVERVIEW.

Two different types of calls were made using InterpreterNow: Video Relay Service and Video Remote Interpreting. Video Relay Service allows Deaf and hearing people to communicate by telephone. The Deaf person connects to the British Sign Language interpreter on InterpreterNow and asks the interpreter to call a phone number. The hearing person will hear the British Sign Language interpreter on the phone and the Deaf person will see the British Sign Language interpreter signing responses on the tablet screen. Video Relay Service is useful for making appointments and for finding out brief health information such as confirming prescriptions or blood test outcomes. During the InterpreterNow trial (April 2016 to October 2017) 30h 3min 54s (67.8% of total call time) of Video Relay Service calls were made.

Video Remote Interpreting allows the Deaf person and a hearing person to communicate when communicating face-to-face. The conversation is interpreted by a British Sign Language interpreter remotely via InterpreterNow. Video Remote Interpreting is suitable for healthcare appointments when a face-to-face British Sign Language interpreter is not available. During the InterpreterNow trial (April 2016 to October 2017), 14h 16min 49s (32.2% of total call time) of Video Remote Interpreting calls were made.

TABLETS USED/ALLOCATED.

In total, 53 tablets were distributed to participants across the four study locations. Out of the 53 tablets, 42 (79%) were used to make at least one call (see Table 19). In total, 526 calls were made from April 2016 to October 2017 by 42 participants. The total duration of all the calls made in this time period was 44h 20min 43s. On average, each person made 13 calls. The average call length was 8min 10s. Figure 10 provides the mean number of times each tablet is used along with the mean call duration and indicates that one tablet was used over 70 times however the majority used InterpreterNow less than 10 times. No clear pattern can be seen for mean duration indicating that everyone used their tablets for differing lengths of time.

Table 19. *Tablets allocated and used (n, %).*

Tablets	Cumbria (N, %)	Greater Mancheste r (n, %)	Merseysid e (n, %)	Worcestershir e (n, %)
Allocated	14 (100)	2 (100)	16 (100)	21 (100)
Used	13 (93)	2 (100)	12 (75)	15 (71)

VIDEO RELAY SERVICE.

Calls by Deaf people were identified as Video Relay Service if the British Sign Language interpreter made a telephone call to a health service. In total, 431 Video Relay Service calls were made (April 2016 to October 2017) lasting 30h 3min 54s. On average, each call lasted 4min 11s. Forty-two different tablets were used for Video Relay Service calls (see Figure 10, more detail is in Appendix 12). Twenty-seven different services (such as GP, hospital, dentist and others) were called 392 times (it was not possible to identify the service called for 39 calls). Each person made 10 calls on average (Range=1 to 78 calls). Deaf people made calls to 137 different numbers in total. Calls were most frequently made to the GP (50%), hospital (9%) and dentist (7%). The least calls were made to the hearing implant services (.001%) (See Appendix 11).

VIDEO REMOTE INTERPRETING.

Calls were considered to be Video Remote Interpreting when there was no outgoing call made and when the call was longer than 4 minutes. The calls were made from 41 different tablets. Ninety-five Video Remote Interpreting calls were made (April 2016 to October 2017), with each call lasting 8min 38s on average per person. Each person made two calls on average (Range=1 to 11 calls). The total time for the calls was 14h 16min 49s (see Appendix 13).

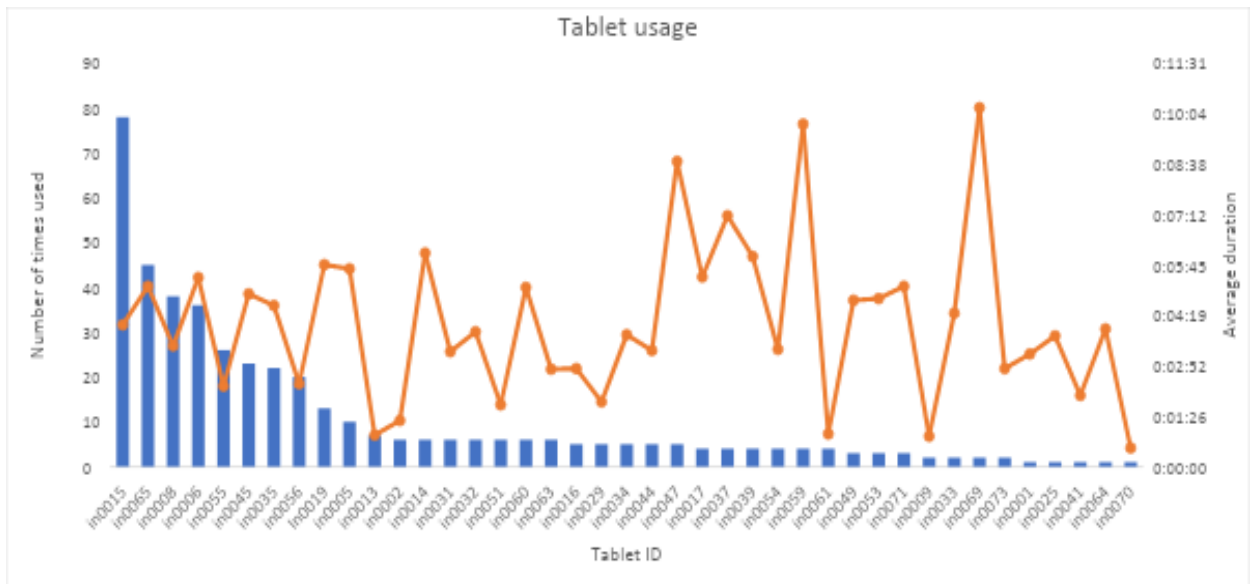


Figure 10. *Tablet usage for Video Relay Service calls.*

6.3.3 COST EVALUATION.

This cost evaluation compares the cost of online interpreting with the provision of face-to-face interpreting. A cost description for the scaling up of InterpreterNow trial to a national level was included and the costs incurred as part of the one year InterpreterNow trial were identified (see Appendix 10 for cost breakdown).

ONLINE INTERPRETING COST SAVINGS.

The cost of a remote British Sign Language Interpreter is £3.50/min. For Video Remote Interpreting calls, the total time was 14h 16min 49s for a total of 95 calls. Therefore, the total cost for all Video Remote Interpreting calls was £2,998.87 (when multiplied by £3.50 per minute). Each Video Remote Interpreting call costs £31.57. For Video Relay Service calls, 431 calls were made, taking 30h 3min 54s. Therefore, the total cost for all calls was £6,313.65. Each Video Relay Service call costs £14.65.

Face-to-face British Sign Language interpreter costs £35/hour with the minimum call out costs of 3 hours (£105.00). The remote British Sign Language interpreters, who work for InterpreterNow, are fully qualified and registered. Therefore, average prices

were also taken for fully qualified and registered face-to-face British Sign Language interpreters. It is also noteworthy that the cost of travel is not included (for instance, on average, British Sign Language interpreters in Cumbria travel 35 miles each way; with the typical payment of £0.45 per mile, that would result in an additional cost saving of £31.50 per online appointment).

Compared to one face-to-face British Sign Language interpreter appointment (mean cost=£105.00), one Video Remote Interpreting appointment (mean cost=£31.57) would save £73.43 per appointment. When comparing a Video Relay Service call (mean cost=£14.65) the cost saving would be £90.35 per appointment. In total, over a one year period, 95 Video Remote Interpreting appointments were conducted indicating that a £6,976.13 saving was made compared to 95 face-to-face appointments. In addition, 431 Video Relay Service calls were conducted over a one year period indicating a £38,941.35 cost savings compared to 431 face-to-face interpreter appointments. Therefore, a total saving of £45,917.48 was made for the 52 Deaf participants that had access to InterpreterNow for one year.

COST DESCRIPTION.

The costs included in scale-up price were British Sign Language remote Interpreter salary (£3.50/min) priced at current study usage, the one-off cost for InterpreterNow setup (£250.00) and costs for InterpreterNow usage (£2.50/min). The total was £8,187.59. This is how much it would cost to run the InterpreterNow service for one year.

The intervention costs are for setting up and running the InterpreterNow trial and were not included in the scale-up cost calculation. Intervention costs include staff (salaries, recruitment, travel, utilities, training and others) and technology (tablets and 4G Sim cards). The total cost for this intervention was £95,564.00. This total provides an idea of funds needed to set up and pilot a new mHealth intervention in the Deaf population. The exact costings are provided in Appendix 10.

COST/TIME SAVINGS.

The InterpreterNow project may benefit existing healthcare services by helping to save time and money. Savings could be achieved from reducing out of hours calls, providing quicker access to British Sign Language interpreters and reducing appointment length.

REDUCED OUT OF HOURS CALLS.

During the InterpreterNow trial, 26 out of hour's calls were made. The out of hours calls were made by nine (17%) of the 52 Deaf people in our sample. This is in contrast to results from the Ipsos MORI 2017 survey which indicates that 32% of Deaf people made out of hours calls in six months, compared to 19% in the general population (Morse, 2014). According to the Out of hours GP service report (Morse, 2014), the cost of an out of hours GP visit is £68.30 per case.

QUICKER ACCESS TO BRITISH SIGN LANGUAGE INTERPRETERS.

In the present study, no calls were abandoned (i.e., where participants did not hang up themselves). On average, calls were answered by British Sign Language interpreters within nine seconds with the longest wait being 2min 58s. If there was a queue (for 225 calls), the average wait time was 45 seconds.

MEETING LENGTH.

For Video Relay Service calls, the minimum call time was 13 seconds and the maximum time was 1h 12min 12s. On average, 1 Video Relay Service call took 3min 42s. For a Video Remote Interpreting call, an average meeting length was 9min 1s (minimum=4 min, maximum=41min 22s).

6.4 DISCUSSION

The purpose of this feasibility study was to ascertain whether Deaf people find the videoconferencing intervention (InterpreterNow) acceptable, easy to use and how much the service was used. In addition, a cost evaluation was conducted to establish the savings that could be made comparing to face-to-face services. Results revealed

that InterpreterNow was acceptable in some healthcare settings (such as for brief appointments and booking appointments) but not others (such as for the opticians and dentists). In addition, participants seemed to be largely satisfied with the service in terms of being able to contact British Sign Language interpreters, technological aspects and access to healthcare services. Usage data analyses revealed that most calls (68% of total calls) were appointment bookings or brief appointments. Lastly, compared to face-to-face interpretation, the InterpreterNow service costs less. Face-to-face British Sign Language interpreters tend to charge extra fees for out of hours (evenings and weekends) bookings, as well as “call-out” charges for short bookings (payment for the session as well as preparation time), often have minimal appointments (bookings for a minimum of two hours) and travel costs. InterpreterNow does not have such extra costs. Therefore, this study provides detailed information about the experiences of Deaf people when they used a videoconferencing service in healthcare settings. The lessons learned from this research are discussed with the aim of developing videoconferencing intervention methodology further as well as implementing strategies for better training of Deaf people and healthcare staff during mHealth interventions.

6.4.1 ACCEPTABILITY.

IMMEDIATE USE.

The InterpreterNow service was found to be acceptable to Deaf people. This can be Participants were also generally satisfied with the interaction outcome (e.g., making a booking, receiving test results or having a successful conversation with their GP about an illness) and stated that it was easy to make contact or make appointments with InterpreterNow. In addition, 64% of the participants rated the connection line highly and also stated that connection “Never” cut out. When answering the open response feedback question, participants stated that InterpreterNow was easy to use across different situations/services (such as making health appointments or using InterpreterNow during appointments with GP or in audiology). The fact that most calls were made to receptionist and GPs suggests that these services are the ones where InterpreterNow was most necessary. However, only 17% of participants filled in the usability questionnaire immediately after using the InterpreterNow service. This limits the generalisability of these findings.

Another limitation is that the service was not fully acceptable, according to respondents of the usability questionnaire. For instance, concerns raised were related to technology issues and education/Deaf awareness. InterpreterNow was said to be inappropriate in certain situations – for instance, some participants thought that InterpreterNow would not be easy to use in appointments which included a lot of movement.

In summary, immediate responses provide limited information about whether the service is easy to use and acceptable (for only 17% of calls). However, as it stands, the information provided gives a snapshot of the views of some Deaf people and their experiences with the InterpreterNow service. The data collected indicated that the service is acceptable in some cases (for instance, for making appointments), and when the connection line does not cut out. However, the feedback also indicated that the service was often not working due to technological issues such as the connection cutting out or unclear images unclear as well as the tablets not working well. The service was therefore not always acceptable to Deaf people or healthcare staff. Therefore, this feedback provides suggestions for improvement of the service in terms of technological problems, as well as highlighting the remit of the use of the service. The improvement could be related to using InterpreterNow on the Deaf people's own devices which Deaf people know how to use and fix if they break. Another improvement would be to ensure that there's a strong internet connection during service use to reduce the image graininess and connection cutting out.

ONE YEAR FOLLOW-UP QUESTIONNAIRE.

The results obtained at one year follow-up indicate that InterpreterNow is generally acceptable to Deaf people. This information was obtained when Deaf people were asked to fill a questionnaire after the tablet with InterpreterNow was returned after 12 months of use. By comparison, the immediate usability questionnaire was filled in throughout the trial, after each use of InterpreterNow.

At one year follow-up, quality of communication (by 69% of participants) and interaction using InterpreterNow (58.5%) were rated as high. In addition, 40% of

participants indicated that they would be most likely to use InterpreterNow at GP surgeries in the future, with 78% of participants being satisfied with their GP. Therefore, this shows that the service was appropriate for Deaf people in healthcare settings. These positive ratings of GPs increased for the intervention group after 12 months suggesting that InterpreterNow has a positive effect on the Deaf people's experiences with communicating with their GP and are more likely to use GP services with InterpreterNow. However, these findings have certain limitations which should be considered. The one year follow-up questions were completed by participants after using the InterpreterNow service for 12 months (526 calls), providing a static indicator (as data was collected at one time point). Also, it could be that InterpreterNow does not affect GP use or experiences. The results show that the likelihood of using GP service in the future (94%) did not change from baseline to follow-up.

Differences between immediate response questionnaire and one year follow-up were identified. The differences were in the likelihood of future InterpreterNow use and quality of interaction. After using the InterpreterNow and immediately filling out the usability questionnaire, 91% of the participants stated that they would be "Very Likely" or "Likely" to use InterpreterNow in the future. Also, after using InterpreterNow and immediately filling the usability questionnaire, 74% of participants rated the quality of interaction as "Good" or "Very Good". The explanation for the difference between the responses could be that after one year of using InterpreterNow, participants had made a higher volume of calls (n=526) compared to participants who submitted a usability questionnaire (n=69). Also, perhaps participants who filled in the immediate response questionnaire were more comfortable with technology (the questionnaire was online), more motivated in terms of providing feedback and looking after their health and had more positive experiences which they wanted to share.

PROJECT WORKER FEEDBACK.

The feedback from project workers indicated that the service was not acceptable to all Deaf participants. The issues highlighted included: technology, queues, a strong preference for face-to-face interpreting and inflexibility of the service (not being able to use at certain times or only available for healthcare settings). Also, certain Deaf participants had no interest or need to use the service. The reasons why some Deaf participants did not use InterpreterNow or had issues with the service could be due to a

lack of training. Project workers highlighted that video training was preferred to written training. They also emphasised that it'd be useful to introduce training for healthcare staff in terms of Deaf awareness and purpose of the InterpreterNow service.

SUMMARY.

The evidence on the acceptability of mobile health interventions is sparse. Overall, studies suggest that whilst some participants find technological interventions acceptable (Wilson & Wells, 2009), others do not (Austen & McGrath, 2006; Hacking et al., 2016). In the present study, the reasons for why InterpreterNow (a videoconferencing service) was acceptable were explored. Reasons for unacceptability were: lack of education/Deaf awareness, technological issues, preference of face-to-face interpretation and service inflexibility. However, some participants still used the intervention despite technological issues as indicated in the immediate usability questionnaire.

The above finding is concurrent with the findings of a videoconferencing study about mental health, where Deaf participants' depression signs and treatment knowledge increased, and depression symptoms improved despite technological issues with the videoconferencing intervention (Wilson & Wells, 2009). Most of the participants in the Wilson and Wells (2009) study were educated above high school level, which could explain why they were able to accept a technological intervention which involved a lecture on depression. Also, intervention participants received the same information at the same level, whereas the present study participants attended different services about different health issues.

Some participants in the current study did not use the InterpreterNow Service at all over the 12-month period as they had no need, interest or motivation to do so. Furthermore, intervention group participants were satisfied with their GP service to the same extent whether they used InterpreterNow or not. These findings support research that suggests that acceptability of videoconferencing can be variable (Crowe, 2017). It could be that the present study participants had already received good healthcare access such as appropriate levels of face-to-face interpretation and connection with healthcare staff (Crowe, 2017; Hacking et al., 2016).

The above findings also agree with previous research (Hacking et al., 2016). Hacking and colleagues (2016) introduced an intervention which attempted to increase hypertension and healthy living knowledge of Deaf people (n=41) via mobile text messages with information on hypertension symptoms, possible hypertension consequences and tips on avoiding or managing high blood pressure via healthy living such as better eating habits and more exercise. Deaf people's knowledge about hypertension and healthy living was increased due to the intervention. However, a third of the participants did not feel that the intervention promoted connection with healthcare staff. Also, 78% of the Deaf participants felt that text messages were not the best way of information delivery for Deaf people. In Hacking et al. (2016) study the technology was text messages, which is different from videoconferencing. Videoconferencing allows to have a longer conversation with healthcare providers and to ask more detailed questions in British Sign Language, the preferred communication method of most Deaf people, compared to writing in mobile phone text messaging interventions (Emond et al., 2015a, and 2015b). Therefore, the current study showed some intervention acceptability. This could be in part due to the mode of intervention delivery (videoconferencing).

Future directions of research could be to encourage a larger number of participants to fill in immediate response questionnaires to obtain more representative data on immediate views after using InterpreterNow. Another way in which this study could be extended is measuring and analysing demographic factors which may influence findings such as participants' use of different types of technology, age, gender, socioeconomic background and educational attainment. Lastly, larger samples of participants analysed over longer timescale could be used to provide more concrete and certain findings.

6.4.2 DEMAND.

USAGE.

Results show that most Deaf people in the InterpreterNow trial used tablets provided to access remote British Sign Language interpreters in healthcare settings. Deaf people mostly used tablets from home for booking appointments and receiving

brief information about tests and medication prescriptions (Video Relay Service calls). InterpreterNow was used the most by Deaf people to contact the GP. A third of calls made by Deaf people with InterpreterNow were during healthcare appointments (Video Remote Interpreting). More Video Relay Service calls were made because Deaf people require telephone functionality. Using Video Relay Service saves money and effort for a Deaf person who wants to communicate with the healthcare service staff to make appointments or to receive simple information. Previously, Deaf people would have had to attend the health service in person.

The Video Remote Interpreting calls are made during healthcare appointments. During the InterpreterNow trial, 95 calls were made, which means that for 95 different situations, it was quicker and easier to access a British Sign Language interpreter online via InterpreterNow than face-to-face. There is a shortage of British Sign Language interpreters in general and particularly at short notice. InterpreterNow can provide access for simple meetings with doctors and when face-to-face British Sign Language interpreters are not available.

SUMMARY.

Reasonably high level of calls made indicates that the service is necessary to fill access gaps for calls that hearing people make by telephone or for instances when face-to-face British Sign Language interpreters are not available (such as medical emergencies) (Emond et al., 2015a, 2015b). The usage findings were that most Deaf participants (79%) had used InterpreterNow to make Video Relay Service and Video Remote Interpreting calls. This highlights the fact that Deaf people are often comfortable using technology regularly (Power et al., 2007). The fact that Deaf people were able to learn how to use the tablet, the InterpreterNow application, to make different types of calls and to use the different application options suggests a higher level of technical proficiency of this sample. The high usage also highlights that Deaf people are interested in having better quality technology, which is interactive, reliable and has a good connection (Power et al., 2007).

6.4.3 COST EVALUATION.

COST OF SERVICE.

The total savings after 52 Deaf people had used InterpreterNow for one year were £45,917.48 compared to face-to-face interpreting. In total, the InterpreterNow service costs £8,187.59 to run for one year. The cost to pilot the service was £95,564.00. The pilot study costs were for staff (project workers, project managers, staff training, and staff travel and researcher costs) and technology (sim cards and tablets for participants). However, these costs would not be incurred when the service is rolled out. Therefore, the service by itself cost below £10,000 for a year. For Video Remote Interpreting calls (95 made), £6,976.13 was saved and for 431 Video Remote Interpreting calls £38,941.35 was saved. Therefore, the InterpreterNow service was particularly effective at saving money via Video Remote Interpreting calls.

COST SAVINGS.

Considerable cost savings were made due to the British Sign Language interpreters not needing to travel as well as there being no minimum time for British Sign Language interpreter appointments. InterpreterNow use also led to the shorter waiting time for British Sign Language interpreters to answer calls and the number of out of hour calls was reduced. Our results also found that 26 out of hours calls were made by 17% of the current study sample, costing £1775.80 (Morse, 2014). This is a smaller percentage than for Deaf people nationwide (32%) as well as that in the general population (19%) (Ipsos MORI, 2017). Lastly, costs were saved due to reduced meeting length. The average meeting for Video Remote Interpreting (when hearing and Deaf person communicate face-to-face with British Sign Language interpreter translating via InterpreterNow) was 9 min 1 sec. The average GP appointment is eight to 10 minutes (Curtis & Netten, 2012), so this means that Deaf people are able to have the same access as hearing people using InterpreterNow. When British Sign Language interpreters are not available, double appointments are often necessary as other methods of communication are difficult and timely (such as lip-reading or writing). Therefore, the cost evaluation has shown that InterpreterNow use could save money compared to face-to-face British Sign Language interpreter appointments. Using

InterpreterNow also results in cost saving due to less out of hours calls, quicker access to British Sign Language interpreter and shorter meetings.

SUMMARY.

The findings about cost partially support previous research. Travel costs were reduced in the present study because British Sign Language interpreters did not have to travel to appointments but could interpreter remotely, which was also found in previous studies (Blaiser et al., 2013; Wilson & Wells, 2009). However, other cost savings were related to the fact that the British Sign Language interpreters have a set minimum time for appointments, which is not the case for InterpreterNow appointments.

Other cost savings in the present study are due to reducing unnecessary appointments. For instance, 431 Video Relay Service calls were made, which means that Deaf people received brief consultations or made appointments remotely, which they would have had to do in person previously. This shows that using InterpreterNow instead of attending services is cheaper, as was suggested by another study (Wilson et al., 2015).

Cost savings which were not seen in Deaf mHealth intervention research previously were shown. These cost saving are related to reduced waiting times, less out of hours calls and quicker access to British Sign Language interpreters. These findings are important as they may help to reduce NHS costs related to the Deaf population such as that for missed diagnosis and poor treatment (£30 million per year) (Emond et al., 2015), higher use of GP services (£76 million per year) and social work services (£60 million per year) (Archbold, Lamb, O'Neill, & Atkins, 2014). Additionally, reducing out of hours calls (17% for current sample compared to 32% in overall Deaf population) is also important for saving costs for out of hours appointments (Ipsos MORI, 2017).

6.4.4 CONCLUSION.

In this study InterpreterNow service acceptability, demand and costs were analysed. InterpreterNow acceptability was explored using an immediate response questionnaire, one year follow-up questionnaire and interviews with project workers. It

was found that during the trial and after one year most Deaf people rated the quality of communication and interaction using InterpreterNow highly. However, other Deaf people did not use InterpreterNow during the trial. The reasons why certain Deaf people did not accept the service were that they felt the service was not flexible enough, due to limited training on using InterpreterNow, issues related to low healthcare staff awareness and problems with the tablet and bad connection.

The demand for the InterpreterNow service is high, with most Deaf people making InterpreterNow calls from their home or during appointments within 12 months. The usage includes different services such as GP, hospital, dentist and opticians. Also, cost savings compared to face-to-face British Sign Language interpreting are considerable and the service does not cost a great amount to roll out nationally. Therefore, the main recommendation of this chapter is that it is feasible to roll out the service on a national level.

CHAPTER 7: GENERAL DISCUSSION

7.1 OBJECTIVES OF THE THESIS

The central rationale for this thesis is that Deaf people experience more health inequity than the general population, which is in part due to the communication issues between doctors and Deaf patients (Emond et al., 2015; Iezzoni et al., 2014; Kritzinger et al., 2014). Non-technological Deaf health interventions have shown some efficacy in terms of promoting health knowledge and awareness, as well as improving communication (e.g., Barnett et al., 2014; Jensen et al., 2013; Zazove et al., 2012). However, importantly, mHealth and especially videoconferencing interventions, have emerged for Deaf people that are as effective as non-technological interventions, but significantly more cost-effective (Blaiser et al., 2013; Wilson et al., 2015). With the potential utility of videoconferencing as a backdrop, this thesis sought to test a new videoconferencing intervention for Deaf people – InterpreterNow – with SDT as a guiding theoretical framework.

In Study 1, the applicability of SDT as an explanatory framework for Deaf health motivation was examined. Then a three-stage approach was taken via Studies 2-4 within which I conducted a rigorous test of the InterpreterNow service in terms of how it affects health access and communication experiences of Deaf participants in healthcare settings, with an insight into the benefits and limitations of the service. Here, SDT was used to provide explanations of mechanisms of Deaf people's health motivation. The objective of this chapter is to provide a summary of the thesis findings. The findings will be discussed in terms of current literature on Deaf healthcare access and communication. Implications will be considered, as well as the limitations of research findings and methodology. Conclusions will be drawn on whether the InterpreterNow service can be used more widely to promote Deaf healthcare communication and access.

7.2. SUMMARY OF FINDINGS

The first study (cross-sectional analysis) showed that Deaf people's need frustration contributed to their controlled motivation in healthcare settings (for example, Boone, Vansteenkiste, Soenens, Kaap-Deeder, & Verstuyf, 2014; Chen et al., 2015; Haerens et al., 2015). In support of SDT, it appears that psychological need frustration carries negative effects in this population. Specifically, the controlled motivation for healthcare appears to be highly likely when Deaf people feel controlled, incompetent, and rejected in the health domain and, therefore, supports for these frustrated needs are required if and when they occur. Such a finding is especially important against a backdrop of frustrated needs in health settings among people from the Deaf community (Emond et al., 2015). As such, interventions that help overcome the sense that one's needs are frustrated is of particular importance. I tested one such intervention – InterpreterNow – in the second study of this thesis.

Building on Study 1, the second study of this thesis examined the effect that InterpreterNow – a new videoconferencing intervention – has on the motivation, access, and communicative experiences of Deaf people in healthcare settings using a one year randomised controlled trial. Results suggested that InterpreterNow was successful in increasing Deaf people's health literacy, communicative satisfaction, and perceptions of autonomy support from professionals. This study also showed that the InterpreterNow service helped to increase the use of preferred methods of communication (i.e., British Sign Language), which is likely to have aided understanding between doctors and patients, as well as better health literacy and knowledge of the patients.

The third study extended the second study by conducting a qualitative assessment of the InterpreterNow service. British Sign Language interpreters, Deaf people and Healthcare Practitioners provided views on the service. Key benefits identified were ease of InterpreterNow use, better communication and access to healthcare as well as Deaf people's improved independence and cost/time reductions. Issues with the service were about technology (e.g., connection and the mobile application or tablet not working) and education (e.g., lack of training for healthcare professionals on Deaf awareness). Suggestions for improvement included a faster internet connection at healthcare services, more training for Deaf people for the

application use, having equipment set up before appointments, online training provision, and healthcare services receiving advance warning about InterpreterNow use, availability of local interpreters, no queues and 24-hour coverage.

The final study completed the evaluation of InterpreterNow and examined the acceptability, feasibility, and cost-effectiveness of the InterpreterNow service. Acceptability was measured by questionnaires as well as project worker interviews. Cost-effectiveness was assessed by conducting a cost evaluation and analysing usage statistics. The acceptability findings from questionnaires (for single time post- test and repeated immediate responses) were that the service interaction was of a high quality, that there were improvements in interaction outcome, that participants would be likely to use InterpreterNow in the future, as well as positive responses on ease of making contact/appointments/connecting to a British Sign Language interpreter. Additionally, communication preferences such as British Sign Language interpreters and online methods were identified (both methods used more in the intervention group after 12 months). However, some issues were raised, which included technological understanding, education (Deaf awareness of staff about Deaf health issues/InterpreterNow purpose) and situations in which it would be difficult to use InterpreterNow (e.g., appointments including a lot of movement). Feasibility findings from project worker feedback were about problems such as queuing, preference of some participants for face-to-face interpreters, and participants' lack of training. Most of the acceptability and feasibility findings support findings from the qualitative study, as well as providing further details from the perspective of service users and providers.

Finally, InterpreterNow was found to be highly cost-effective. The service cost £8,187.59 to run for one year (for 52 Deaf people), with total savings of £45,917.48 compared to face-to-face translation. These cost savings arose primarily due to British Sign Language interpreters requiring minimal booking times and saving associated with travel and scheduling. Other cost reductions were related to less out of hours calls made by Deaf participants, as well as reducing appointment time by InterpreterNow use. Usage findings were that most Deaf participants had used InterpreterNow (79%), with most calls being Video Relay Service (67.8%) calls made to GP surgery. Video Relay Service allows Deaf people to access the telephone in the same manner as a hearing person would instead of having to go to the GP surgery for brief consultations or

to make an appointment. The fact that most calls were Video Relay Service means that access to a telephone for healthcare purposes is useful for Deaf people. This study shows the cost-effectiveness of mHealth interventions compared to face-to-face translation.

7.3 THE UNIQUE CONTRIBUTIONS OF THIS THESIS AND FUTURE RESEARCH SUGGESTIONS

The research presented within this thesis contributes significantly to both the academic literature and healthcare practice. The academic literature contributions lie predominantly in extending the evidence base for mHealth interventions to be used with Deaf participants. The positive findings regarding the effects of the InterpreterNow service on health communication, literacy and autonomy support, substantiate and extend previous research into using videoconferencing with Deaf populations (Blaiser et al., 2013; Crowe et al., 2016; Wilson & Wells, 2009; Wilson et al., 2015). The primary implication here is that InterpreterNow is a potentially effective intervention to be considered alongside these other interventions, which can aid health outcomes in the Deaf population.

There is a further unique contribution in regard to the assessment of views of British Sign Language interpreters and healthcare professionals, as well as Deaf people in the qualitative study. Here, the qualitative study extends previous work by providing rich detail about when services like InterpreterNow service are appropriate (and when they are not). Lastly, and perhaps most importantly, this project studied the cost-effectiveness of InterpreterNow. Previous studies show that mHealth interventions are highly cost-effective with no disadvantage to health outcomes (e.g., Blaiser et al., 2015; Wilson et al., 2015; Wilson & Wells, 2009). It was shown that it costs less to run the InterpreterNow service than face-to-face British Sign Language interpreter provision. This finding substantiates and adds to literature regarding costs of videoconferencing interventions for Deaf health, compared to usual care. On the basis of these contributions, several important future directions emerge.

7.3.1 FUTURE RESEARCH TOPIC 1: LARGE-SCALE RCT THAT BUILDS ON LEARNINGS FROM THE TRIAL AND FEASIBILITY RESULTS.

The key lessons learned from the current project are about the appropriateness of the InterpreterNow service and Deaf people's motivation. In terms of InterpreterNow, it was possible to establish when InterpreterNow works well, and when it does not. I also uncovered some data on what changes Deaf people would like to be implemented. Future research is therefore needed to take these insights and develop the tool with a view to subjecting it to a larger scale trial. If the groups were more segmented (for instance, late deafness onset vs early, elderly vs younger Deaf people), it would be possible to make more specific conclusions about improvements or changes to InterpreterNow that would be useful to specific groups of Deaf people.

Relatedly, another direction for future research is concerned with ensuring the rigour of the methodology to support the quality of the data. This could be achieved by conducting a study with a larger sample to ensure that the findings are more definitive and reflect the experiences of the Deaf population more broadly. A larger timescale for the study would ensure that enough Deaf people use InterpreterNow, which would help to make the findings more varied (due to different services used), as well as more conclusive.

7.3.2 FUTURE RESEARCH TOPIC 2: SDT AS AN EXPLANATORY FRAMEWORK.

In the cross-sectional study, limited support was found for SDT. I have speculated in those studies that these findings may be sample specific effects of the Deaf population. This was on the basis that Deaf people have specific needs and appear to experience considerable need frustration due to elevated perceptions of control (for example, Emond et al., 2015; Iezzoni et al., 2004; Steinberg et al., 2006). In this work, though, I only measured perceptions of autonomy support. Other climate measures such as the amount of control professionals provide, or the amount of competence support they give may have been better indicators of the specific environmental conditions experienced in this population. SDT studies in the learning and exercise domains showed that controlling environments are positively associated with need frustration (Bartholomew et al., 2011; Edmunds et al., 2007; Reeve & Jang,

2006; Reeve, 2012; Standage et al., 2003; Standage et al., 2005; Williams, 2002). A control measure has also been used for school environments (Barber, 1996; Costa, Cuzzocrea, Gugliandolo, & Larcan, 2016; van den Berghe, Soenens, Vansteenkiste, Aelterman, Cardon, Tallir, & Haerens, 2013) and exercise settings (Bartholomew et al., 2011). Extending this work to the healthcare domain, and in particular, the Deaf health domain is likely to be an especially fruitful avenue of future work in this area.

7.3.3 FUTURE RESEARCH TOPIC 3: FORMAL COST STUDY.

Conducting a formal cost-effectiveness analysis, cost-utility analysis or cost benefits analysis would allow to obtain more details about how effective, useful or beneficial the InterpreterNow service is. This would be more valuable than the current partial cost evaluation, which can only provide limited data on how much money was saved. Formal cost evaluations help to promote financial accountability for charitable stakeholders and researchers conducting the project, help to set up priorities when resources are limited, as well as providing clear and persuasive financial evidence to policymakers and funders. Therefore, future research should include a full cost evaluation.

QOL (quality of life) would be the key measure for the cost utility analysis. Quality of life is an important measure as this outcome contributes to decisions about the allocation of resources to health interventions (Richardson, 1994). Health-related questionnaires about quality of life include specific instruments, generic profiles and preference-based. Specific instruments are targeted on a particular disability. Generic profiles are appropriate to use across different populations. Lastly, preference-based measures are calculated as a single score of quality of life, based on participant preferences related to intervention outcomes. Brief Symptom Inventory (BSI) (specific), General Health questionnaire (general) and WHO Quality of Life questionnaire (preference-based) have been translated into sign language with good reliability for video questionnaires for Deaf participants (when compared to written versions for the general population) (Fellinger, Holzinger, Dobner, Gerich, Lehner, Lenz, & Goldberg, 2005). Therefore, cost utility of interventions for Deaf people can be measured using the above questionnaires. In particular, the reliability of the BSI was higher for Deaf people than for hearing people using the written questionnaire format (Fellinger et al., 2005). This might be because this questionnaire includes quite short questions. However, BSI in the

Fellinger et al., (2005) study was used only to assess severity of certain psychological issues but not overall life quality, which suggests it will only be applicable for measuring interventions which have an effect on psychological factors. In comparison, WHO Quality of Life questionnaire measures quality of life in general, which could be used across more health interventions which focus on a variety of outcomes.

Cost-benefit analysis involves comparing all benefits to all costs of an intervention. Some of the costs of the intervention and saving to the NHS have been already identified in the present thesis. Additional costs (as well as those present in current thesis) that are needed for a detailed cost- benefit analysis are opportunity costs (Johns, Baltussen, & Hutubessy, 2003). Opportunity costs occur from missed opportunity due to a decision made. In cost-benefit analyses, quality of life measures are used to estimate QALYs. QALYs data is then combined with information about costs of intervention to ascertain a cost/benefit ratio (if ratio is over 1.0, it means that the project is expected to deliver positive value) (Dhont, Farriaux, Saily, & Lebrun, 1991). The costs can be obtained from information from app developers as well as data on how much it costs to run the intervention from the charity partners and also from estimates of salaries of BSL interpreters available online and through charity partners.

In summary, there are different measures available that can be used to conduct a formal cost study. Measures employed should be appropriate to the participants' needs (in sign language), validated with the particular sample, as well as general to quality of life (as opposed to specific to psychological factors). Lastly, it is useful to measure both quality of life and intervention costs in order to inform funding bids to the government and healthcare services that are helping to provide funding to InterpreterNow.

7.4 PRACTICAL IMPLICATIONS

As well as adding to the Deaf health literature, this thesis also has practical implications. In what follows, I list each of these implications in turn.

7.4.1 PRACTICAL IMPLICATION 1: PROMOTE AUTONOMY SUPPORT PERCEPTIONS.

It was found in the cross-sectional study that Deaf people generally experience controlled motivation during healthcare appointments. Controlled motivation is obtained via low need satisfaction and high need frustration. This is supported by Deaf healthcare research, which shows that Deaf people tend to experience low autonomy supporting environments when dealing with health issues, which can lead to need frustration and then controlled motivation towards health behaviours, which could then potentially lead to Deaf people's health deteriorating (Emond et al., 2015a, 2015b).

Autonomy support is increased via the improvement of Deaf-hearing communication and access via InterpreterNow. Also, in the intervention group, autonomous motivation increased and controlled decreased after using InterpreterNow. Therefore, this study supports the idea that InterpreterNow is effective in enhancing perceptions of autonomy support that are instrumental in need satisfying experiences and autonomous motivation (Chen et al., 2015; Haerens et al., 2015; Ng et al., 2012).

Teaching doctors to communicate in a more patient-centred way could improve Deaf patients' perceptions of the healthcare environment (Hall et al., 1995; Hibbard et al., 2004; Saha et al., 2008). This type of communication involves the physician accounting for the basic psychological needs of the patient. In patient-centred communication, doctors are advised to encourage the patient to actively make health decisions (autonomy), to use supportive language (relatedness) and to encourage patient independence by providing appropriate materials for the patient to learn about health conditions (competency). Promoting the basic psychological needs of the patients is likely to make the patients improve the autonomy support perceptions and also to lead to autonomous motivation for health-promoting behaviours. One of the ways to do this, as this thesis shows, is via the implementation of InterpreterNow.

7.4.2 PRACTICAL IMPLICATION 2: ACCOUNT FOR THE ROLE OF IMPORTANT OTHERS.

Deaf healthcare studies have shown that Deaf people often feel a strong sense of belonging to the Deaf culture and little affiliation with the hearing population (Allen et al., 2002; Bat-Chava, 1993; Jambor & Elliott, 2005; Obrzut et al., 1999). This was shown in the second study of this thesis. It was found that important other autonomy support perceptions were higher than healthcare autonomy support perceptions. Important other autonomy support perceptions were unaffected by time or group (intervention or control) differences. This finding could be explained by the fact that Deaf people share more common experiences and a language with other Deaf people and also feel more supported in the Deaf community (Bat-Chava, 1993; Graybill et al., 2010; Harmer, 1999; Johnston, 2004; Scheier, 2009; Terry et al., 2016). In comparison, during healthcare experiences with hearing doctors and receptionists, Deaf people often report feeling disrespected, belittled, confused and nervous (Emond et al., 2015a, 2015b; Steinberg et al., 2002). In fact, Emond et al. (2015) provide a case study for a participant who felt more comforted by bonding with a Deaf cleaner than from a conversation with the doctor about their health.

Therefore, the practical implication is for doctors to be aware of the bonds between Deaf patients and their Deaf friends and family. This knowledge can be used to improve the healthcare experiences of Deaf people. For instance, the Deaf person could be asked about their communication preferences (in sign language, through lip-reading, by written text, etc.) And about whether they would like a Deaf friend or partner with them in the appointment. Another way in which the importance of social support for Deaf people could be accounted for is by attempting to increase awareness of illnesses not just of the single Deaf patient but also of their social circle. This might mean increasing the availability of materials on health topics available online, or by having British Sign Language classes at Deaf centres about certain illnesses. If the influence of Deaf people's friends and family is consistently stronger than that of healthcare staff (over and above the effect of promoting healthcare autonomy support perceptions with InterpreterNow introduction), then medical services should be aware and accepting of this aspect of Deaf people's lives and use it to improve the healthcare experiences.

7.4.3 PRACTICAL IMPLICATION 3: REDUCE CONTROLLED MOTIVATION.

The cross-sectional study showed that before using InterpreterNow, Deaf people experienced controlled motivation during healthcare interactions. This is supported by previous Deaf literature which shows that Deaf people often don't feel supported by their doctors. For instance, doctors have been shown to not to encourage questions (competency frustration), being disinterested in patient views (autonomy frustration) and to make Deaf people feel controlled and patronised and additionally not make efforts to form supporting relationships with patients (relatedness frustration; Beck et al., 2002; Emond et al., 2015a, 2015b; Iezzoni et al., 2004; Steinberg et al., 2002). This frustration of basic psychological needs leads to Deaf people experiencing controlled motivation in healthcare settings. To reduce controlled motivation of Deaf people, doctors could make efforts to promote patient-centred care, which often leads to more positive experiences of patients and better health outcomes (Stewart, 1995). Patient-centred care is generally viewed as being autonomy-supportive and as that which helps to increased need satisfaction (Kitson et al., 2012).

Although there has been an overall move in healthcare for using patient-centred communication for better health outcomes and positive experiences in health, this has not yet fully reached the Deaf people's health domain. To extend the reach of patient-centred approaches to Deaf people, the government and Deaf charities should make efforts to promote Deaf needs awareness to doctors. For instance, NHS England published the Accessible Information Standard (2015) which provides guidelines to services for improving health access for Deaf people such as asking Deaf people for their communication preferences and having access to British Sign Language interpreters. Healthcare professionals who participated in qualitative interviews in this thesis stated that they do not have enough time to attend lengthy Deaf awareness training. A solution for increasing Deaf awareness of healthcare professionals might be to create a website or a mobile application where Deaf communication needs are presented in a simple quick format that healthcare professionals can look at before appointments with Deaf patients.

7.4.4 PRACTICAL IMPLICATION 4: AWARENESS OF DIFFERENCES WITHIN THE DEAF POPULATION.

Deaf awareness has often shown to be low at healthcare services, which results in doctors and receptionists not understanding Deaf communication needs and preferences, being controlling and refusing to accept interventions such as InterpreterNow or refusing to help Deaf people get access to British Sign Language interpreters (Emond et al., 2015a, 2015b). In the qualitative and feasibility thesis chapters, it was shown that InterpreterNow service was not always appropriate and acceptable. It was deemed not appropriate to use for appointments which involved a lot of movement such as opticians or dentists, as well as private (e.g., sexual health) appointments. Deaf people also did not use InterpreterNow if they had a strong preference for face-to-face British Sign Language interpreters or felt more comfortable with family or friends interpreting.

Therefore, the findings highlight that Deaf people's needs are not uniform across the Deaf population. Healthcare staff need to be aware of this. Not all Deaf people would feel more comfortable using videoconferencing in healthcare settings. Deaf awareness training is necessary for medical staff to understand the importance of the variation within the Deaf population. Conversely, some Deaf people interviewed in Chapter 5, reported high interest in using InterpreterNow. It is likely that these Deaf people are comfortable to communicate with the hearing population, are younger and often use technology to communicate such as mobile phones, video chat and emails (Maiorana-Basas & Pagliaro, 2014; Thoren et al., 2013). Making medical staff aware of Deaf population differences could help to make the healthcare service experience more comfortable for different Deaf people, potentially leading to improved healthcare behaviours and better health of this population.

7.5 LIMITATIONS OF THE THESIS

Despite the many strengths of this work in terms of reach, breath, and rigour of analyses and methodologies, it nonetheless has some limitations. One of the issues with findings for Study 1 and 2 were low sample numbers, which has the power to detect effects. The reason that the participant numbers were low was that (a) this is an especially hard to reach population, (b) the study took a relatively long time (at least 12 months) and (c) because the assessments took a long time to conduct (around 1 hour).

Other issues in Study 1 and 2 are that questionnaires in baseline and follow-up assessments may have been difficult for Deaf people to understand. As the questionnaires were not validated with Deaf people (except for the health literacy measure), it remains unclear whether they are appropriate for testing this sample. In addition, the Deaf population includes some people who struggle to use technology, some who are happy with the current service in healthcare settings and some who have learning difficulties as well as others who do not like change. Additionally, different participants used the InterpreterNow service in different ways (some participants used it an exceptionally high amount and other barely at all). Therefore, it is difficult to generalise across the diverse use of InterpreterNow. It is possible that focus group information from Study 3 is more relevant as qualitative methodology accounts for low participant numbers.

Another issue I have documented is regarding the breadth of instruments employed. I measured only autonomy support as a measure of the climate, but the climate is more multifaceted than this narrow conceptualisation. The climate contains other important elements such as levels of control and structure (competence support). In healthcare contexts more generally, this appears to a limitation and it would be important for future work to overcome this limitation by broadening the scope of climate measurement to these features. In the context of healthcare climates that are especially perceived to be high in control, like those that Deaf people experience (Emond et al., 2015), this is a highly salient avenue of future work. In summary, the issues within the research can be grouped as low participant numbers, length of the trial, questionnaire issues and concept issues, as well as the specific Deaf sample characteristics.

7.6 OVERALL CONCLUSION

Patient-centred care has been consistently shown to be more effective in promoting healthcare than doctor-centred (Stewart, 1995). According to the system theory of patient-centred care (McCormack & McCane, 2006), patient-centred care is delivered via the processes of working with patients' values, accepting and accounting for psychological/social/communication/cultural needs of patients, shared decision making between healthcare staff and patients, doctors being sensitive and kind to patients as well as, doctors and patients being actively engaged in the care process. Patient-centred care has been shown to lead to positive outcomes such as patient well-being and higher quality of life, improved communication with healthcare staff, satisfaction, improved mental health, stronger motivation for participating in own healthcare, as well as reductions in unnecessary referrals and appointment time (Anderson, Funnell, Butler, Arnold, Fitzgerald, & Feste, 1995; Kinmonth, Woodcock, Griffin, Spiegel, & Campbell, 1998; Stewart, 1995, 2001, 2005; Stewart, Brown, Levenstein, McCracken, & McWhinney, 1986). However, Deaf people often do not receive patient-centred care. Deaf health studies report findings about issues that Deaf people and healthcare staff have in establishing relationships, lack of staff Deaf awareness, misunderstanding between Deaf patients and staff due to communication problems, low access to British Sign Language interpreters, and low health knowledge of Deaf people (Fellinger et al., 2012; Levine, 2014; Pollard & Barnett, 2009; Pollard, Betts, Carroll, Waxmonsky, Barnett, Pickler, & Kellar-Guenther, 2014; Pollard et al., 2009). Using SDT, the results of this thesis help to improve understanding of Deaf motivation and experiences in healthcare by testing the efficacy of a new mHealth videoconferencing intervention; InterpreterNow.

To summarise the body of work contained herein, it appears that Deaf motivation and access within healthcare settings can be improved by InterpreterNow, which is built to support healthcare access and allow Deaf people to utilise their preferred communication method. Providing the InterpreterNow service to Deaf people who have the desire to learn about new technologies and communicate through online methods is likely to be more beneficial than giving access to all Deaf people. This is the case because not all Deaf people are able to or interested in making any changes to the way they communicate in healthcare settings. The current findings, as well as literature

about Deaf people's access and preferences in healthcare suggest that interventions which account for Deaf needs and preferences are likely to be effective in promoting motivation and positive feelings during healthcare appointments. In conclusion, the current thesis findings provide clear guidance on what should be changed for the InterpreterNow service to become more usable and accessible to Deaf people, to promote healthcare engagement and improve Deaf people's independence.

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APPENDICES

APPENDIX 1. QUESTIONNAIRES AND REFERENCES FOR THE OUTCOMES MEASURED

Outcome	Measure	Definition	Measurement
Health Anxiety	Health Anxiety Inventory (Salkovskis, Rimes, Warwick, & Clark, 2002)	Persistent worry and preoccupation about illness. Can be mild to severe.	14 questions, with 4 statements each. All groups of 4 statements are scored 0, 1, 2 or 3 depending on the statement selected. If more than one statement is selected, use the highest-scoring statement of those chosen. Items are summed to obtain the total score. The higher the total score, the higher a patient's health anxiety.
Autonomy Support (Important others)	Important Other Care Climate Questionnaire (Williams et al., 2006)	This scale measures the extent to which patients experience the environment created by important others (such as friends and family) as autonomy-supportive.	There are 6 questions with responses 1 (strongly agree) to 7 (strongly disagree). An average score of 6 questions is taken. The higher the score, the more autonomy-supportive the person

			perceives their important other climate to be.
Need Satisfaction and Frustration	Basic Psychological Need Scale and Need Frustration Scale (Chen et al., 2015)	The extent to which the basic psychological need of autonomy, competency and relatedness are satisfied or frustrated. If the needs are satisfied, people will experience a higher quality motivation. If needs are frustrated, the motivation will be of a lower quality.	This scale is made up of 24 questions. The items are rated 1 (not true at all) to 5 (completely true). There are 6 sub-scales each with four items. To obtain each sub-scale, the items are averaged. The higher the score, the higher the tendency on that sub-scale.
Motivation	Treatment Self-regulation Scale (Levesque et al., 2007)	The quality of motivation experienced in terms of self-regulating treatment. Autonomous motivation is a high quality of motivation. Someone who is autonomously motivated will be likely to look after their own treatment in the way that their	The items are ranked from 1 (strongly agree) to 7 (strongly disagree). This scale has 15 items: 6 that assess autonomous motivation, 6 that assess controlled motivation, and 3 that assess amotivation. The sub-scales are obtained by averaging across the items per scale. A

		<p>doctor prescribed. Conversely, controlled motivation is of a lower quality. Finally, amotivation is when the person is not motivated.</p>	<p>higher score represents a tendency towards that type of motivation.</p>
<p>Health locus of control</p>	<p>Multidimensional Health Locus of Control (Wallston, 2013)</p>	<p>Locus of control refers to whether people feel that they can control life events (Rotter, 1966). Health locus of control is about people's health. If someone has an internal locus of control, they believe that they control their own health. If someone's outcome is Powerful Others, they think that someone else (such as doctors or family members) control their health. If someone's locus of control scale results indicate Chance, then they believe that their health state occurs due to chance.</p>	<p>The score on each subscale is the <u>sum of the values</u> circled for each item on the subscale (i.e., where 1 = "strongly disagree" and 6 = "strongly agree"). No items need to be reversed before summing. All of the subscales are independent of one another. There is no such thing as a "total" score. A score of 23 to 30 on any subscale means someone has a strong inclination toward that particular subscale. A score of 15 to 22 means someone is moderate on that particular subscale. A score of</p>

Health Literacy	REALM (Rapid Estimate of Adult Literacy in Medicine) scale (66 items) (Davis et al., 1993; Pollard & Barnett, 2009)	Health literacy questionnaires measure the extent to which people can understand simple health information (David, 1993)	6 to 14 means someone is low on that particular subscale. Davis et al. (1993) suggests that the result values should be scored as school grade levels and provides definitions for each level. If a participant scores between 0 and 18 (3rd grade or below, 9 years old or less) that means that they are not able to read easy health materials, that they require repeated instructions in British Sign Language and materials composed of videotapes or images. A score of 19 to 44 words (4th to 6th grade, 9 to 12 years old) means that participants need easy materials and that they are likely to be unable to repeat
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prescription labels. If participants recognise 45 to 60 words (7th to 8th grade, 12 to 14 years old), it means that they will struggle with most patient education materials. If participants knew 61 to 66 words (high school, 14 years old and over), then they should be able to read most patient education materials about health. Patient scores are estimate of literacy, not grade equivalents. The grade for the participant scores just gives a group for the participants with a meaning. Generally, participants scoring below 61 suggests low health literacy.

**APPENDIX 2. MOST COMMON USED AND PREFERRED COMMUNICATION METHODS (N,
%) FOR DIFFERENT HEALTHCARE SERVICES**

Healthcare services	Intervention				Control	
	Baseline		Post-test		Baseline	
	Most Common	Preferred	Most Common	Preferred	Most Common	Preferred
GP						
British Sign Language Interpreter	32 (80)	43 (94)	25 (78)	31 (89)	18 (56)	35 (83)
British Sign Language no interpreter	2 (5)	0	0	0	1 (3)	1 (2)
Spoken English and Lip-reading	4 (10)	1 (2)	4 (13)	3 (9)	6 (19)	2 (5)
Speaking and Signing	1 (3)	2 (4)	1 (3)	1 (3)	2 (6)	4 (10)
Written	1 (3)	0	2 (6)	0	5 (16)	0
Hospital						
British Sign Language Interpreter	36 (84)	42 (93)	30 (88)	32 (94)	21 (66)	35 (85)
British Sign Language no interpreter	0	0	0	0	0	0
Spoken English and Lip-reading	5 (12)	1 (2)	4 (12)	1 (3)	4 (13)	2 (5)
Speaking and Signing	1 (2)	2 (4)	0	1 (3)	4 (13)	4 (10)
Written	1 (2)	0	0	0	3	0
Chemist						
British Sign Language Interpreter	14 (39)	32 (80)	16 (52)	23 (74)	5 (16)	29 (74)
British Sign Language no interpreter	3 (8)	1 (3)	1 (3)	0	2 (6)	1 (3)

Spoken English and Lip-reading	9 (25)	5 (13)	7 (23)	5 (16)	10 (31)	5 (13)
Speaking and Signing	2 (6)	2 (5)	3 (10)	2 (6)	3 (9)	3 (8)
Written	8 (22)	0	4 (13)	1 (3)	12 (38)	1 (3)
Opticians						
British Sign Language Interpreter	18 (58)	38 (88)	20 (65)	31 (86)	12 (38)	30 (79)
British Sign Language no interpreter	3 (10)	1 (2)	1 (3)	0	2 (6)	1 (3)
Spoken English and Lip-reading	5 (16)	2 (5)	6 (19)	2 (6)	12 (38)	4 (11)
Speaking and Signing	1 (3)	2 (5)	2 (6)	2 (6)	2 (6)	3 (8)
Written	4 (13)	0	2 (6)	1 (3)	4 (13)	0
Dentist						
British Sign Language Interpreter	18 (56)	35 (88)	20 (69)	29 (85)	10 (30)	30 (77)
British Sign Language no interpreter	4 (11)	1 (3)	0	0	2 (6)	1 (3)
Spoken English and Lip-reading	7 (19)	2 (5)	4 (14)	2 (6)	12 (36)	4 (10)
Speaking and Signing	3 (8)	2 (5)	2 (7)	2 (6)	5 (15)	3 (8)
Written	4 (11)	0	3 (10)	1 (3)	4 (12)	1 (3)

APPENDIX 3. COMMUNICATION METHODS USED AT BASELINE AND POST-TEST (N, %)

Healthcare services	Intervention		Control	
	Baseline	Post-test	Baseline	Post-test
GP				
In person	18 (37)	6 (19)	16 (48)	12 (48)
Online	4 (10)	12 (39)	0	0
Deaf Club	2 (5)	4 (13)	2 (6)	0
Fax	2 (5)	0	0	1 (4)
Typetalk	1 (3)	1 (3)	2 (6)	2 (8)
Text message	6 (15)	5 (16)	2 (6)	0
Member of family or friend	6 (15)	3 (10)	11 (33)	10 (40)
Letter	0	0	0	0
Hospital				
In person	10 (28)	8 (29)	7 (23)	7 (24)
Online	2 (6)	6 (21)	1 (3)	2 (7)
Deaf Club	5 (14)	4 (14)	3 (10)	1 (3)
Fax	1 (3)	0	0	1 (3)
Typetalk	3 (9)	1 (4)	4 (13)	1 (3)
Text message	2 (6)	2 (7)	1 (3)	2 (7)
Member of family or friend	11 (31)	4 (14)	12 (40)	12 (41)
Letter	1 (3)	3 (11)	2 (7)	3(10)
Chemist				
In person	20 (71)	14 (54)	22 (81)	20 (67)

Online	1 (4)	5 (19)	0	0
Deaf Club	2 (7)	3 (12)	1 (4)	3 (10)
Fax	0	1 (4)	0	0
Typetalk	1 (4)	1 (4)	1 (4)	0
Text message	0	0	0	1 (3)
Member of family or friend	4 (14)	2 (8)	5 (19)	6 (20)
Letter	0	0	0	0

Opticians

In person	22 (63)	13 (43)	23 (72)	18 (60)
Online	2 (6)	3 (10)	0	1 (3)
Deaf Club	2 (6)	3 (10)	2 (6)	1 (3)
Fax	1 (3)	0	0	1 (3)
Typetalk	9 (26)	1 (3)	5 (16)	2 (7)
Text message	1 (3)	1 (3)	1 (3)	1 (3)
Member of family or friend	0	4 (13)	1 (3)	6 (20)
Letter	0	5 (17)	0	0

Dentist

In person	21 (55)	11 (38)	20 (56)	14 (52)
Online	2 (5)	8 (28)	1 (3)	1 (4)
Deaf Club	1 (3)	1 (3)	2 (6)	1 (4)
Fax	1 (3)	0	0	0
Typetalk	3 (8)	1 (3)	2 (6)	1 (4)
Text message	1 (3)	3 (10)	2 (6)	3 (11)

Member of family or friend	8 (21)	3 (10)	9 (25)	7 (26)
Letter	1 (3)	2 (7)	0	0

APPENDIX 4. RATINGS OF INTERPRETER NOW (TOTAL N=69)

Questions	Answers (n, %)				
Please rate how you found making contact or booking an appointment?	Very Easy	Easy	Neither	Hard	Very Hard
	22 (33)	23 (34)	16 (24)	2 (3)	2 (3)
When with the health professional, was it easy to connect to a British Sign Language interpreter?	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
	20 (30)	27 (41)	8 (12)	1 (2)	10 (15)
How would you rate the quality of the connection line with the interpreter?	Very Good	Good	Average	Poor	Very Poor
	9 (14)	29 (44)	9 (14)	10 (15)	9 (14)
How frequently did the connection cut out?	Never	1 to 2 times	3 to 4 times	5 to 6 times	6 times or more
	41 (64)	13 (20)	8 (12)	2 (3)	0
How would you rate the quality of interaction with the health professional?	Very Good	Good	Average	Poor	Very Poor
	19 (31)	26 (43)	7 (11)	3 (5)	6 (10)
Did Interpreter Now improve	Definitely better	Better	Same	Worse	Definitely Worse

communication between you and your healthcare professional?	15 (24)	27 (42)	16 (25)	2 (3)	2 (3)
Did InterpreterNow improve your healthcare experience?	Definitely better	Better	Same	Worse	Definitely Worse
	21 (32)	27 (41)	5 (8)	4 (6)	9 (14)
How satisfied were you with the outcome of the interaction?	Very Satisfied	Satisfied	Neither	Unsatisfied	Very Unsatisfied
	25 (40)	21 (34)	10 (16)	5 (8)	1 (2)
How likely are you to use InterpreterNow for your next interaction with healthcare professional?	Very Likely	Likely	Unsure	Unlikely	Very Unlikely
	34 (54)	23 (37)	4 (6)	2 (3)	0

APPENDIX 5. EASE OF MAKING CONTACT (N, %)

Healthcare services	Intervention		Control	
	Baseline	Post-test	Baseline	Post-test
GP				
Very Easy	9 (21)	13 (33)	3 (8)	1 (3)
Easy	11 (26)	14 (34)	9 (25)	9 (30)
Neither	12 (29)	4 (10)	14 (39)	9 (30)
Hard	9 (21)	4 (10)	10 (28)	6 (20)
Very Hard	1 (2)	5 (13)	0	5 (17)
Hospital				
Very Easy	7 (17)	6 (19)	3 (8)	1 (3)
Easy	8 (20)	7 (23)	6 (17)	5 (17)
Neither	9 (23)	9 (29)	10 (28)	8 (27)
Hard	7 (17)	3 (10)	9 (25)	10 (33)
Very Hard	9 (23)	6 (19)	8 (22)	6 (20)
Chemist				
Very Easy	5 (16)	6 (19)	4 (12)	2 (7)
Easy	6 (19)	9 (29)	10 (30)	9 (31)
Neither	7 (23)	7 (23)	11 (33)	11 (8)
Hard	5 (16)	4 (13)	4 (12)	4 (14)
Very Hard	8 (26)	5 (16)	4 (12)	3 (10)
Opticians				
Very Easy	9 (23)	7 (20)	6 (16)	1 (4)
Easy	12 (30)	14 (4)	9 (24)	10 (36)
Neither	7 (18)	7 (20)	13 (35)	7 (25)
Hard	2 (5)	3 (9)	4 (11)	6 (21)
Very Hard	10 (25)	4 (11)	5 (14)	4 (14)
Dentist				
Very Easy	9 (21)	8 (23)	7 (19)	0
Easy	12 (29)	10 (29)	7 (19)	13 (45)
Neither	6 (14)	10 (29)	14 (38)	8 (28)
Hard	7 (17)	5 (14)	7 (19)	5 (17)
Very Hard	8 (19)	2 (6)	5 (14)	3 (10)

APPENDIX 6. LIKELIHOOD OF USING HEALTHCARE SERVICES IN NEXT 12 MONTHS (N, %)

Healthcare services	Intervention		Control	
	Baseline	Post-test	Baseline	Post-test
GP				
Very likely	28 (58)	23 (62)	29 (63)	22 (67)
Likely	17 (35)	12 (32)	6 (13)	6 (18)
Unsure	0	1 (3)	7 (15)	5 (15)
Unlikely	1 (2)	2 (5)	2 (4)	0
Very unlikely	2 (4)	0	2 (4)	0
Hospital				
Very likely	14 (32)	11 (29)	14 (32)	14 (42)
Likely	9 (21)	10 (26)	5 (11)	2 (6)
Unsure	15 (34)	9 (24)	13 (30)	11 (33)
Unlikely	2 (5)	6 (16)	4 (9)	4 (12)
Very unlikely	4 (9)	0	8 (18)	2 (6)
Chemist				
Very likely	23 (55)	19 (53)	20 (48)	13 (42)
Likely	11 (26)	10 (28)	9 (21)	8 (26)
Unsure	4 (10)	6 (17)	6 (14)	9 (29)
Unlikely	0	1 (3)	1 (2)	1 (3)
Very unlikely	4 (10)	0	6 (14)	0
Opticians				
Very likely	14 (33)	16 (42)	10 (24)	11 (35)
Likely	10 (23)	16 (42)	14 (34)	8 (26)
Unsure	5 (12)	3 (8)	9 (22)	7 (23)
Unlikely	4 (9)	0	3 (7)	2 (6)
Very unlikely	10 (23)	3 (8)	5 (12)	3 (10)
Dentist				
Very likely	22 (50)	16 (43)	18 (42)	13 (43)
Likely	12 (27)	15 (40)	15 (35)	10 (33)
Unsure	3 (7)	5 (14)	5 (12)	6 (20)
Unlikely	2 (5)	0	1 (2)	1 (3)
Very unlikely	5 (11)	1 (3)	4 (9)	0

APPENDIX 7. SATISFACTION WITH CARE AT HEALTHCARE SERVICES.

Satisfaction level	Intervention		Control	
	Baseline	Post-test	Baseline	Post-test
GP				
Very satisfied	22 (45)	16 (43)	14 (31)	11 (33)
Fairly satisfied	11 (22)	13 (35)	15 (33)	11 (33)
Neither	10 (20)	7 (19)	11 (24)	8 (24)
Fairly dissatisfied	3 (6)	0	2 (4)	2 (6)
Very dissatisfied	3 (6)	1 (3)	3 (7)	1 (3)
Hospital				
Very satisfied	6 (16)	8 (25)	6 (16)	7 (22)
Fairly satisfied	14 (37)	12 (38)	12 (32)	14 (44)
Neither	10 (26)	7 (22)	9 (24)	9 (28)
Fairly dissatisfied	3 (8)	3 (9)	5 (13)	2 (6)
Very dissatisfied	5 (13)	2 (6)	6 (16)	0
Chemist				
Very satisfied	14 (33)	7 (23)	9 (24)	8 (25)
Fairly satisfied	6 (14)	14 (44)	14 (38)	11 (34)
Neither	15 (35)	7 (23)	8 (22)	10 (31)
Fairly dissatisfied	4 (9)	0	2 (5)	3 (9)
Very dissatisfied	4 (9)	0	4 (11)	0
Opticians				

Very satisfied	13 (31)	11 (31)	6 (15)	10 (32)
Fairly satisfied	9 (21)	18 (51)	18 (46)	10 (32)
Neither	11 (26)	5 (14)	10 (26)	9 (29)
Fairly dissatisfied	2 (5)	0	3 (8)	2 (6)
Very dissatisfied	7 (16)	1 (3)	2 (5)	0
Dentist				
Very satisfied	18 (41)	10 (29)	7 (18)	5 (17)
Fairly satisfied	10 (23)	16 (46)	16 (40)	14 (48)
Neither	8 (18)	7 (20)	11 (28)	8 (28)
Fairly dissatisfied	2 (5)	1 (3)	3 (8)	1 (3)
Very dissatisfied	6 (14)	1 (3)	3 (8)	1 (3)

APPENDIX 8. COMMUNICATION QUALITY (N, %)

Healthcare services	Intervention		Control	
	Baseline	Post-test	Baseline	Post-test
GP				
Very Good	13 (39)	14 (37)	5 (12)	7 (21)
Good	16 (36)	12 (32)	17 (41)	11 (33)
Neither	8 (17)	6 (16)	10 (24)	8 (24)
Poor	7 (16)	4 (11)	2 (5)	4 (12)
Very Poor	1 (2)	2 (5)	7 (17)	3 (9)
Consultant				
Very Good	7 (16)	9 (26)	5 (16)	6 (21)
Good	15 (35)	12 (35)	10 (32)	8 (28)
Neither	5 (12)	9 (26)	3 (10)	7 (24)
Poor	12 (28)	3 (9)	5 (16)	5 (17)
Very Poor	4 (9)	1 (3)	8 (26)	3 (10)
Nurse				
Very Good	11 (24)	9 (24)	5 (15)	6 (19)
Good	16 (26)	15 (41)	11 (32)	13 (42)
Neither	8 (18)	9 (24)	9 (26)	7 (23)
Poor	9 (20)	2 (5)	3 (9)	4 (13)
Very Poor	1 (2)	2 (5)	6 (18)	1 (3)
Chemist				
Very Good	4 (10)	7 (21)	3 (14)	3 (11)
Good	11 (26)	10 (30)	12 (56)	10 (37)
Neither	19 (45)	12 (36)	8 (22)	7 (26)

Poor	7 (17)	2 (6)	6 (28)	4 (15)
Very Poor	1 (2)	2 (6)	7 (19)	3 (11)
<hr/>				
Opticians				
<hr/>				
Very Good	10 (23)	9 (26)	5 (14)	3 (10)
Good	12 (28)	12 (35)	11 (31)	11 (38)
Neither	10 (23)	8 (24)	13 (37)	9 (32)
Poor	5 (12)	3 (9)	2 (6)	3 (10)
Very Poor	6 (14)	2 (6)	4 (11)	3 (10)
<hr/>				
Dentist				
<hr/>				
Very Good	8 (19)	11 (32)	5 (14)	4 (14)
Good	15 (25)	11 (32)	13 (37)	12 (41)
Neither	11 (26)	8 (24)	8 (23)	6 (21)
Poor	8 (19)	4 (12)	5 (14)	4 (14)
Very Poor	1 (2)	0	4 (11)	3 (10)
<hr/>				
Receptionist				
<hr/>				
Very Good	7 (17)	7 (19)	5 (13)	6 (19)
Good	15 (36)	16 (44)	12 (30)	7 (23)
Neither	12 (29)	8 (22)	11 (28)	10 (32)
Poor	7 (17)	2 (6)	3 (8)	7 (23)
Very Poor	1 (2)	3 (8)	9 (23)	1 (3)
<hr/>				

APPENDIX 9. GP QUALITIES (N, %)

GP Qualities	Intervention		Control	
	Baseline	Post-test	Baseline	Post-test
Giving you enough time				
Very Good	17 (37)	13 (33)	9 (21)	6 (18)
Good	14 (30)	24 (61)	14 (33)	13 (39)
Neither	7 (15)	1 (3)	14 (33)	11 (33)
Poor	5 (11)	1 (3)	4 (10)	2 (6)
Very Poor	3 (7)	0	1 (2)	1 (3)
Asking about your symptoms				
Very Good	13 (32)	11 (30)	5 (14)	4 (13)
Good	14 (34)	17 (46)	12 (33)	14 (45)
Neither	8 (20)	8 (21)	12 (33)	11 (35)
Poor	3 (7)	1 (3)	6 (17)	1 (3)
Very Poor	3 (7)	0	1 (3)	1 (3)
Listening to you				
Very Good	17 (38)	13 (33)	8 (20)	6 (18)
Good	13 (29)	18 (46)	16 (39)	16 (48)
Neither	9 (20)	5 (13)	11 (27)	9 (27)
Poor	3 (7)	3 (8)	4 (10)	1 (3)
Very Poor	3 (7)	0	2 (5)	1 (3)
Explaining tests and treatments				
Very Good	13 (32)	11 (28)	8 (21)	6 (19)
Good	10 (24)	16 (41)	11 (28)	12 (39)
Neither	8 (20)	10 (25)	11 (28)	9 (29)
Poor	7 (17)	2 (5)	7 (17)	3 (10)
Very Poor	3 (7)	0	2 (5)	1 (3)
Involving you in decisions about your care				
Very Good	13 (34)	11 (29)	4 (11)	4 (13)
Good	10 (26)	15 (39)	10 (26)	14 (47)
Neither	8 (21)	6 (16)	15 (39)	8 (27)

Poor	5 (13)	5 (13)	5 (13)	3 (10)
Very Poor	4 (11)	0	4 (11)	2 (7)

Treating you with care and concern

Very Good	13 (32)	10 (25)	8 (21)	5 (16)
Good	16 (38)	20 (50)	15 (38)	15 (48)
Neither	6 (15)	9 (22)	8 (21)	8 (26)
Poor	4 (10)	1 (3)	5 (13)	3 (10)
Very Poor	2 (5)	0	2 (5)	1 (3)

Taking your problems seriously

Very Good	15 (35)	8 (21)	7 (18)	6 (19)
Good	15 (35)	16 (41)	15 (39)	15 (48)
Neither	7 (16)	14 (36)	8 (21)	5 (16)
Poor	3 (7)	0	6 (16)	3 (10)
Very Poor	3 (7)	1 (3)	2 (5)	1 (3)

APPENDIX 10. COST BREAKDOWN

Scaling up costs

Group	Item	Type	Amount	Notes	Totals
Staff	British Sign Language Remote Interpreters salary	Recurrent; Implementation	£3.50/min	11:31:53 time for Video Remote Interpreting calls and 10:41:28 time for Video Relay Service	£4,666.72
Technology	InterpreterNow setup	Capital; Start Up	250.00		£250.00
Technology	InterpreterNow usage	Recurrent; Implementation	£2.50/min	11:31:53 time for Video Remote Interpreting calls and 10:41:28 time for Video Relay Service	£3270.87
Total					£8,187.59

Intervention costs (not for scale-up)

Group	Item	Type	Amount	Notes	Totals
Staff	Project Manager Salary	Capital; Start up	30000.00		£30,000.00
Staff	Project worker	Capital; Start up	11000.00	3 project workers	£33,000.00
Staff	Recruitment costs	Capital; Start up	600.00		£600.00
Staff	Travel	Capital; Implementation	7650.00		£7,650.00
Staff	Manager's meeting	Capital; Monitoring	1400.00		£1,400.00
Staff	Telephone	Capital; Implementation	960.00		£960.00
Staff	Utilities	Capital; Start up	2400.00		£2,400.00
Staff	Other/stationary/consumables	Capital; Implementation	960.00		£960.00
Staff	Project worker extra costs	Capital; Implementation	2178.00	Three project workers	£6,534.00
Staff	Training	Capital; Start up	1800.00		£1,800.00
Technology	Tablets	Capital; Start up	150.00	60 tablets	£9,000.00
Technology	4 G SIM cards (Vodafone) (vat 20% included)	Capital; Start up	21.00	60 SIM cards	£1,260.00
Total					£95,564.00

Evaluation costs (not for scale-up)

Group	Item	Type	Amount	Notes	Totals
Qualitative interviews and focus group	Translation of Questionnaires Into British Sign Language	Capital; Evaluation	1500.00		£1,500.00
Qualitative interviews and focus group	Evaluator salary	Capital; Evaluation	7276.48	Three years	£21,829.44
Qualitative interviews and focus group	British Sign Language interpreters for Evaluator	Capital; Evaluation	1000.00		£1,000.00
Total					£24,329.44

APPENDIX 11. SERVICES CALLED AND PERCENTAGE OF CALL TIME FOR VIDEO RELAY

SERVICE

Services	Number of calls made	Percentage of call time (%)
Transport	5	1
Sexual health clinic	2	1
Rheumatology	4	1
Podiatry	2	0.2
Physiotherapy consultant	6	1
Pharmacy	4	0.4
Paediatric diabetes consultant	1	0.2
Other service	22	9
Orthodontics	23	2
Opticians	6	2
NHS 111	3	9
Mental health	1	0.1
Interpreting	3	1
Hospital	28	9
Hearing implant	1	0.001
Hearing aids	1	0.3
GP	183	50
Eye hospital	1	0.2
Exercise	1	0.02
E-referral	2	1
Equipment	6	1
Endoscopy	1	0.2
Diabetes service	2	0.1
Dermatology	1	0.3
Dentist	42	7
Deaf club	5	1
Council	3	1

Child health	1	0.4
Bariatric surgery	1	0.1
Audiology	16	1
AOHL	3	1

APPENDIX 12. AVERAGE VIDEO RELAY SERVICE CALL DURATION FOR EACH TABLET

Tablet ID	Number of times tablet used	Average of Outgoing call duration
In0001	1	00:03:13
In0025	1	00:03:44
In0041	1	00:02:02
In0064	1	00:03:56
In0070	1	00:00:32
In0009	2	00:00:52
In0033	2	00:04:23
In0069	2	00:10:15
In0073	2	00:02:48
In0049	3	00:04:45
In0053	3	00:04:48
In0071	3	00:05:09
In0017	4	00:05:25

In0037	4	00:07:10
In0039	4	00:06:00
In0054	4	00:03:21
In0059	4	00:09:47
In0061	4	00:00:56
In0016	5	00:02:48
In0029	5	00:01:51
In0034	5	00:03:46
In0044	5	00:03:19
In0047	5	00:08:43
In0002	6	00:01:19
In0014	6	00:06:06
In0031	6	00:03:17
In0032	6	00:03:51
In0051	6	00:01:46

In0060	6	00:05:07
In0063	6	00:02:47
In0013	7	00:00:54
In0005	10	00:05:39
In0019	13	00:05:46
In0056	20	00:02:22
In0035	22	00:04:36
In0045	23	00:04:56
In0055	26	00:02:18
In0006	36	00:05:24
In0008	38	00:03:27
In0065	45	00:05:09
In0015	78	00:04:03

APPENDIX 13. AVERAGE VIDEO REMOTE INTERPRETING CALL DURATION FOR EACH

TABLET

Tablet ID	Number of calls made	Average call duration
In0001	3	00:05:08
In0002	3	00:11:23
In0003	1	00:11:31
In0005	1	00:06:03
In0006	2	00:04:11
In0007	1	00:04:44
In0008	1	00:04:08
In0009	1	00:06:48
In0011	2	00:06:10
In0014	2	00:05:02
In0015	4	00:05:04
In0016	3	00:09:35
In0017	4	00:07:59
In0019	11	00:11:51
In0029	5	00:11:10
In0030	1	00:04:00
In0031	1	00:05:37
In0032	2	00:06:18
In0035	1	00:04:55
In0037	3	00:09:08
In0038	2	00:09:47
In0040	1	00:14:33
In0041	3	00:11:44
In0042	3	00:16:33

In0043	9	00:09:27
In0044	1	00:04:49
In0045	3	00:10:09
In0049	4	00:05:36
In0051	1	00:05:31
In0054	1	00:41:22
In0055	1	00:05:31
In0057	2	00:05:11
In0059	1	00:08:54
In0060	1	00:12:14
In0061	2	00:06:49
In0064	1	00:05:55
In0065	2	00:10:39
In0073	1	00:04:51
In0074	1	00:08:54
In0075	1	00:07:52
In0076	2	00:06:48

APPENDIX 14. INTERVIEW GUIDES

Deaf participants focus group interview guide (questions with potential probes)

Project: InterpreterNow

Date _____ Time _____

Location _____

Interviewer _

Interviewees _____ ID codes _____

Consent form signed? _____

Cover notes

Notes to interviewees:

[A bit of information about yourself, your evaluation, your interest in the apps or working with Deaf people can put your participants at ease and see you as not just an “interviewer”]

- Introduction of interviewer to participants – I am Elizabeth, I am a PhD researcher at the University of Bath, I am conducting this interview as part of a larger project evaluating the InterpreterNow (tablets4health) service.
- Thank you for your participation. I appreciate your time and believe your input will make an important and valuable contribution to this evaluation and help to improve healthcare service for Deaf people.
- Confidentiality of anything you say is guaranteed - you will be given an ID number; you will not be mentioned by name in the evaluation

Purpose of the evaluation:

Find out about experiences and reflection of Deaf participants on InterpreterNow

Methods of disseminating results: lay language report available of final overall results for SignHealth charity

Warm up

Just to start off, what are your thoughts on using technology to help in healthcare settings?

Moving now to IN service specifically, what do you think the main purpose of IN is?

Main questions

Question	Probes	Alternative ways of asking questions
How did you find using IN?	What were the positive/negative experiences? How well were you able to communicate? What were the effects on Deaf _____ people's _____ (your) health/access/communication/knowledge? How appropriate is IN for healthcare interactions with Deaf people?	Could you please discuss your experience of using IN?
How did Deaf people (you) find using the mobile	Any particular features (icons) that were easier than others? Any features that you would get rid of? What did Deaf people	What would be your view on the Deaf

application and tablet?	use IN/tablet for? Did the mobile application work well? (Ease of use?)	people's use of the app?
What common issues and questions did the Deaf people (you) have?	If there weren't any issues, what do you feel went well? Or if you can't report any issues at all, how about any minor problems that you noticed? (What were the negative/positive things Deaf people said about InterpreterNow?)	Could you please tell me about the common issues and questions Deaf people flagged to you?
Do you have any suggestions for improving InterpreterNow?	Can you please provide more detail on that? What exactly do you mean by that....?	What would be your advice on improving IN?
How have you (Deaf participants) previously communicated in healthcare settings?	What do you think about using face-to-face British Sign Language interpreters (compared to the app)? What do you think about family and friends interpreting for patients? How easy is it to get a message across by writing information down? What is your favourite method of communication?	Could you please tell me about the communication methods that you've previously used with Deaf patients?
Could you please discuss your views on the locality of the British Sign Language interpreters?	What do you think about the fact that some participants and British Sign Language interpreters know each other? Why do you prefer/dislike this option?	What do you think of British Sign Language interpreters occasionally being known

to the Deaf
participants?

Supplementary questions

[The purpose of this is ask any questions the participants haven't answered]

How do you think IN helps Deaf people and healthcare professionals? [What are the benefits of IN?]

Exit question

Is there anything you'd like to share before we finish the interview?

Health professionals interview guide

Project: InterpreterNow

Date _____

Time _____

Location _____

Interviewer _____

Interviewee _____

Consent form signed? _____

Cover notes

Notes to interviewee:

[A bit of information about yourself, your evaluation, your interest in the apps or working with Deaf people can put your participants at ease and see you as not just an “interviewer”]

- Introduction of interviewer to participants – I am Elizabeth, I am a PhD researcher at the University of Bath, I am conducting this interview as part of a larger project evaluating the InterpreterNow service.
- Thank you for your participation. I appreciate your time and believe your input will make an important and valuable contribution to this evaluation and help to improve healthcare service for Deaf people.
- Confidentiality of anything you say is guaranteed - you will be given an ID number; you will not be mentioned by name in the Evaluation
- Note down the service of project workers

Purpose of Evaluation:

Find out about experiences and reflection of healthcare professionals on InterpreterNow

Methods of disseminating results: lay language report available of final overall results for SignHealth charity

Warm up

Just to start off, what are your thoughts on using technology to help in healthcare settings?

Moving now to IN service specifically, what do you think the main purpose of IN is?

Main questions

Question	Probes	Alternative ways of asking questions
How did you find using IN?	What were the positive/negative experiences? How well were you able to communicate? What were the effects on Deaf people's health/access/communication/knowledge? How appropriate is IN for healthcare interactions with Deaf people?	Could you please discuss your experience of using IN?
How did Deaf people find using the mobile application and tablet?	Any particular features that were easier than others? Any features that you would get rid of? What did Deaf people use IN/tablet for? Did the mobile application work well? (Ease of use?)	What would be your view on the Deaf people's use of the app?
What common issues and questions did the Deaf people have?	If there weren't any issues, what do you feel went well? Or if you can't report any issues at all, how about any minor problems that you noticed? (What were the negative/positive things Deaf people said about InterpreterNow?)	Could you please tell me about the common issues and questions Deaf people flagged to you?
Do you have any suggestions for	Can you please provide more detail on that? What exactly do you mean by that....?	What would be your advice on improving IN?

improving
InterpreterNow
?

What previous communication methods have you used before with Deaf patients?	What do you think about using face-to-face British Sign Language interpreters (compared to the app)? What do you think about family and friends interpreting for patients? How easy is it to get a message across by writing information down?	Could you please tell me about the communication methods that you've previously used with Deaf patients?
--	--	--

Supplementary questions

[The purpose of this is ask any questions the participants haven't answered]

How do you think IN helps Deaf people and healthcare professionals? [What are the benefits of IN?]

Exit question

Is there anything you'd like to share before we finish the interview?

British Sign Language Interpreters interview guide

Project: InterpreterNow

Date _____

Time _____

Location _____

Interviewer _____

Interviewee _____

Consent form signed? _____

Cover notes

Notes to interviewee:

[A bit of information about yourself, your Evaluation, your interest in the apps or working with Deaf people can put your participants at ease and see you as not just an “interviewer”. Use intro qs as warm up – get myself to explore/summarise their answers]

- Introduction of interviewer to participants – I am Elizabeth, I am a PhD researcher at the University of Bath, I am conducting this interview as part of a larger project evaluating the InterpreterNow service.
- Thank you for your participation. I appreciate your time and believe your input will make an important and valuable contribution to this Evaluation and help to improve healthcare service for Deaf people.
- Confidentiality of anything you say is guaranteed - you will be given an ID number; you will not be mentioned by name in the Evaluation
- Note down the service and areas where participants are from
- Approximate length of interview: 30 minutes, five major questions

Purpose of Evaluation:

Find out about experiences and reflection of interpreters/project workers on InterpreterNow

Methods of disseminating results: lay language report available of final overall results for SignHealth charity

Warm up

Just to start off, what are your thoughts on using technology to help in healthcare settings?

Moving now to IN service specifically, what do you think the main purpose of IN is?

Main questions

Question	Probes
How (in your experience) is InterpreterNow used?	For what purpose/service (p/s)? Why is it used more in this p/s? Why is this p/s more popular? What were the particular benefits for using InterpreterNow in this p/s?
Moving more specifically to your experience, what issues did you experience in delivering the interpretation for InterpreterNow?	What exactly do you mean by that....? If there weren't any issues, what do you feel went well? Or if you can't report any issues, how about any minor problems that you noticed?
How did you find the technology?	Did the mobile application work well? How was the connection? How the tablet (ease to use)? What sort of problems did you find? What were the largest problems? How often did

these problems come up? How did you overcome them? If there were no problems, do you have any suggestions for improvement?

How did you find the coverage? (In terms of interpreter numbers)

How do you overcome that issue? That's good, is there any way it could be improved?

How easy was the mobile application to use?

Any particular features that were easier than others? Any features that you would get rid of?

Do you have any suggestions for improving InterpreterNow?

Can you please provide more detail on that?

Supplementary Questions

[The purpose of this is ask any questions the participants haven't answered]

- How do you think the service helps Deaf people and healthcare professionals?

Exit question

Is there anything you'd like to share before we wrap up?