



“I WOULD LIKE BROADBAND ... LIKE EVERYONE ELSE”

THE ROLE OF HIGH-CAPACITY BROADBAND IN CONNECTING PEOPLE WITH LITTLE OR NO SPEECH AND GPs

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The authors present the findings of a small exploratory pilot study investigating how people with little or no speech communicate with General Practitioners (GPs) and whether there is any potential for high-capacity broadband to facilitate communication in this context. A focus group with four individuals with little or no speech and three interviews with GPs were conducted in Melbourne in 2011. Thematic analysis of the data collected indicated that the main challenges to effective communication were the time allocated to face-to-face consultations, patient frustration at being misunderstood, patients' experiences of communicating with GPs through receptionists and other staff, and GPs' understanding of the patient's unique communication needs. Factors said to support effective communication included having an ongoing relationship with a regular GP, allocating patients a longer appointment time-slot, and training in communication disability for all primary health care staff. Patients and GPs felt there was potential for the use of telecommunications, including high-capacity broadband, in this context but their views differed. Patients expressed a concern that broadband was not affordable and a desire to use email to communicate with GPs. GPs were open to considering the use of email in principle but expressed concerns about security of transmission, staffing infrastructure, determining urgency, and medico-legal constraints. The authors conclude that research surrounding the future of telehealth must be firmly grounded in the needs of the user (patient/GP) and the communicative function the technology is designed to enable. Further rigorous research on this topic is needed.

INTRODUCTION

This paper documents a small exploratory pilot study funded by the Institute for a Broadband-Enabled Society (IBES). The authors explore the role of high-capacity broadband in connecting people with little or no speech (LONS) with General Practitioners (GPs) and present the findings of a focus group and three interviews with participants from both of these populations. Conclusions are then drawn about the issues surrounding communication and the role of Internet technology in this context.

BACKGROUND

The federal government announced in 2009 that it would fund a national network connecting Australian premises to a high-capacity broadband service ([NBNC0 2011](#)). One of the central justifications was the capacity to provide sophisticated and reliable applications for Internet-based healthcare. High-capacity broadband could facilitate communication among and

between patients, health professionals and health services, addressing issues of access, availability, workforce distribution and distance. The National Broadband Network (NBN) is expected to help patients overcome barriers including distance, cultural and linguistic differences and disability. While some services already exist, such as the National Relay Service (NRS), “a phone solution for people with hearing or speech impairment” ([NRS 2011](#)), they face unmet challenges that need to be addressed.

While most Australians interact with the health system by a visit or two to a GP each year, there are many with complex needs who engage with a wide range of healthcare providers. Many people with and without disabilities require regular access to health services and in some cases people with disabilities experience a number of additional barriers and access issues.

One in seven Australians has a communication disability ([Speech Pathology Australia 2011](#)). Some of these individuals experience difficulties with the physical production of speech sounds (expressive speech), which may be due to a physical impairment such as Cerebral Palsy. In some cases people may only be able to produce a little unintelligible speech. The authors refer to this population as having little or no speech (LONS). Research has shown that people with LONS due to a physiological disability can experience sub-standard care due, directly or indirectly, to their disability ([O'Halloran, Hickson et al. 2008](#); [Aulagnier, Verger et al. 2005](#)). This research aimed to explore the potential of high-capacity broadband to facilitate communication between people with LONS and health professionals, specifically GPs.

LITERATURE

A narrative literature review was conducted with the aim of exploring what is currently known about:

1. communication needs in healthcare,
2. the standard of healthcare provided for people with a disability, particularly those with LONS and their interaction with their GP, and
3. the use of technological solutions that enable communication in healthcare ([Greenstock and Wickham 2011](#)).

These aims involved a number of overlapping and interrelated areas of research which would inform a small pilot study. A number of studies concluded that communication is a critical part of healthcare and that breakdowns can have severe consequences for patient safety. For example, in a review of surgical malpractice cases, 60 out of the 444 cases, 13%, were found to be related to an incidence of communication breakdown ([Greenberg, Regenbogen et al. 2007](#)), indicating the severity of the costs of poor communication.

Receiving meaningful communication that is “open, timely and appropriate” is a formally acknowledged right for patients in Australia ([Australian Charter of Healthcare Rights 2010](#)), yet there are a number of patient groups for whom communication in this context is challenging. People representing linguistic minorities and people with communication disability may be among those most at-risk of communication breakdown in healthcare ([Balandin, Hemsley et al. 2007](#); [Greenberg, Regenbogen et al. 2007](#); [Smith 2009](#)). Research has shown that persons with disabilities are at “an increased risk of experiencing ineffective patient- physician communication” ([Smith 2009](#), 206). Healthcare professionals can be misled by their perceptions and misunderstandings of disabilities ([Addington-Hall and Kalra 2001](#); [Aulagnier, Verger et al. 2005](#)), which can result in difficulties in accurately understanding the patient’s communication needs. The impact on these patients can be significant and there is also evidence to suggest that these populations “use primary preventive health services less than general populations ... have poorer overall health outcomes ... more preventable emergency room visits and hospitalisations ... and they report more unmet needs and dissatisfaction in the services they do receive” ([Hwang et al. 2009](#), 28). Patients with disabilities may be most at risk of “injury through neglect, delayed diagnoses, or inadequate

treatment” ([Kirschner, Breslin et al. 2007](#)). Patients with disabilities report a poorer standard of care ([Balandin, Hemsley et al. 2007](#); [Nieuwenhuijsen, van der Laar et al. 2008](#)).

People with LONS suffer from an inequity of access to the higher level of quality healthcare that most non-disabled Australians take for granted. There is evidence to suggest that access to healthcare for this cohort is even poorer than that of the broader disabled population, and that their health and right to actively participate in decisions about their healthcare can be directly compromised ([O'Halloran, Worrall et al. 2009](#), 601).

The existing literature indicates that people with communication disabilities are at risk of substandard care and adverse events, possibly even resulting in harm or maltreatment. Very little literature was identified which explored these risks in any detail or identified possible ways to address this issue, other than having a family or caregiver present in consultations ([Aulagnier, Verger et al. 2005](#)). Many patients with LONS depend on specialised equipment to overcome their difficulties with speech. This equipment ranges from relatively low-tech (e.g. electronic ‘pads’ that speak aloud typed symbols) to very high-tech (technology exists that is able to respond to the tiniest muscle contraction).

Though these technologies exist in a health care context the communicative preferences of the patient may come up against a lack of appropriate infrastructure and varying levels of adoption by health professionals, and other staff. There is very little research on this topic.

Despite the complexity inherent to the sector, there are examples that demonstrate technology’s capacity to contribute to better healthcare. Ehealth has been conceptualised as a broad overarching move towards increasing and improving the role of electronic systems in health. A major review by the Swedish Ministry of Social Affairs entitled “eHealth for a Healthier Europe” concluded that the application of ehealth in actual clinical settings improved patient safety and clinical efficiency and reduced costs ([Gartner 2009](#)). For example, electronic systems reduced duplicated laboratory tests, reduced hospital admissions through the use of telehealth home monitoring systems and reduced prescription errors.

To be more specific, telecommunication technologies afford significant opportunities for LONS patients, particularly in situations when it is possible to provide healthcare at a distance. However, telehealth models of care appear to be under-researched and so there is little to inform the development of strategies that would empower patients to engage with healthcare professionals. Many telehealth solutions rely on a suitable standard of Internet connection. Current research indicates that this is another barrier to redressing the inequity of access. [Amichai-Hamburger et al. \(2008\)](#) referred to the ‘disability divide’ in Internet access and use and there is evidence to suggest that people with disabilities are less likely to have an Internet connection at home or use a mobile phone ([D'Aubin 2007](#); [Amichai-Hamburger, McKenna et al. 2008](#)).

METHODOLOGY

The research was given full ethical approval by the Human Research Ethics Committee at the University of Melbourne (reference number 1034339.1).

The research adopted an exploratory qualitative study design and utilised an inductive approach in the collection and analysis of data. A combination of one focus group and three one to one semi-structured interviews were used.

Participants

Participants were recruited from two population groups identified in the sampling criteria below.

Population Group 1	People who meet the following criteria: Have little or no speech (self report) (focusing on individuals with Cerebral Palsy and Acquired Brain Injury) Use or have used the Internet (self report) Live in Victoria
Population Group 2	People who meet the following criteria: General Practitioners who have, or may have, patients with little or no speech (self report) Use or have used the Internet (self report) Live and work in Victoria

Figure 1 – Sampling criteria

The population of individuals with LONS were identified by Communication Rights Australia, an organisation that has professional links with, and provides advocacy, for a number of these individuals. It initially identified potential participants for Population Group 1 (people with little or no speech). A number of individuals with LONS had previously consented to sharing their contact details with Communication Rights Australia prior to this study. A representative from Communication Rights Australia sent the initial project information to individuals meeting the sampling criteria. Contact details were not shared with the researchers or any third party. Participants sent a return email to Communication Rights Australia indicating they are interested in taking part.

After responding to the advertisement through Communication Rights Australia, participants with LONS were invited to take part in a focus group. The four participants took part in a focus group two hours in length, which was audio and video-recorded with their full informed consent. Chief Investigators followed a framework of questions (see Appendix 1) and ensured all participants had the opportunity to respond. Two participants spoke unaided during the focus group, one used a communication aid (a Polyana Communication Device supplied by Technical Solutions Australia) in addition to unaided speech, and the fourth used speech interpreted by a facilitator (the CEO of Communication Rights Australia). Participants were reimbursed for their travel costs and were remunerated with a sitting fee for their time and participation.

For Population Group 2, an advertisement was simultaneously sent to GPs via the Victorian Primary Care Practice-based Research Network (VicReN) coordinated by the Department of General Practice at The University of Melbourne. GP members of VicReN received information about the project by email. There was no response from GPs to this advertisement. One of the Chief Investigators was employed by, and positioned at, General Practice Victoria. The advertisement was then sent to GPs using a weekly bulletin operated by GPV. Three GPs made contact as a result of sending the information out through this medium.

Two interviews were conducted over the phone and one was conducted face to face at the GP clinic in the suburbs of Melbourne. The Chief Investigator followed a framework of questions (see Appendix 2) and encouraged participants to speak openly about their experiences surrounding the interview topics. Interviews were audio-recorded with the full informed consent of the participant.

The focus group and interviews were transcribed and anonymised. Transcripts were then thematically analysed with the support of QSR NVivo data management software. Coding was discussed by the researchers and meanings were negotiated to ensure inter-rater reliability. The most prevalent nodes were developed into themes and passages were extracted.

FINDINGS

Four main themes arose in the interviews. In descending order of prevalence, these were:

1. communication in health care,
2. disability awareness and training,
3. the Internet and email, and
4. patient-centred care and continuity of care.

1. COMMUNICATION IN HEALTH CARE

All of the participants placed a great deal of importance on the ability to effectively communicate in their interactions with a GP or a patient. Communication in the General Practice health care context was seen to be of critical importance.

GP1: [communication is] critically important, that's what makes people doctors as opposed to vets isn't it [laughs]?" (GP1)

All of the GPs and patients interviewed had experienced the complexities of patient-doctor communication when the patient was experiencing communication difficulties. The presence of difficulties with expressive speech was not seen as an insurmountable barrier to effective communication. Factors supporting doctor-patient communication were related to **who** was communicating with whom, **what** was being communicated, **where** the communication was taking place, **why** the communication was necessary, and **how** the message was being communicated.

Outside of a face-to-face consultation, patients were largely making contact to request an appointment or ask a question based on a health concern. During the face-to-face consultations the length of the appointment was sometimes seen as an issue.

"a lot of extra time is required to be able to give that person the full attention and do everything that you need to do within a consultation The biggest challenge is having allocated enough time" (GP3)

Communication between patients and GPs took place at various locations. Most often patients initiated contact from their home via the telephone or went into the clinic to make or attend an appointment. Similarly, GPs were almost always in the clinic at their current place of work when communicating with patients with LONS. Most frequently, patients made contact with the GP, via the clinic receptionist, in order to request an appointment. Messages were communicated between patient and GP using a variety of methods or communication modes and channels including: standard telephone calls, text messages (SMS), written notes, paging, email, fax and the National Relay Service (NRS). In many cases a blend of these communication channels was used to meet the needs of the patient and the GP.

"for somebody with expressive difficulty, there is a range of techniques that we would use" (GP2)

Face to face verbal communication was commonly referred to by all of the participants but patients and GPs alike had experienced difficulties with this, mostly relating to the patient's difficulties with expressive speech.

"Hopefully I can make myself understood but my speech quality varies considerably" (FG3)

Telephone also held the same challenges of negotiating meaning as were experienced when communicating verbally face to face. Several of the patient participants had received information about appointments with the GP by SMS/text message but several of the GPs raised concerns about the accuracy and interpretation of the message contained within a text and the difficulty in clarifying the intention of the message.

“generally we make an appointment ... and the day before they will send a text to confirm” (FG2)

“It’s all very well for people to text, but if they don’t text the practice appropriately for somebody that’s going to answer them then they’re wasting their time” (GP1)

Diagrams and visual systems were sometimes linked to communication aids used by some individuals with communication difficulties. Two of the patient participants were interested in the idea of a diagram designed to allow patients with difficulties with expressive speech to point to a picture of the human body and indicate what type of symptoms they were experiencing.

“that diagram idea ... if you could put that up on an interactive Website that would be terrific ... you would have to have the GP at the other end ... you could just mouse click wherever you were feeling pain” (FG1)

Email was raised by many interviewees and has been developed into Theme 3 (see below).

2. DISABILITY AWARENESS AND TRAINING

Patient participants spoke in detail about their experiences of how well- or un-trained health professionals were in the area of disability awareness. Understanding the nature of various ‘types’ of communication disability was an issue that some patients and one of the GPs felt was lacking for some health professionals. In particular, the sensitivity of the differences between individuals with expressive and receptive language difficulties was mentioned by several of the participants, patients and one GP.

“A lot of GPs don’t understand or haven’t thought about the differences in receptive and expressive abilities” (GP2)

Two of the patient participants expressed a great deal of emotion relating to interactions they had had with medical professionals in the past. In several cases, they had been offended by being judged as intellectually disabled because of their speech.

“ ... their (GPs) education seems to be on prescribing or picking bones ... surely you can teach a bit of bedside manner before you let them loose on the public” (FG1)

Patients’ experiences of receptionists and ‘gatekeepers’ indicated that training and improved disability awareness were important for these professionals as well.

“the attitude of some Receptionists in General Practice that seem to regard themselves as gate keepers and ... getting past them to the Doctor can be pretty confrontational as well” (FG1)

“The receptionist is the front person, the first port of call. Sometimes, far too often, receptionists probably don’t get the kind of induction and in-service training that they really need in order to play that important role, particularly for vulnerable people” (GP2)

3. HEALTH, THE INTERNET AND EMAIL

Having discussed the factors influencing communication between GPs and patients with LONS, participants were asked to explore their thoughts and experiences of the role of the Internet in facilitating these interactions and the transmission of information between the patient and GP. The two major themes that emerged were email and online teleconsultations. Email was more of a prevalent theme among the patient participants, while GPs discussed the concept of online teleconsultations.

“With this new broadband ... they're talking about the possibility that it's going to be like having somebody virtually in the room with you ... that sort of scenario ... would make it ... more realistic, for people, the health professional and the patient” (GP3)

GPs expressed caution overall at the notion of ‘replacing’ face to face consultations with online consultations and suggested that some of the same issues would remain, for example, needing longer consultations if the patient has a communication difficulty. GP2 felt strongly that online consultations should not become the standard for people with disabilities as this may contribute to further social exclusion.

“You’ve got the same time issues face to face as you would on a video conference type thing. But I don’t think that would ... make it better or worse. But it might make it easier at the other end (patient end)” (GP1)

“One wouldn’t want to see people with disabilities sort of always having these teleconferences instead of seeing their doctor in person” (GP2)

In contrast to GPs, patients did not raise the concept of online consultations and did not outwardly express a link between having mobility difficulties and seeking an alternative to face-to-face appointments at the clinic. This finding may be partially related to the patients’ concerns about the affordability of broadband, which was a theme within the data.

“I think at least three of us here are on Dial-up ... if you are on Dial-up you can sit there for 10 minutes waiting for it to load” (FG3)

“I would like Broadband. Like everyone else” (FG1)

“[I would like] broadband ... to be able to use it to send a message to ... local GP” (FG2)

Patients’ conversations about the role of the Internet in facilitating communication with GPs were primarily related to the increased role of email. All four patient participants were very interested in using email to send and receive messages from their GP and other health professionals for various communicative purposes. Initiating contact and making appointments was the main circumstance in which this would apply. For patients with communication disability the benefits of using email was that they could compose a message in their own time and could read and check the message they had composed.

“Maybe it would have been better if I could have emailed the specific Doctor” (FG2)

“I find it easier if I email the relevant ... I ... express myself better in email” (FG4)

GPs were generally in support of using email in principle but expressed concerns about the security of email for sensitive health-related information, their medico-legal rights.

“We could have an exchange of e-mail without any difficulty at all ...” (GP2)

“There’s no reason why we couldn’t set up an email but we don’t want an open slather” (GP1)

A concern for GPs was the lack of existing infrastructure and appropriate staffing arrangements to support email communication with patients. It was generally agreed that an email system would require a dedicated member of staff attending to the emails being received at all times.

“if it was going to be something that somebody used where they required an immediate response, you’d need to have something set up so if you weren’t there somebody else could take that email” (GP3)

A further concern for GPs was the negotiation of the urgency of the information contained in the email, which, it was argued, would be difficult to determine through purely the email content.

“it would be quite hard for a receptionist to work out from an email sometimes the urgency of it” (GP2)

This would largely relate to who was receiving the email, for example, the doctor at the clinic would be more appropriately trained to further explore the urgency of the matter.

“it’s not going to work in an emergency situation or an urgent - I need an appointment today situation. But it might work I need an appointment within the next two weeks to have my blood pressure checked and repeat some prescriptions” (GP1)

Patients also reported problems with using email in a health care context. Several of the patient participants had experienced emails ‘bouncing back’ and in several cases there was a delay in receiving a response, which further supported the GPs’ concerns about addressing the urgency of the matter.

“I have actually had a problem twice and it hasn’t been the message but it has been the over-zealous filter ... you don’t expect them [emails] to bounce with a Health Service” (FG1)

“my email will bounce, I keep trying and trying” (FG4)

Some GPs had concerns about the medico-legal factors involved in using emails and expressed caution over adopting an email system in dealing with patients.

“I guess with using email, my first response would be to check with my medical defence organisation” (GP3)

4. PATIENT-CENTRED CARE AND CONTINUITY OF CARE

There was a general consensus among the participants that having a regular GP was best for ensuring continuity of care and learning the best way to communicate effectively so that the patient’s needs are met. GPs made clear that they prefer to ‘know’ something about the patients they meet and the more detailed this information the better. This was also the patients’ preference.

“I have known my GP for 20 years and go there every month ... He drops in every month. ... I deal with him directly ... He knows my communication” (FG4)

“I think it is important to keep the same GP as far as possible but at the same time as well as keeping a good relationship” (FG3)

One of the reasons that GPs and patients favoured the development of a continuous patient-doctor relationship was the time taken to negotiate meanings and ensure that both conversation partners have been able to make their meanings understood.

“Most of the time I think we end up with the right answer but it takes a longer to get there” (GP1)

DISCUSSION

This research found that patient-doctor communication is central to patient satisfaction. The patients in this study did not appear to interpret their experiences of healthcare as ‘substandard’ but expressed some strong opinions about the training of GPs and other professionals in understanding types of disability. The most severe ‘adverse events’ reported were related to insensitive assumptions about the nature of the patients’ abilities or disabilities, namely a health professional assuming that a patient has an intellectual

impairment. Patients who had interpreted a GP's style of communication as insensitive or disrespectful appeared distressed by this experience.

GPs in the study appeared committed to accommodating the communication preferences of patients and adhering to the Charter of Healthcare Rights for communication in healthcare. All three GPs, however, were very cautious about the constraints of infrastructure, staffing and legal factors. There was a slight mismatch in how patients wanted to communicate with GPs and what GPs thought was currently 'possible' or 'allowed'.

All four patient-participants appeared to have developed ways to navigate the health system effectively by developing a relationship with a GP. Having a regular GP who was familiar with their communication preferences was one such strategy. The research found that patients and GPs are frequently flexible in negotiating how to communicate and would be open to considering the role of high-capacity broadband and other technologies. The execution of any form of broadband-facilitated communication would depend upon the patient being able to afford the technology and installation, and the health setting having a staffing, infrastructure and legal framework in place.

LIMITATIONS

This study had a number of limitations relating to its size and duration, the researchers' understanding of the needs of the research populations, and the lack of conclusive evidence on which to base future testing of broadband solutions. In the future the researchers would endeavour to collect baseline quantitative data about access to broadband technology in the research populations to guide the formulation of research projects grounded more fully in the needs of the research populations.

CONCLUSION

In conclusion, all patients deserve access to the same level of health care. Communication is an essential component of effective healthcare, yet patients with LONS are often disadvantaged by barriers to communicating with healthcare professionals and from the misunderstandings often propagated within the healthcare setting. This study suggests that when communication is not optimal, both healthcare providers and patients must make allowances and develop suitable methods for overcoming the deficiencies.

Technology has been shown to improve health care, but the mere existence of technological infrastructure does not intrinsically guarantee benefit. Great care must be taken to design and develop solutions that will appropriately and suitably address the needs of specific patient groups. The design process must include consultation with all stakeholders, particularly the patients and clinicians who are the ultimate users of ehealth systems.

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APPENDIX 1 – FOCUS GROUP TOPIC GUIDE

Focus Group 1 – Participants with little or no speech Topic Guide

Introduction

Ethical considerations: How the reference group will operate

Aims of the reference group

1. Participants with little or no speech are invited to say a little about how they make contact with their GP and how their GP makes contact with them
Comments/discussion invited
2. Participants with little or no speech asked to talk about the challenges they have experienced in making contact with their GP
Comments/discussion invited
3. Participants with little or no speech asked to talk about what would make it easier for them and what would be their preferred method of making contact
Comments/discussion invited
4. Participants are asked about their experiences of using telecommunications in their communications with GPs
Comments/discussion invited
5. Participants invited to discuss their thoughts about the role of the internet in connecting them with GPs
Comments/discussion invited
6. Further discussion of the points raised
7. Researcher summarises key points and shares with group to confirm
8. Final comments

APPENDIX 2 – GP INTERVIEWS TOPIC GUIDE

Focus Group 2 – General Practitioners

Topic Guide

Introduction

Ethical considerations: How the reference group will operate

Aims of the reference group

1. GP participants are invited to say a little about how their patients with little or no speech make contact with them and how they make contact with their patients
Comments/discussion invited
2. GPs asked to talk about the challenges they have experienced in making contact with their patients with little or no speech
Comments/discussion invited
3. GPs asked to talk about what would make it easier for them to make contact with their patients with little or no speech and what would be their preferred method of making contact
Comments/discussion invited
4. Refer to key themes from focus group 1 and ask participant to respond
5. Further discussion of the points raised
6. Researcher summarises key points and shares with group to confirm
7. Final comments

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