Bold Shield

Focus Groups Report V2.0

Work Package 3 and 5

Deliverables D13 and D14

Relevant Other Deliverables: D6 and D12

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Executive Report

The Background

There are a number of vulnerable groups in the health care system in the UK. For them, access to social care and health care is rather more complex than a telephone call to care worker or health professional. One "group" are those who are termed "learning disabled". This project focuses on their needs and how to address them in a way which through technology may improve their quality of life … and reduce the strain on society in general.

However, it is quite difficult to obtain a meaningful consensus on what "learning disability" actually means.

The following description is perhaps one of the better ones:

Adopted by the Learning Disabilities Association of Canada January 30, 2002

Re- endorsed on March 2, 2015

Learning Disabilities refer to a number of disorders which may affect the acquisition, organization, retention, understanding or use of verbal or nonverbal information. These disorders affect learning in individuals who otherwise demonstrate at least average abilities essential for thinking and/or reasoning. As such, learning disabilities are distinct from global intellectual deficiency.

Learning disabilities result from impairments in one or more processes related to perceiving, thinking, remembering or learning. These include, but are not limited to: language processing; phonological processing; visual spatial processing; processing speed; memory and attention; and executive functions (e.g. planning and decision-making).

Learning disabilities range in severity and may interfere with the acquisition and use of one or more of the following:

• oral language (e.g. listening, speaking, understanding);

• reading (e.g. decoding, phonetic knowledge, word recognition, comprehension);

• written language (e.g. spelling and written expression); and

• mathematics (e.g. computation, problem solving).

Learning disabilities may also involve difficulties with organizational skills, social perception, social interaction and perspective taking.
Learning disabilities are lifelong. The way in which they are expressed may vary over an individual's lifetime, depending on the interaction between the demands of the environment and the individual's strengths and needs. Learning disabilities are suggested by unexpected academic under-achievement or achievement which is maintained only by unusually high levels of effort and support.

Unfortunately, for much of the time, in the UK, LD is associated not with these competences but rather with the extent of service provision and care offered to that individual. Attempts to reach self-determined description are often hampered by the service provision itself. BoldShield was set up specifically to address this weakness ie to attempt reach a user-centred design for video technology intervention which would increase independence and improve quality of life.

The Project

The project aim which is set out in the SBRi contract, was threefold:

• to extend the successful Sandwell LD greater independence project[1] to include healthcare;

• to extend the combined offering to include location and improved security;

• to extend the combined service to include deaf people in order to identify the benefits of enhanced communication provided by video communication and the challenges of integrating third party services.

The objective was to undertake user-centred design together with service re-design leading to a small-scale feasibility (not clinical) trial of a service and technology implementation and dissemination.

Deaf Studies Trust (DST) was engaged to provide a Deaf perspective on current and potential future products. DST collected data through focus groups on the current means of access to health care and the potential of technology to improve that access, provide efficient health servicing and to achieve cost savings. The starting point and workplan for DST involved an approach which invoked Personas and Use Cases (see DST – Deliverable D12).

In May 2015, a total of 20 Deaf people took part in focus groups which posed questions concerning current access to health care, aspirations for access to health and social care and reactions to the possibilities of the V-Connect system. All of the participants can be considered to be disenfranchised from the health care systems and 13 were already receiving social care and help with independent living (ie had an individual care plan) and were either in a sheltered housing location or were in the community.

Analysis of the video recorded sessions indicated:

    (a) Deaf people have no direct means to reach help in the case of a personal health problem. They have to "hope for the best", hope that the problem will go

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[1] This project provided a video link through a set top box between those with learning disabilities and carers.

away or else wait until there is a hearing person who can intervene on their behalf

(b) Few of the participants expressed confidence in the provision of text information and some specifically reported personal health issues arising from their inability to read leaflets or instructions regarding medication

(c) Most of the participants view interpreting provision as the solution – whether live on-site or through relay services online

(d) Total Conversation – video, voice and text – is the telecoms standard which Deaf people prefer for person to person and person to relay conversation

(e) Devices which might help deaf people independently to monitor their own health characteristics were welcomed with enthusiasm

(f) Data Security and Protection of Identity are *non-factors* for Deaf people since those have long been removed from their control (ie since childhood); however, they were keen to have some personal and private passwords or codes which would identify care workers or health staff and which would allow themselves to be identified.

Conclusions

Deaf people considered themselves disabled by society's (in our case, health and social care systems') inability to communicate. Where there is an additional learning disability of an intellectual nature (whether caused by language deprivation or by cognitive difficulties), it has proved hard for the individuals to express meaningful aspirations for their own interaction with health care.

LD BoldShield Introduction

User-Centred Design, Service Redesign and Technology Redesign in Support of LD Clients

The goal of the project entitled Bold Shield (as contracted) was to

> *"generate a framework for engaging users of assistive technology who have both learning disabilities and are deaf in user-centred design that results in real system change."*

> *"A key outcome was to develop a framework for the evaluation for the phase 2 when services are deployed to clients at scale. It will be necessary to evaluate the impact on the current ways of delivering care as well as the effectiveness of user-centred design on technology implementation. There will need to be system benefits but the goal of the project is to understand what clients value and how they would want to be supported. More specifically this framework will set out:*

> - *How to engage LD clients and their carers in user centred design.*
>
> - *How to translate the user centred design approach into technology evolution and service redesign.*
>
> - *How to evaluate in a way that is meaningful both to the system and to the design process itself.*

> *"The impact of phase 1 will be to provide the team with a much better understanding of how clients and the carers want to be supported and how a technology platform could evolve to support this.*

Learning Disability

This proves somewhat difficult to define and there appear to be two differing perspectives: the first examines the capabilities of the individual and their participation in society; and the second considers the extent of provision required as determined by assessors (gatekeepers), in order to establish a "perceived" minimum quality of life. The assessors are usually persons who do not have learning disabilities nor have ever experienced the condition of being learning disabled. The first definition links to user-focused models and the second invokes systems-focused models. Inevitably the system focused view references extent of provision and from there, the financial resource needed. Many of the concerns about learning disability stem from the second model and are driven by issues of finance.

User–centred design draws on the first model and is likely to challenge the second model at many points.

Deaf People

Deaf people are those who are born with a hearing loss or who acquire a hearing loss early in life, who are likely to have experienced special provision in education on account of their hearing loss and as young adults are likely to have identified with other Deaf people. They will prefer to use sign language (in the UK, British Sign Language) and identify themselves as members of the Deaf Community. As a result of current policies and practices in education (see Kyle and Ladd, 2009) they are likely to have difficulties in spoken and written English. It is also the case that many having been deprived of BSL at an early age, develop learning disabilities arising from this language deprivation. It is also true that a larger percentage of those born Deaf (than of the 'mainstream' population) have additional difficulties of a physical, sensory or intellectual nature. The Deaf Community is not separated geographically from the rest of the population as most Deaf people (a) are born into hearing families, (b) when married to other Deaf people, will have hearing children and (c) will live and work in the community as a whole. A sub-group of Deaf people will require specialist support as adults and will have individual care plans. Some of these will live in the community and others will be found in sheltered and supported living circumstances. All Deaf people will experience exclusion and disenfranchisement from hearing society as a result of their different language choice (sign language rather than spoken language).

In this study, Deaf Studies Trust has met with and discussed with those in sheltered accommodation, those supported in the community and those who live independent lives in the community.

Deaf Health

Deaf people are known to have difficulties in *access* to health services, but there has been a lack of research evidence concerning their health *outcomes*. However, between 2011 and 2014, Deaf Studies Trust participated in a national comparative study of Deaf health.

Priority health concerns for the adult population of the UK are highlighted in the Health Survey of England (HSE 2010 and 2011), and include cardiovascular disease, hypertension, diabetes, obesity, respiratory and mental health problems. These create a major strain on the National Health Service and have received considerable attention as decisions concerning resource allocation become more complex. The quality of service provided (particularly by GP practices), has also come to prominence. It is also the case that minority groups, and linguistic minorities in particular, pose special problems for practitioners in consultation, diagnosis and treatment.

An indicative sample of 300 was planned, stratified by age and gender and ethnicity to reflect the overall UK population at the 2011 census. These Deaf sign language users completed health assessments at Bupa centres in Bristol, London, Brighton, Solihull, Nottingham, Manchester, Cardiff, and Glasgow. In each session they were accompanied by signing Deaf advisers and BSL interpreters. The structured health assessment consisted of the standard well person health check provided by a Bupa health adviser and an interview with a Deaf adviser (to collect data on use of GP

services) which would allow direct comparison with health survey data for the general population, using routinely collected GP data in England (eg the GP Patient Survey - GPSS).

The health assessments showed significantly higher rates than the general population of obesity, and hypertension. Many of the Deaf participants were unaware of the health problems they had and most seemed unclear about the implications of the problem, the nature of their treatment and the prognosis.

Deaf patients reported difficulties in accessing primary care, seeing the doctor they wanted, and in communicating with doctors. Compared to the general population Deaf people expressed greater dissatisfaction with their interactions with doctors. Some positive views of GPs were expressed when relationships had been built up over a long period of time. However, Deaf people have lower levels of trust in the doctors they see, compared to the patients in the general population.

In spite of some improvements in the availability of BSL interpreters, many barriers remain for the Deaf community in accessing health care. The role of the interpreter in the three-part consultation is not resolved clearly and there is limited awareness on the part of Deaf people of how an interpreter could be part of the development of "cultural competence" in the practitioner in delivering the health care.

Deaf health is a pressing problem; access to health care is a significant issue.

Deaf Telecommunications

Interestingly, solutions to communication at a distance and in contact with hearing people have existed for some time. As early as 1997, DST was involved in providing videophone solutions to Deaf users in Bristol and in other parts of the UK. National video relay services have existed in the USA and Sweden for over 15 years. The need has been recognised at the level of the European Union.

REACH112 (2009-2012) was a project of implementation of the telecoms solution based on the European standard of Total Conversation. This implementation was designed to make telephony accessible to all those people who have difficulty with voice phones. This is at least 3.5 million people across the EU. REACH112 was set up in five countries with over 7,500 registered users. In REACH112 users were able to call each other (in video, voice and text mode), reach voice phone users through relay services and make calls directly and through relay to emergency service centres. The service has been developed on all platforms: videophones, textphones, PC, Mac, notebooks, tablets and smartphones, as well as simple web browser plug-ins. Developments from this between 2012-2015, used a downloadable app (MyFriend) for iOS, Android and as a web-browser plug in. This technology supported nearly a million Total Conversation Calls and 125,000 relay calls in one test period of 12 months. Sadly, despite Welsh Government support, the cost of the sign language relay service (potentially £1m per annum) was not embraced by the UK government and as a result the technology (developed in the UK) is now used from the UK to support Deaf people in the USA; where it currently supports over 1 million minutes of video relay each month.

We have the technological solution to provide inclusive services to Deaf people but not yet (in the UK) the will for implementation on a national scale.

The Project work – Focus Groups

The framework for project work in regard to user-centred design is set out in the DST contribution to D6 (see the paper D6: Deaf Focus Groups Procedures).

Several pilot sessions were conducted prior to group sessions with Deaf people (LD) in sheltered accommodation (2 sessions), Deaf people (LD) in the community and Deaf people in mainstream. Sessions lasted between one hour and two and a half hours. All sessions were conducted in sign language by a Deaf moderator and were video recorded and annotated by a Deaf researcher/observer. All participants were supplied with project information sheets (Appendix 1) and these were also explained in sign language. All participants signed the consent forms (Appendix 2). All sessions used the themes as shown in Appendix 5 as stimulus questions. The second part of each session was devoted to hands-on and explanations of the potential technologies.

The users are as described in Table 1.

Table 1: Participants in the Focus Groups

Participants	Group	Number	Age Range	Gender	Other characteristics
Deaf LD – in accommodation	LD-A	8	21-43 years	3M; 5F	All need support worker for translations; various health problems
Deaf LD in the community	LD-C	5	44-54 years	3M; 2F	All need support worker; have care plan; live in the community
Deaf mainstream	D	7	35-70 years	3M; 4F	5 in employment; various health issues – tumour, cancer, ulcer

Analysis

An initial analysis of the primary themes in each section: current experiences, preferred systems for access and responses to technology is provided here.

Current Experiences

A: Information access – text/leaflet/letter/video

The general view was that leaflets were inaccessible. Half of the LD-A group said they would have to ask their support worker to understand what was in a health leaflet. Most of the LD-C said they threw away the leaflets and also mentioned in passing, that it was not acceptable to have a child in the family to "interpret" the details (a suggestion made by one person in the D group).

None of the LD-A nor the LD-C participants were aware that there were information videos in BSL. In the D group when this was raised, three participants were not aware there were resources like this.

B: You feel ill – need medical attention

Much of this section was taken up in discussing contact with the GP. The responses confirmed what we had already known from the Deaf Health project: Deaf people have little faith in the interaction with doctors. From the D group:

> *I always use interpreter as my GP prefers that way. Once there was no interpreter or a duty GP there, it is difficult. I don't really understand when GP thinks I do. I would be very suspicious of different tablets. (Female, 70 years)*

> *Happened to me, about tablets. Interpreter was there. I really valued it, when she explained what tablet was for. I said it's wrong. It affects me. They thought xxxx I said 'no its blood pressure'. It's part of the tablets review every 3-6 months. (Female, 55)*

> *GP prefers to talk, I could not lip-read. (Female, 58)*

The LD-A group described situations where the promised interpreter was not there (probably due to the Health Centre forgetting to make the booking). Everyone (in all groups) pointed out that there was no provision in an emergency. This led in all cases to frustration and confusion. There was no effective access. This could have very serious consequences. One LD-C participant said:

> *"I was walking home with my husband, late in the morning, he was struggling to walk and unable to breathe properly. I was frightened to leave him so I tried to drag him home. Once we were home my husband collapsed. I ran upstairs and had to wake up my hearing son for him to contact the paramedic. This had a profound effect on the family" (Female, 49)*

The impact of lack of access is felt by all of the family.

C: At home – need help

Perhaps the most taken for granted service in the community is the possibility to reach a health advisor or practitioner at all times….. by voice. The LD-A group agreed that they had to wait for a support worker to call on their behalf. In the LD-C group, the majority would relay on a hearing member of the family – even a child under 16 years

old. Commonly they would text the family member and ask them to make an onward call for help. In the D group, participants explained:

I use Face Time with my daughter to contact GP/Surgery (Question: if daughter not there?) Big PROBLEM (Male, 70)

I use WhatsApp to my Family group, where all my children share. They phone for me. (Female, 55)

If I ask my son, I lose my privacy. It is DIFFICULT. I did leave it out, it was about WRONG tablet makes my HEART beat fast. I cried… so I TYPETALK [textphone – relay] my surgery to ask GP to see me. Was told to use 111 - all CONFUSED via TYPETALK . I GAVE UP and was upset. (Female, 70)

There were many seriously bad experiences described by the D group:

Was ill on arrival at work. Got to my surgery, reception sent me to see a Dr. Friend had to take me to hospital, there Dr waited for me. TOOK AGES to find out what wrong with me. Others in the ward had an operation, not me. I had a 10-pint blood transfusion for my burst ulcer. (Male, 70)

*I wish they could be ALERTED for any injury. e.g. my dislocated shoulder. I HAD to lip-read throughout with great DIFFICULTY. I had to write down reply in my non-dominant hand. I'd be AT A LOSS if both arms were injured. Reply * At triage, you should have a VIDEO RELAY * [ALL IN AGREEMENT} (Male, 35)*

One LD-A participant said:

Once, I suddenly felt ill. It was my head, it didn't feel right. I couldn't phone the NHS, so I crawled out of my flat and went to another flat for help. My friend is hard of hearing, but managed to call an ambulance for me. The ambulance came 4 hours later (Male, 21)

The pattern was very clear: all participants had difficulty in contacting a doctor and nearly all had to wait for a hearing person to act as intermediary or even as a booking agent. One LD-A participant summed this up:

It's important for me to have access to the service so I don't have to rely on hearing people. But the service must be 24 hour, if it isn't, then I will still have to rely on someone to contact the doctor for me. (Female, 21)

This reliance on hearing people was not desired and was considered to lead to problems of miscommunication and misunderstanding.

D: With a long term condition and need contact with doctor/pharmacist

Serious problems in regard to medication were reported. One LD-C participant said:

"I had to see a different GP. When I explained the problem, the GP gave me the medication, I went home took it and then my face and throat swelled up. After admission to hospital and treatment, it was discovered I had an allergic reaction to penicillin. I felt that by being given the medication without any clear explanation (I had put all MY trust in the GP) and was unaware of the risks involved in taking the medication" (Female , 44)

Many of the LD-C group said they often took medication that was prescribed to them without having clear guidelines on how to correctly take them or what effects they could have on them.

They all stated that they were putting all their trust in the medical professionals; the only information they would be clear on is the actual dosage to take. It became clear from the discussion and from the incident of the allergic reaction the impact this had on the group and the realization that they were all at such risk.

When health staff needed to contact Deaf people there were often problems. One of the D Group reported:

My deaf sister-in-law got voice messages but threw them away. She did not realise the hospital had been trying to tell her for my brother-in-law, that they had a vacancy for hip replacement operation next day. Only after many voice messages, they sent a text message. BUT subsequent enquiries about interpreter mix-up, dropped my brother-in-law back in the queue. Only after a visit to the hospital next day, with Discrimination of Equal Rights action, that the hospital finally agreed to set a date. (Female, 58)

Many of the LD-C group reported receiving telephone calls from their GP, despite knowing they are Deaf. Often they did not know who was calling and so resorted to using their children to answer the call. GPs then relayed confidential details to the children about their parents health issues without parental consent. One person from the group had received correspondence through email from their GP and this was a positive, however they all agreed that the language barrier is still an issue. Especially when having to respond directly in English to the GP and the fears of not being understood.

We see again and again inappropriate attempts to contact Deaf people by professionals even though the simple existing ubiquitous technology of text messaging would solve many of the problems (and even though those very same staff use text messaging all the time in their personal lives).

Separate issues were raised concerning pharmacists but mainly revolving around the communication issue. The D group were most clear:

It is impossible to lip-read the pharmacist. They have NO Deaf awareness at all. I had to get paper and pen; problem is I could not read their written replies! So I always us NHS DIRECT at home to check what tablets are for. (Male, 35)

> *I notice most Pharmacists are not native English users, which exacerbates the communication barriers. My biggest fear is not new tablets but whether it is compatible with current tablets I take (Female, 58)*

Even when the visual contact is made (in this case, live onsite), the form of English being used and the lack of Deaf awareness means that communication fails. This has major implications for the provision of video contact as the health practitioner or care worker still needs to be trained in visual interaction.

E: Contact with family/Friends

Although it is common practice to create self-help or patient support groups, the LD-C group were not convinced. When discussing contacting people to share experiences or relate with people who have the same health conditions such as forums or groups, the group felt it was something you never discussed with each other in the Deaf community. They were unaware that was something that they could have access to, they appeared to accept their health issue and move on. They felt that there was no service like this that was available to them.

The D group debated this issue:

> *Sometimes you share with family or talk to a best friend. I can't share in public*

> ** REPLY – but a support group is confidential and they share the same experiences*

> *There is used to be a Deaf women's health network*

> *The Deaf community has a network so that people can contact others with the same condition.*

> *But remember no two illness will be the same (Female, 55)*

However, there was no realisation that this interaction might be achieved through video.

F: Service Side Confidentiality

The response from the LD-A group was interesting. Most of the participants agreed that they had been raised through life being supported by another person. They agreed that using a third party to communicate was not an issue as this was something they were used to. One participant added that they felt it was perfectly natural to use a BSL/English interpreter, support worker, or family member at appointments. They did not see BSL/English interpreters or other support as a breach of their confidentiality, but as giving them fair access to communication. The moderator suggested a comparison that when a hearing person visits their GP they have 100% privacy between themselves and the GP. By comparison, a Deaf person must have a third party present to facilitate communication. The group quietly considered this comparison and realised that quite often their personal information is exposed to third parties.

The D group had more to say on this: they considered factors of control as well as "eavesdropping" as breach of privacy:

> *It happened a few months ago; my husband was unwell and my son's partner took control of the issue with 111 and the ambulance. She had not consulted with my husband and myself. AND she decided that my husband should use an inhaler which was not right one. GP confirmed he should use the same 'purple' one! We were* **not very happy** *(Female, 70)*

> *Yes I see that everyday in my support work role. GP visits deaf patients at a sheltered home, but using a hearing support worker. They (the doctor and the support worker) do NOT explain properly – I am trying to ensure that deaf residents get as much information (Female, 55).*

There was general agreement towards he end of the group discussion that passwords and codes were needed to make sure that the health practitioner and the Deaf person were able to identify themselves. They were also clear that in certain circumstances they would prefer not to have an interpreter.

Varying views on use of Typetalk (the text relay service). Some good, some never used it.

> ** I need other person's password to ensure I am talking to THAT person.*

> ** question raised about receiving calls from the GP*

> *Again I would want a password to authenticate the caller.*

> *REPLY * My surgery faxes me but that does not solve the privacy/ID issue. **

This point was agreed by all.

Summary

The results in this section are much as expected as we have considerable data already on Deaf experience of contact with Health services. Put very simply, Deaf people have had to accept from an early age that they will be unable to deal directly with health service providers and as a result, they have abdicated responsibility for their own health to other people – family, friends, care workers, social workers. When pressed they are extremely upset by the situation but feel powerless to alter it. The fact that they have already seen technological solutions creates more frustration.

Aspiration

There is a very simple message which runs through this whole section – all groups wish to have more control over their contact with social care and with health services. To do so they wish to invoke verifiable BSL interpreting services – either live onsite or live online (in the form of relay).

A: Information access – text/leaflet/letter/video

The LD-A and LD-C group believed that video leaflets would be an advantage and certainly if they were in BSL, would be welcomed.

B: You feel ill – need medical attention

The consensus was that there should be a provision of interpreters. Members of the Deaf-A group were clear:

> *simple solution to this problem of access…a video phone system to contact GPs and emergency services. (Male, 49)*

> *I want to be independent. I don't want to rely on others. At the moment I have to share my medical information with others and I lose the confidentiality that I would like to have (Female , 49)*

Video contact was the only meaningful option to deal with doctors.

C: At home – need help/ D: need contact with Pharmacy/ E: Contact family/Friends

These are grouped together as the aspiration was the same throughout. One of the LD-A group summed it up:

> *VRS should be available 24 hours (Female, 21)*

Since this is standard provision in the USA and in Sweden, we can understand their frustration.

The D Group added the requirement to be able to use text in the call.

F: Service Side Confidentiality

As indicated above the experience was that every transaction they involves a considerable breach of privacy, if a third party is involved (care worker, or interpreter). However, they also wished to see a system to protect their own identity and also a means to determine that the person they were in contact with also was genuine. So some form of password protection was required on both sides and also some form of guarantee about access to the information supplied was needed. The LD-A group said:

If have ID then I don't have a problem (Female , 44)

Make sure they are qualified interpreters, that is important, I want to be independent, able to call them myself, I don't want to rely on my children and family also I don't want them to worry about me (Male, 49)

The system required to be one where the password transaction was not visible to a third part (care worker or interpreter).

The LD-C group added in discussion that:

They are already giving up their privacy due to communication barriers (Male, 49)

My privacy is already exposed to my children, when they were involved and this had damage long-term effect on my family. My children are taking on the role of 'carer/interpreter' by having to interpret for me and my wife in a variety of situations (Male, 49)

There was a reliance on using a sibling to make phone calls on their behalf for an adult who has a family of their own. This often resulted in the feeling of having no privacy within their family. The majority of the group concluded that by using an interpreter they are having their own privacy and confidentiality respected whilst still maintaining their own independence.

Want to be independent directly without having to rely on their children, family or a complete stranger (Female, 44)

The group felt that it was really important to be independent.

General cases of discrimination

In virtually all group discussions with Deaf people there are accounts of discrimination and exclusion. Despite complaints the Health provision does not seem to be able to manage to deal with the problems.

Another issue, I received letter asking for Breast test, I tried to confirm interpreter arrangement and was shocked to find the interpreting booking contact person at Southmead hospital said it is nothing to do with them. I cited that this is a case of discrimination, only with support from Interpreting agency I was able to resolve this issue, as I knew my rights. But does others?
* REPLY * Do you need interpreter for a breast test?
* RESPONSE * It is to see a consultant hence the need for one (Female, 58)

Developing awareness and consequent provision is a major priority.

Response to Technology – V-Connect

In the second part of the sessions or in the case of the LD-A group, in a second session, the V-Connect system was demonstrated.

The two LD groups were impressed and below are their comments, followed in a next section by the questions they asked. The D Group were more concerned to have relay interpreter services included.

LD-A Responses

Participants were given the opportunity to try making and receiving a call.

> *The very simple design makes it accessible and easy for me to use as a Deaf person with a visual impairment (Female, 43)*

> *That is the first time I have ever been able to make a call direct to another person without having to rely on someone else (Female, 38)*

> *I am not very good with technology, but this looks very simple to use and I would be keen to be able to make calls without relying on my support worker (Feamle, 38)*

> *I do not have an iPhone, but if v-connect is compatible with my TV or iPad, that would be good (Male, 21)*

> *I am impressed with how quickly the call connects (several agreed)*

The initial impressions they had were favourable.

LD-A Questions about V-Connect

The session also produced a series of questions:

> *Would it be possible to leave/be left a video message when people are unavailable to take the call?*

> *What is the cost of the software?*

> *Are there monthly payments or just a one off fee?*

> *Will a trial be available for people who are interested?*

> *Will I be able to contact someone who can't sign, like booking my car for an MOT? Will there be an interpreter facility linked to v-connect?*

> *Will there be a text box where either person can type to help ensure clarity in the conversation?*

> *Has the technology been launched and is it being used nationally?*

> *Can I use v-connect 24hrs a day?*

> *Can the size of the video boxes be adjusted to suit a person's individual needs? For example, making the screen of yourself smaller and enlarging the video of the other person.*

Is it ready to install now?

These may be helpful in planning a development of the system.

LD-C Responses

As with LD-A there was a positive response to the demonstration:

This is fantastic! It's simple to use and it's great that other people can contact me directly without me having to rely on my children (Male, 49)

This means that the doctor can contact ME, in my own home, instead of me having to visit the surgery time and time again. It's fantastic! I want it NOW (Female, 49)

Using this technology means that I can express myself more freely using BSL. This would be especially good when communicating with a doctor who uses medical jargon (Female, 49)

This is fantastic! I love the fact that it offers various options of preferred methods of communication. And it's great that it can be plugged into the TV (Male, 54)

Wow! I'm so impressed with this! It's so much better than texting (Female, 44)

It's so clear and simple to use. Can I take it home with me now! (Male, 52)

LD- C Questions about V-Connect

There were also questions about the system:

Is this system only available to be used with GPs?

Does this software work with i-Phones?

How much would it cost to buy the software?

Does this system work via the phone line or the internet?

If it uses the phone line, what would be the monthly charge for this system

If I was to buy this system to be linked with my TV, would this mean that a call would go through to all of my devices so that I can then choose which medium to use each time?

How will I be alerted to an incoming call if I am anywhere in the house? Will a flashing light be activated or would a separate flashing light device be required

When will this system be available to buy?

Perhaps the most simple question and yet the more complex issue is the one concerning the alerting system. If you are Deaf then the typical alarm/ringing do not apply and the visual alert does not work if the person is not in the room.

D-Group

This group are more sophisticated in video telecommunications and their responses were different. They welcomed the potential of an extra facility to access the health services through V-Connect however they had observations and questions:

One asked

>   *So it is not a RELAY service? (Male, 35)*

This is to distinguish it from current services that offer Deaf people the possibility to contact any voice phone user through (sign language) video relay service. After a hands-on session one person commented:

>   *We need a 3rd SCREEN for interpreter as GP/Practice staff do not use sign language.   (Female, 55)*

So this option would need to be added to the system. Others asked

>   *Can we TYPE through this system? (Male, 35)*

>   *Need TEXT option for HoH or those preferred in TEXT (Male, 35)*

So there is a need for the option to use text. Another participant then thinking it through, said

>   *We would need the device at every GP/Practice? (Female, 55)*

Overall the group welcomed the potential that the system/platform could bring to the Deaf community but wished to be consulted to make it a fully deaf friendly system.

Reflections on Technology – Apple Gear

LD-A Group

The moderator explained the benefits of the Apple watch and how it can be used to monitor factors related to health. The watch was passed around the group, giving each participant the opportunity to try it on and check their heart rate.

One participant B38F found it useful to see changes in heart rate in real time. B38F commented to the group that the watch was showing a rise in heart rate. Another participant E28F noticed that her heart rate was considerably lower than some of the other members of the group and wondered why. There was discussion amongst the participants about their varying results and it was good to see them discussing their health with each other. The moderator commented that if the results are unusually high or low, it is advisable to visit the GP for further tests and advice.

The blood pressure monitor was shown and explained; it was explained how it provided instant readings to the iPhone. While each check was carried out, all the other participants were focussed on the person and keen to find out their results. They were very interested in knowing what the results indicated about their health and as with the heart rate checks, there was a great deal of discussion about each other's results.

Two participants had low readings and commented:

C21M said *"I feel light headed and dizzy"*

E28F stated *"I feel dizzy a lot, I am low"*

One participant informed the moderator that they had high blood pressure.

G21M explained *"I do not bother to take the tablets that were prescribed by their GP"*

This participant's result was lower than he had expected and he discussed with his support worker as to whether he should inform the GP.

In the last session there was little discussion amongst the group about their health. However, by having a practical device such as the watch to facilitate discussion, the group was far more interested and engaged in this session. There were a considerable amount of questions raised after trying the device and a large amount of comparison and discussion in relation to each other's results.

Additional questions raised by the group:
1. How many steps am I supposed to do each day? (A22M)
2. Will the watch tell me when I have reached a healthy level of activity for the day? (B38F)
3. Can I use the watch to monitor my heart rate whilst running? (B38F)
4. How much is the watch and blood pressure monitor? (B38F)
5. Is the watch compatible with an iPad? (A22M)

LD-C Group

When demonstrating the watch the group were very excited by it, especially when shown how to use the activity app and how to monitor your heart and blood pressure. It generated a lot of questions and discussion, they were very keen and said they would be more than happy to become participants if this was to be used in a trial. The group became very conscious of the importance of tracking your own heart and blood pressure; it generated lots of positive discussion.

The group stated that the only downside was linked to the cost of the watch. Overall they were very impressed and had a better understanding of their own health as a result.

Personal view on the sessions from the moderator

Buckley Court – Supported Living

When giving a presentation to the tenants at Buckley Court the content had to be thoroughly explained. Owing to the tenants' variation and limited language, and the difficulties some of them have relating concepts to real life extra explanations, visual prompts and examples had to be added, thus extending the time of the presentation. The tenants have difficulty with group discussions and learning from each other and where therefore very focused on the presenter. Their comments were very individual resulting in the presentation lasting an hour and a half longer than it would normally take.

Historically the tenants did not have Smart phones and relied on their friends and family to do things for them. It has been added to their support plans to encourage the tenants to purchase Smart phones and use the internet as this will benefit them in becoming independent. This needs to be reiterated as the tenants have never had independence and therefore find it difficult to look to the future and imagine life using technology independently and the scope of what they could do.

D-Group

The focus group participants found the Apple watch and its associated gear such as BP checker and weight scale fascinating; and commented:

Diana said "The BP checker is really brilliant" as she went on to express her concern "Apple gear is VITAL as more and more people having STROKE, as recent survey shows increase of 40-55 age group having STROKE".

Cheryl followed this on "Does any device check CHOLESTEROL?" which shows there's great concern on such issue in the deaf community.

Valerie summed it up "I feel such gear is GREAT BENEFIT for Deaf people's HEALTH AWARENESS as everything is VISUAL".

Everyone agreed by quoting "It raises one's health AWARENESS as everything is VISUAL".

It shows the great potential and difference that Apple Watch and gear could bring to the deaf community especially with that quote "***Love the idea of alerting if anything not NORMAL by Control centre via HEALTH app***". It also breaks barriers that deaf people face every day life.

Further Observations from the Moderators/Observers

In each group there was an observer in addition to the moderator. The observer of the LD groups said:

They liked the potential of V-Connect but strongly request extras such as the interpreter on screen as well. Some wanted a text facility added. Asked if they still need support work to access it, some said they would not, so this shows some independence given to them, had they able to access V-Connect. This could be vital in their being more independent in their lives. One person with a sight problem found the layout overwhelming; we need to be aware of the range of needs.

For the BSL oriented group (LD-C): they also loved the V-Connect option requesting that they have BSL interpreter as the main feature of using such facility. It is vital that such group be asked for feedback should there be opportunity to develop a Deaf friendly platform.

The LD-C group shares attributes with the mainstream D group in their experience of the health issues which they face in every day life. They are even more dependent on family members or other Deaf friends to manage their contact with health practitioners. There continue to be too many horror stories from this group about contact with GP and about using medication in blind faith. They have suffered in consequence, with reports of further problems after seeing/using GP/medication. It is appalling to witness such things continuing to happen even in 21st Century.

The notes from the second researcher contained the following:

LD-A group

When giving a presentation to the tenants the content had to be thoroughly explained. Owing to the tenants' variation and limited language, and the difficulties some of them have relating concepts to real life extra explanations, visual prompts and examples had to be added, thus extending the time of the presentation. The tenants have difficulty with group discussions and learning from each other and were therefore very focused on the presenter. Their comments were very individual resulting in the presentation lasting an hour and a half longer than it would normally take.

The tenants did not have Smart phones and relied on their friends and family to do things for them. It has been added to their support plans to encourage the tenants to purchase Smartphones and use the Internet as this will benefit them in becoming independent. This needs to be reiterated as the tenants have never had independence and therefore find it difficult to look to the future and imagine life using technology independently and the scope of what they could do.

V-connect: During the technology session the tenants tried out the equipment and found it was quite simply to use. It would be beneficial, to build confidence, to have a few more sessions. It would also be beneficial for the staff to be trained so they could, in turn, train the tenants during support time.

LD-C Group: Sensory Support Service, Service Users have a Support Worker and some have Care Plan

This is a very strong group and they interact and give their opinions actively. Over half of the group have children who they relied on for their technological and communication needs. This group have realised how much they miss this support now that their children have left home. Regarding technology and communication, they are familiar with barriers and have hopes and dreams for the future.

With examples and a visual PowerPoint, this group could respond to the questions. They needed time to consider their wishes for the future but eventually came up with video calls as the answer to breaking down barriers, especially with GPs and hospitals, so they could give explanations in their first language, BSL. Although they used technology they were not fully independent, that is, they would Facetime their family and ask them to ring the GP to make an appointment.

V-connect: During the technology session the tenants tried out the equipment and found it was quite simply to use and were very impressed by it, in fact they wanted to start using it immediately so they no longer needed to rely on their children or families. (In my view, as a moderator, I have noticed that since their children have left home they come for support more regularly as their children are not supporting them.) The level of confidence and knowledge varies within the group but it would be beneficial for them all to have more sessions. It would also be beneficial for the sensory support staff to be trained so they could support the service users with any issues/queries they may have.

Integration of the system into the Support Service

I believe it would be a great benefit to this service, it would mean support workers could communicate with service users in their first language without the barrier of English based text messaging. Not only would this give clarity it would also save vast amounts of time, that is, not needing to meet to clarify issues in BSL.

There is the cost implication to be considered, the service has to be financially viable with a variety of service users willing to use the service.

Personally, it would be of great benefit to me within the realms of my freelance work, giving me equal footing with my hearing colleagues, that is, being able to 'speak' directly with someone via video phone. My only concern is the cost implication and that all my equipment is Apple and therefore not compatible with the software; I would not have a separate item just for this. Of course, when it becomes compatible with Apple I would consider using it.

Reflections on the D Group

This group felt strongly that their communication should be done independently, therefore with confidentiality and privacy. The majority did not have a problem with English but could empathise with those who did so they were aware of the barriers and that there was not equal access compared to their hearing counterparts. The main

problem they found was when they needed to contact/be contacted by GP/hospitals but they might find a way around this, that is, using an interpreter/email.

In my view, I believe that all groups would benefit from this but the LD-C group would benefit most; such a system would solve a lot of their issues with communication and improve their wellbeing. With the LD-A group the benefits may take longer to accrue.

Conclusions

Analysis of the video recorded sessions indicated:

(a) Deaf people have no direct means to reach help in the case of a personal health problem. They have to "hope for the best", hope that the problem will go away or else wait until there is a hearing person who can intervene on their behalf

(b) Few of the participants expressed confidence in the provision of text information and some specifically reported personal health issues arising from their inability to read leaflets or instructions regarding medication

(c) Most of the participants view interpreting provision as the solution – whether live on-site or through relay services online

(d) Total Conversation – video, voice and text – is the telecoms standard which Deaf people prefer for person to person and person to relay conversation

(e) Data Security and Protection of Identity are currently *non-factors* for Deaf people since those have long been removed from their control (ie since childhood). **However**, they *were* keen to have some personal and private passwords or codes which would identify care workers or health staff and which would allow themselves to be identified.

(f) V-Connect was seen as a positive development and for some, this was the first time they had been able to use a video system for person to person remote contact.

Deaf people considered themselves disabled by society's (in this case, health and social care systems') inability to communicate. Where there is an additional learning disability of an intellectual nature (whether caused by language deprivation or by cognitive difficulties), it has proved hard for the individuals to express meaningful aspirations for their own interaction with health care. They are disempowered and see no connections in their interactions which would alter their relation to the healthcare provision. At present their only means of contacting health practitioners is through a third party and this remains uncontrolled and unsatisfactory – since there are no standards for the communication abilities of the care staff or relatives.

The user-centred design approach produces a series of challenges to current practices.

Appendices

1. Project Summary
2. Consent Form
3. Deaf Studies Trust
4. The questions used in the Focus Groups

Appendix 1: Information Sheet

BOLD SHIELD PROJECT (2014-2015)

BETTER OUTCOMES FOR DEAF CLIENTS

We know that Deaf people have poorer health than the rest of the community. We probably know why Deaf people have poorer health because of communication and access issues. But we need to know what to do about it. Instead of just setting up new services by doctors and hospitals, the Bold Shield Project is starting from the Deaf side.
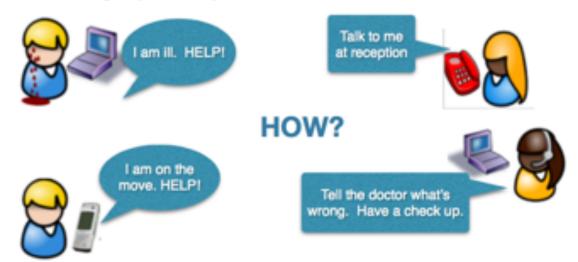
- What do you think should be available?

- What do you do when you have a health problem?

- What sorts of technology would be best for Deaf people to use?

The BOLD SHIELD project wants to adapt and develop new technology to meet the needs of the Deaf community.

We want to see Deaf people with equal access and the same quality of health care. So how can we do that?

- We believe the first step is to ask Deaf people to draw up the plan. (It is called User-Centred Design)

- Then we can consider what technology can fit the plan.

- Then we have to convince the Health Service to put the plan into practice.

There is a possibility in this project to create a strong plan so that in phase 2 we can put a new service into action. We are asking Deaf people to come to meetings to discuss this and then later on to come along to try out new ways to connect to health services.

The project is funded by the Small Business Research Initiative - a cooperation between the Technology Strategy Board and the Health Service. The project is led by Red Embedded Ltd: a videoconferencing for health company. The other partners are:
FAST (The Foundation for Assistive Technology): designing assistive technology
Sandwell MBC: A local Authority using video conferencing with people who have learning disabilities
The Deaf Studies Trust: research charity working on video technology
HW Communications: technology for security and privacy.

Contact: jim.kyle@deafstudiestrust.org   DST, Vassall Centre, Gill Avenue, Bristol BS16 2QQ

Appendix 2: Consent Form

Principal Investigators: Professor Jim Kyle and Ms Lorna Allsop

Bold Shield Project

Participant Consent Form

Study ID						Initials			

We wish to ask you to sign to show that you understand the Bold Shield Project; it is important that you say you agree to take part.

Please read this consent form (we will explain in BSL) and put your initials or tick in the boxes where you agree.

Please initial or tick box

1. I confirm that the Bold Shield project has been explained to me in BSL ☐

   I confirm that the Bold Shield project has been explained to me in English/text ☐

2. I understand that I am free to quit the project at any time ☐

4. I understand that I will take part in an interview or group meeting. ☐

5. If selected, I may also be contacted at a later date to take part in a focus group or other interview – I am able to accept or decline to take part at that stage. ☐

6. When interviewed, I may be video-recorded or audio-recorded, but understand this is only to help with the data collection and will not be shown to anyone but the researchers. ☐

7. I give permission for the data collected about me to be used

   - As part of a general data collection and report by the project team where I cannot be identified ☐

   - In the form of quotations or descriptions – where I cannot be identified ☐

   - For video/audio analysis by the researchers in the project team, only ☐

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Person taking consent   Date   Signature

When completed, 1 copy for participant : 1 for researcher site file; participant receives a project information sheet with contact details of project management.

Appendix 3: Deaf Studies Trust

The Deaf Studies Trust is research-based registered charity which works with and on behalf of deaf people to reduce isolation and to increase understanding. It focuses on the deaf community and implements a model of research-led innovation whereby initial research within the community is used as a base for the development of initiatives which develop opportunities for deaf people and improve access and inclusion of the deaf children and adults.

The Deaf Studies Trust was set up in 1984 and has an unbroken record of research and development activities in the field, ever since. Most recent projects include DPIC (1997-2000, £395,000, Community Fund), DPIC II (2001-2, £88,000, Community Fund), Sign 50+ (2002-4, £130,000, BT), Deafblind Worlds (2004-6, £210,000, Big Lottery Fund) BSL Access in Scotland (2003-5, £33,000, Scottish Executive Social Research); and projects as partners SignWorks (1997-2000, £800,000, DTI), WISDOM (2001-2003, 6m euros, EC), SignAware (2004-5, £330,000, DWP).

In addition DST has collected data on deaf television viewing in 1991 for BBC & IBA, for BBC See Hear in 2003 and in regard to information access in general for the Scottish Executive in 2005. From these and community research over the last 10 years, there is a considerable database of information on deaf television viewing.

Recently we have completed smaller scale projects on deaf people in the workplace (2005), deaf young people and sport (2004), deaf People's views on the new BSL channel (2008) and also perhaps more relevant, on Parents of deaf children's experiences of family services (2009), Deaf Health (2013-14).
DST has considerable experience of managing and developing projects. These involve all stages of the development from initial planning, to staffing, financial monitoring, development and supervision of the workplan (assessing progress against the milestones and deliverables), creating and working with an external Steering group as well as internal reporting and accountability to Trustees.
Deaf Studies Trust, Vassall Centre, Gill Avenue, Bristol BS16 2QQ
Tel: 0117 958 3040; fax: 0117 958 304

Charity Number 289302

Jim Kyle is Emeritus Professor of Deaf Studies at University of Bristol and Secretary of Deaf Studies Trust, an R&D charity set up up 30 years ago.. He has an extensive background in research work in Deaf Studies with over 60 managed projects. Recent and relevant are: large partnership projects (Wisdom 20012004, EC, €800k); REACH112, 20092012 EC €4m, Deaf Health 20102013, Lottery, £150k). In REACH112, he set up a UK national Total Conversation Service with over 2000 users and a relay service, with access to emergency services (www.myfriendcentral.com and www.reach112.co.uk).

Jim Kyle is a Chartered Psychologist and Fellow of the British Psychological Society.

Appendix 4: Focus Group Questions

Health Situations …… (not all cases with all groups)
YOU need information or need to respond to information supplied in text/leaflet/letter
A1: Text - paper
A2: video
A3: online
YOU feel ill - need medical attention/consultation
B1: YOU are at home - alone
B2: YOU are outside on the move alone
B3: YOU are in a public place with other (hearing people) around
B4: YOU are at the health centre/hospital/clinic/ minor injuries unit
YOU are at home with a long term condition (LTC) or are signed off from work - You have regular medicine to take
C1: YOU need to get information from the doctor - YOU need to call nurse/doctor
C2: YOU need to send information like blood pressure/heart rate
C3: Doctor/Nurse needs to contact YOU
C4: if there was an emergency because your blood pressure got to high - the nurse/doctor needs to contact YOU
C5: if there was an emergency/accident at home
C7: YOU need to request support from Social Worker or Care worker
C8: YOU want to make a complaint
YOU need to get in touch with chemist
D1 YOU have a query on medication
D2 YOU need to request repeat medicine
YOU are ill and want to contact friends or family or other people with the same problem
E1 YOU just want to have a chat
E2 YOU want to ask questions about how you are feeling or the other person is feeling
Service side - confidentiality
F1a: YOU are at home; doctor calls through video relay service - YOU happy to have a third party?
F1b: YOU are at home with hearing friend or family - the doctor calls - YOU happy for the doctor to talk to the hearing person?
F1c: YOU are at home with hearing social worker or care worker - the doctor calls - YOU happy for the doctor to talk to the hearing person?
F2: YOU at home but want to see what is in your medical files

F3a: YOU call doctor through relay - You cannot see the doctor. How do you know this is a qualified doctor you are talking to?
F3b: YOU are at home, doctor calls through relay. YOU happy for doctor to refer to your medical records in the call? How do you know it is a qualified doctor calling?
F3c: YOU in a relay call with doctor - Doctor wants some basic personal information - age, recent illness, last period - you could type this information - but would you be happy for relay person to see this?
F4: YOU make a call in BT text/text relay - YOU happy for unknown operator to speak your words to doctor?
F5: YOU receive a text call direct from doctor? Doctor types to you. How do you know it is the doctor? How do you know he/she is qualified?