



ACCESS TO HEALTH AND SOCIAL CARE SERVICES FOR DEAF AND HARD OF HEARING PEOPLE IN WOLVERHAMPTON

Healthwatch Wolverhampton in conjunction with the University of
Wolverhampton

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Foreword

As Chief Officer of Healthwatch Wolverhampton, I was delighted to be approached by researchers at the University of Wolverhampton, Faculty of Social Sciences to work in partnership with our Deaf and Hard of Hearing communities. Our collaborative events in July 2017 provided the opportunity to become involved in a comprehensive study aimed at fully understanding the experiences of health and social care for Deaf and Hard of Hearing service users across our city.

Healthwatch Wolverhampton is the independent champion for people who need health and social care in the city. We are here to make sure that those who provide, and commission services put people at the heart of care. We want to give a stronger voice to all our communities, especially those whose views often go unheard. Healthwatch Wolverhampton became aware that Deaf people and their families are a group of people who are likely to experience difficulties in accessing health and social care services. We wanted to find out more about what these problems were.

In July 2017, we held two public events at the University of Wolverhampton, which attracted over 60 attendees. The events provided a rich source of information about what it is like to be a Deaf or Hard of Hearing user of health and social care services in Wolverhampton.

This study has highlighted that there are many barriers faced by Deaf and Hard of Hearing people in accessing local health and social care provision. Deaf people are also excluded from a wide range of engagement events as no provision is made for their inclusion. People were very enthusiastic to share their experiences, and this has enabled us to put forward some detailed recommendations in this joint report.

Looking ahead, we would like to see local partners adopt the recommendations made to ensure that local services are more accessible, and the Deaf and Hard of Hearing Community are an integral part of service planning, design and decision making. The next step for us will be to hold those services to account for making the changes and improving equality of access and quality of service delivery for all our population.

Elizabeth Learoyd

Chief Officer

Healthwatch Wolverhampton

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Introduction

In 2012 Johannes Fellingner and colleagues highlighted a growing concern for signs of health inequality amongst D/deaf individuals, in the area of both general and mental health, within their respective community/country. The claim was even made that deafness itself can endanger your health (Alexander, Ladd and Powell, 2012). It was also established that the level of poor communication between D/deaf patients and health professionals, exacerbated the barriers to health care, which D/deaf people experienced. Barnett et.al. examining health inequality experienced by D/deaf people argued that *"... It appears that addressing language barriers improves adherence with some preventive services and may help prevent chronic diseases or improve patient's long-term outcomes through earlier detection"* (Barnett, et al, 2011:2). This is supported by Alexander, Ladd and Powell, who advocate that *"good communication is the key"* (2012:980), given that it is *"the bedrock of diagnosis and treatment"* (The Lancet, 2012:977) and has the potential to avoid offering a lower standard of service (Sign Health 2014).

The UK has had anti-discrimination legislation in place to prevent any gaps or differentiation in service delivery to individual/specific groups within society, for example, the *Disability Discrimination Act 1995* and the *Equality Act 2010*. In 2011 the government also introduced the *Public-Sector Equality Duty*, aimed at 'advancing equality of opportunity between persons who share a relevant protected characteristic [which includes deafness] and persons who do not share it'. This includes the setting of 'equality objectives', at least every four years, which a public authority, including the NHS, thinks it should achieve. This implies a responsibility on service providers to consult and gather feedback from service users, including D/deaf people, in order to adequately identify their needs. Yet Alexander, et. al. (2012:979) state that *"Ignorance leads to... patients from the Deaf community enduring both individual and institutional discrimination"*

Further studies looking into the likely causes for the Health inequality experienced by D/deaf people, identified two areas for consideration. Firstly, potential gaps in service provision and secondly social determinants (Smith and Chin, 2012). *"... Deaf people face a unique combination of social and communication barriers which appear to have resulted in health disparities between Deaf and hearing people"* (Smith & Chin, 2012:449). The focus on social determinants falls outside the scope of this current report. The World Health Organisation (WHO, 2017), however, confirmed that, *"Poverty, social exclusion, poor housing and poor health systems are among the main social causes of ill health"*. Where these determinants can also be found to overlap with the demographics of D/deaf people, such as education, *"almost two thirds (58.9%) of deaf children are failing to achieve the government's expected benchmark of five GCSEs at grade A* - C (including English and Maths), compared to just 35.8% of other children with no identified special educational need"* (NDCS, 2016) and employment, *"Discrimination plays a large part in the working lives of deaf*

people, and many deaf people are forced to exit employment because of it." (total Jobs, 2016:4), their subsequent impact on housing, nutrition and leisure/sport engagement should not be underestimated.

Since the revelations in The Lancet, and the call that, "Research is needed to establish whether people from the Deaf community have poorer health than do hearing individuals, and to explore underlying causes." (Alexander et. al., 2012:979), we have seen a steady stream of publications and reports focussing on health issues and inequality within the D/deaf community. Amongst the general need for greater D/Deaf Awareness throughout the NHS, they have identified some common themes:

- A significant proportion of Deaf BSL users avoid going to their GP, at times caused by a lack of trust (Ringham, 2012; Kyle, et.al. 2013)
- Difficulty in making appointments and accessing health and social care services, bringing about feelings of oppression and discrimination, and resulting in a potential failure to comply with existing UK legislation. (Healthwatch York, 2013; SignHealth, 2014; Healthwatch Oxfordshire, 2014; Healthwatch Islington, 2014; Mitsi et.al. 2014; Kuenburg, et. al. 2015)
- Frustration that issues have been raised in the past with no subsequent action (Healthwatch York 2013)
- Refusal of the right to be provided with a sign language interpreter. Insufficient awareness by NHS service providers on how to obtain an interpreter, hence forcing other means of communication upon Deaf patients, and an unfortunate reliance on non-professionals, such as family members. (Ringham, 2012; Healthwatch Worcestershire 2014; Healthwatch Islington, 2014)
- Misunderstanding in consultations due to inadequate communication, and therefore, an insufficient awareness of the medical condition/s by the D/deaf patient as a result, impacting upon future treatment (Ringham, 2012; Alexander, Ladd, Powell, 2012; Kyle et al. 2013; SignHealth 2014; Healthwatch Oxfordshire, 2014)
- Impact of socio-economic status, reduced educational opportunities and communication barriers on health inequality (Kuenburg et. al. 2016).

The NHS, aware of the need to be accessible to the widest possible range of service users, and in the case of the Deaf community, the criticism that "*Patient information leaflets and government health advice should be available in BSL*" (Alexander et.al., 2012:980), announced the introduction of the new *Accessible Information Standard* in June 2015, which came into effect in July 2016. Pertinent to D/deaf people it states that:

1. "*For most Deaf people, English is a second language and as such they may have a limited ability to read, write or speak English.*" (NHS, 2015:6)

2. "Organisations *MUST* ensure that communication professionals (including British Sign Language interpreters and deafblind manual interpreters) used in health and social care settings have:

- *Appropriate qualifications; AND*
- *Disclosure and Barring Service (DBS) clearance; AND*
- *Signed up to a relevant professional code of conduct. "*

(NHS, 2015:28)

3. "As the Accessible Information Standard aims to support individuals' rights to autonomy and, specifically, their ability to access health and social care services independently, in general, British Sign Language (BSL) interpretation and other communication support *SHOULD* be provided by an appropriately qualified and registered [NRCPD] professional (see section 11.4.4.1) and not by an individual's family members, friends or carers. "(NHS, 2015:34)

Now that the NHS information standard has been in place for over a year, and 7 years since the introduction of the Equality Act 2010, Healthwatch Wolverhampton in partnership with the University of Wolverhampton decided to ascertain whether D/deaf people in Wolverhampton were experiencing any issues in service provision within health and social care settings, which might lead to health inequality.

We already know from the GP access survey conducted by Healthwatch Wolverhampton (2017) that, in relation to Deaf British Sign Language users, "GP's need to have British Sign Language (BSL) interpreters more readily available and not assume Deaf patients do not require an interpreter or that a family member can be there instead of a trained interpreter " and "Sometimes, the BSL interpreter does not turn up to my appointments" (Healthwatch Wolverhampton, 2017:8). The GP access survey also made specific recommendations such as: the promotion of online booking systems, interpretation services or British Sign Language for patients if required, and "Ensure that information regarding booking British Sign Language interpreters is made readily available to patients and staff are also aware of the process to follow if an interpreter is required. Offer Deaf Awareness training to all staff." (Healthwatch Wolverhampton, 2017:9).

For the purpose of obtaining a comprehensive overview of the experiences of D/deaf service users, a public consultation event was organised at the University, aimed at both people who are Deaf and use British Sign Language (BSL) as a first or preferred language, and at people who are Hard of Hearing and use speech as their first and preferred method of communication. The forum provided the opportunity for both groups to feedback on their experiences of accessing health and social care services in Wolverhampton. A Healthwatch facilitator was present at each discussion group, and the Deaf BSL users group had sign language interpreters present who provided translation from BSL into English and from English into BSL. Discussions from both groups were live audio recorded, with provision for discrete feedback where requested.

The following report is interspersed with the views and experiences from both Deaf BSL and hard of hearing service users. A full transcript of the consumer feedback can be found at the end of this document on Appendix Section A – People who are Deaf BSL users, Section B – Hard of Hearing People.

“Through the eyes and ears of local Healthwatch, and using our own information, we will identify national trends and areas of concern. Where there are significant issues or long-term problems we will take action and put forward recommendations across health and social care.” (Healthwatch England, 2017)

Cultural information

Local Deaf community

According to the NHS Information Centre¹, there are 1055 people registered as Deaf and hard of hearing in Wolverhampton.

Understanding Deaf and Hard of Hearing Terminology

In this report, there are distinctions between ‘D’ (Deaf) and ‘d’ (deaf) as follows:

- Big D deaf people are those who are born deaf or experience hearing loss before spoken language is acquired and regard their deafness as part of their identity and culture rather than as a disability. They form the Deaf Community and are predominantly British Sign Language (BSL) users.
- Small d deaf people are those who have become deafened or hard of hearing in later life, after they have acquired a spoken language and so identify themselves with the hearing community. Small d deaf people are more likely to use hearing aids and develop lipreading skills².

Within the report VRS/VRI and Sign Video technology is referred to, and for further information on this provision, please see;

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- <http://deafcouncil.org.uk/deaf-access-to-communications/vrs-vri>
 - <https://www.signvideo.co.uk>
-

¹ Health and Social Care information centre (HSCIC), People registered as Deaf or Hard of Hearing- England, Year Ending 31 March 2010 <http://www.hscic.gov.uk/pubs/regdeaf10>

² <http://www.ageukhearingaids.co.uk/hearing-aid-news/what-are-big-d-and-little-d/>

Bibliography

Alexander, A., Ladd, P., Powell, S. (2012) Deafness Might Damage Your Health. *The Lancet* Volume 379, pp.979-981.

Barnett, S. Et. al. (2011) Deaf sign language users, health inequities, and public health: opportunity for social justice in *Preventing Chronic disease – public health research, practice and policy* Volume 8(2) p1-6

Disability Discrimination Act (1995) [online] [accessed August 2017] Available at: http://www.legislation.gov.uk/ukpga/1995/50/pdfs/ukpga_19950050_en.pdf

Equality Act (2010) [online] [accessed August 2017] Available at: http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf

Fellinger, J., Holzinger, D. and Pollard, R. (2012) Mental health of deaf people in *The Lancet* Volume 379: 1037–44

Healthwatch Islington (2014) *Experiences of Deaf service users in local hospitals*. Islington: Healthwatch

Healthwatch Oxfordshire (2014) *Survey to help to understand the healthcare needs of the Oxfordshire Deaf Community*. Oxfordshire: Healthwatch
<http://signlingual.org.uk/research/>

Healthwatch Wolverhampton (2017) *GP Access: Patient experiences in Wolverhampton*. Wolverhampton: Healthwatch Wolverhampton.

Healthwatch York (2013) *Access to health and social care services for Deaf people*. York: Healthwatch

Kuenburg, A., Fellinger, P. and Fellinger, J. (2015). Health Care Access Among Deaf People. *Journal of Deaf Studies and Deaf Education*, 21(1), pp. 1-10.

Kyle, J., Sutherland, H., Allsop, L., Ridd, M. and Emond, A. (2013). *Deaf Health – Analysis of the current health and access to health care of Deaf people in the UK – Executive Summary* [Online]. [Accessed August 2017]. Available at: <http://www.deafstudiestrust.org/files/pdf/reports/Deaf%20Health-exec-final.pdf>

Mitsi, D., Armyra, C., Fradelos, E. (2014) Deaf Peoples Accessibility in Health Services. *Health Sciences Research*. 1 (4), pp.102-106.

NDCS (2016) New GCSE figures show extensive attainment gap for deaf children. [Online] accessed August 2017. Available at: http://www.ndcs.org.uk/news/new_gcse_figures.html

NHS (2015) *Accessible Information: Specification and Implementation Guidance*. London: NHS England.

Public Sector Equality Duty (2011) [online] [accessed August 2017] Available at: http://www.legislation.gov.uk/uksi/2011/2260/pdfs/uksi_20112260_en.pdf

Ringham, L. (2012) *Access to all areas: A report into the experiences of people with hearing loss when accessing healthcare*, London: AoHL.

Sign Health (2014) Sick of it: a report into the health of Deaf people in the UK. [Online] [Accessed August 2017]. Available at: <http://signhealth.org.uk/wp-content/uploads/2016/09/Sick-Of-It-Report.pdf>

Smith, S. and Chin, N. (2012) Social determinants of health in Deaf communities, in Maddock, J. (ed.) *Public health – Social and behavioural health*. Intech p.449-46

The Lancet (2012) The health of deaf people: communication breakdown. *The Lancet* Volume 379:977, Editorial.

totalJobs (2016) Deaf jobseeker and employee experiences survey [Online] [Accessed August 2017]. Available at: <https://www.totaljobs.com/insidejob/deaf-jobseeker-employee-report-2016/>

WHO (2017). *Social determinants of health* [Online] [Accessed August 2017]. Available at: http://www.who.int/social_determinants/sdh_definition/en/

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Findings

Experiences from Deaf People (British Sign Language users)

1 GP surgeries and GP provision

Deaf sign language users' experiences

Variable to non-compliance with the Equality Act 2010 and NHS Accessible Information Standards 2015/16, for example, refusing to book an interpreter.

Significant examples of communication difficulties were relayed at both the level of receptionists and with the general practitioner due to either: no sign language interpreter provision; the GP deciding when an appointment merited provision or not; and frequently being refused provision.

"... they would say, "No, if you are really ill, then yes, we will bring an interpreter but if it's just a general medication or blood test then no it's not necessary."

"...my ex-partner, she would phone, make an appointment for me, request to book an interpreter, and I would be told "No X, you can lip read well, so we can communicate fine", so she would explain how X can express details and issues, but they have refused to book interpreters. So, I'll attend, explain you don't have to pay for interpreters, it comes from the NHS budget, so there are no concerns there in regard to your budget, but again I'd be told, "But you can lip-read", and I'll explain [about the] difficulty explaining my health issues, [the] clarification of details, but we just continue how it was...."

Patients found themselves being 'forced' into alternative methods of communication such as via writing and or being asked to lip-read, when for many, they experienced difficulty with English language proficiency/understanding.

"....my writing skills are not very good, so it was like communicating in 18th Century fashion in black ink, and I didn't understand what was being written..."

Where interpreters had been provided they were not always registered [NRCPD] qualified sign language interpreters, but people of lower experience and qualification.

"With GPs, sometimes they book interpreters for me, but when they actually do book an interpreter they use an agency which is a very poor service, - they sort of use cowboy interpreters unfortunately the interpreters will come along and quite often they are not qualified and

they are not experienced enough, so the information they are interpreting for me, is incorrect, so that is very dangerous. So, the commissioners need to be aware that some interpreter agencies shouldn't be used, and they need to make sure they pick the correct and qualified interpreting agencies. They need to be qualified interpreters."

"I'll say I want an interpreter – this [particular] interpreter, but no, we have got to use this [particular] agency, so obviously before when it was under the PCT, we could have a bit of a choice - we could recommend that...."

There had been no choice for a Deaf patient as to how they would choose an interpreter if one was provided. There were instances of patients using interpreters via other publicly funded sources, e.g. 'Access to Work' in order to ensure effective communication. There was also anger demonstrated by one general practitioner towards a Deaf patient when they had brought along an interpreter who was not from the CCG contracted translation agency. There was also a general impression of an insufficient supply of interpreters in the Wolverhampton area.

".... there are not enough interpreters for the number of Deaf people in Wolverhampton. It is the same all over really."

"...we want Deaf Awareness as well for all staff that work in the GP [practice]."

"...we need more posters as well, [on] how to deal with Deaf people... to remind people and the staff about how to do that, about speaking slowly to make sure the Deaf person understands, - gestures, fingerspelling and the importance of booking an interpreter as well."

Experiences included a lack of general Deaf Awareness such as: clear communication tactics; positive body language; not turning the back on the client; not standing/sitting with the light behind the speaker; beards and moustaches covering mouth and lips; speaking too quickly; stern facial expressions and, some met with pity at the condition of Deafness.

"Some professionals say, "My God, I am so sorry she is Deaf, you know it is such a shame, it is awful to be Deaf". That is really, not a nice thing to say. So, they need to be more aware, but it does vary with each professional you meet."

"I feel half of the time I have to educate them about Deafness and it is not my job, you know I am teaching them, it drags on my appointment time..."

One person found themselves banned from their doctor's practice due to friction when trying to communicate with the surgery without an interpreter present.

"...they banned my husband from going to the doctors because he was having an argument with the receptionist and through writing notes.... The doctor said they got into an argument because communication was not going very well, and he got a letter through the post to say he had been banned from the doctors – and that was due to [poor] communication."

People found themselves with insufficient time within the appointment, due to being unaware of the ability to request a double appointment with or without an interpreter present.

".... I was given medication, but again, it's the communication, it's all typed, and my English isn't very good, and I can read, but you know, I need an interpreter, and everything was being typed out, but I really did need an interpreter."

There were examples of prescriptions for medication being given when ineffective communication had taken place, thus raising the risk of safety, subsequent consequences, leaving the patient confused and having to find other means to understand the condition and treatment via the internet, social media, friends/family, other provision e.g. pharmacist. This resulted in additional resource usage for repeat appointments or the patient being bounced across other services, e.g., from GP to pharmacist, to walk-in centre, to GP, to hospital and so on. The extended period of diagnosis due to communication issues again raised the level of risk for the patient.

".... the doctor hasn't explained any of this information to me, I've just had to find it out for myself, and been told, "It's gout, it happens". 8 years of that though, it's a waste, if she'd told me the first year what foods to avoid, I would have been ok."

Patients found in some instances that clear information did not always follow the patient between services such as, labelling the files 'Deaf' and the preferred means of communication.

'Patient Choice' e.g. of hospital or consultant for treatment had not been communicated to the respondents present and is something that they would have welcomed.

The process of booking appointments varied with patients preferring to have the option to do so by text but, not granted it.

"I had a letter sent to me, asking me to go to a meeting at the GP and that was because I'd given some feedback. I'd written on the feedback form my grievance really with them refusing to text and so they'd asked me to go along to this meeting, but they didn't provide an interpreter!"

"In the past, I have had an experience where I saw a GP, I asked them to book an interpreter, but they weren't sure whether the interpreter was available and whether they could get one, so they said they would let me know and they said they would phone me. I said, "Well you can't do that, you know, if you could text me" and they said "No, no, we can't, we can't offer that service". You'd have to come back."

"Sometimes the dentist can send you a text message, but doctors are sort of thirty years behind aren't they. So, what's the problem?"

This left them either having to ask a third person (which raises issues of confidentiality) to ring on their behalf or use the internet where some were connected to but others not. Interpreters could not be provided for same day/emergency appointments, resulting in the patient having to wait until one could be booked – if agreed to by the surgery, or, being forced to go through the appointment communication by other means, such as writing. Routine appointments such as the 'Over 50' check-up did not offer interpreter provision either.

Obtaining test results had proved difficult e.g., having to chase up to receive results, and difficulty in doing so without an interpreter.

Other areas of concern included the waiting room and need for visual screen indication to alert as to when it was their turn to see the GP, rather than the receptionist calling out their name.

"...and they come out and say your 'name' and everybody looks at me and, I say "You know, they should know better, I'm Deaf", and they say, "Oh, I'm sorry, I'm sorry, "and we carry on into the room."

"...technology is so advanced isn't it, you've got the screens, so that's good."

"...obviously you have to watch that all the time to make sure you catch your name if it comes up, and I literally don't take my eyes off the screen."

There had been no interpreter provision in Walk-In centres.

There were instances of Deaf people using I.C.E – 'In case of emergency' via the family for emergencies.

One good practice example was cited of a GP booking an interpreter for Deaf parents of a hearing child and another whose GP would only see them with an

interpreter present, but, this is turn led to issues about emergency/same day access if an interpreter could not be sourced.

"My GP - I am really impressed with them to be honest, because they will NOT see me without an interpreter, you know, if there is a [funding] cut and I am adamant we need to sort it out, - they are adamant they have to have an interpreter there. Which I think, is really good."

There was on the whole, perception by both Deaf and hard of hearing people that hearing people received a service which was quicker to access with more choice, which is not always the case.

Hard of Hearing Peoples' experience

Overall, there was frustration at the difficulty in achieving clear and effective communication with medical professionals and in-service provision. People who fall within this category felt there was an assumption that they could and would wish to learn sign language, when in fact, the feedback indicated the reverse. It was clearly evident that appropriate Deaf Awareness training was needed for receptionists and GPs, and the importance for them to know the difference and communicative needs between hard of hearing people and profoundly Deaf sign language users.

"An issue that deaf people have [is] making themselves understood."

"It's important that receptionists have training in Deaf Awareness and understand the difference between somebody that is hard of hearing and somebody that actually has no hearing."

"Well over the phone sometimes the [GP] receptionist's not very good, - so you have problems."

"You can get telephones with amplified sound can't you? That's part of the thing about when you are diagnosed with hearing loss, - you are not told about what's available."

"It's a big jump, isn't it? It's a big jump to signing, - it's almost like accepting that you are not going to hear and you've got to change your way of communicating. I depend on lip reading."

"This is one of the difficulties, - people assume you know signing which is one way of communicating, but when you are hard of hearing, you've got to find a way which might be writing on bits of paper which again, is fine if you can write on bits of paper but there will be people who are hard of hearing, especially with an increasing older population, who are going to become deaf or related to age, they

are going to struggle more to communicate I think. They might have mobility issues or something with writing."

There was a tendency and assumption that speaking louder would help communication, when in fact it usually distorted the facial and mouth patterns and did not assist hearing aid users. There was comment that the spoken tone and pitch is more important for this group dependent upon the level and type of hearing loss, and awareness was required that hypersensitivity to sound can also be present. There was preference indicated for written communication, but a requirement to recognise that this could take longer.

"X has got hypersensitive hearing, so actually sometimes sound hurt. So actually, it is an issue that isn't picked up in hearing services – it's like an over-sensitivity."

Communication conducted over the telephone (e.g. with a receptionist) can be particularly difficult to hear and understand, and a loop system for hearing aid users and indication of its presence (displayed signage) is needed in the GP surgery to cover all areas.

"I find, even when they say "There's a loop [system]" - there's not one.

"The reception has one', [but] not the doctor himself."

"I do position myself, (especially at the hospital), to make sure I'm in the right position for where they come out, so that I can see them when they are saying my name."

"Often in a GP surgery like ours, it goes up on a screen but in a hospital, often they come out and say 6 or 8 names and people coming out from different places – and presumably you have to watch, to know what they've said [lip read] ...but again, ...it depends if they speak clearly enough."

In order to book an appointment at the surgery, being able to use text requests was the preferred method. Not everyone can access the internet, and currently the experience of text communication was for confirmation or reminders of appointments to come.

"When booking a GP – it's not an option to book via text, and I think that would be good."

"Always by text [test results] and I told them not to because since the stroke, my brain doesn't know how to work appliances including phones so, texting is a real problem, not just for me but for other people I know who've got vascular dementia."

"I think there is access via the internet but, it's been a bit of a problem getting that access. I don't know why, so it's an issue for me being able to access the appointment, but then again, you are not always going

to have internet access are you? So, I think text would be good access."

"For me, people assume because you are deaf or hard of hearing if you speak louder you can hear, but, actually for me, it is a certain tone and pitch I can hear, so it wouldn't matter how loudly you say things, I wouldn't hear it. My receptionist at the GP is actually, quite patient – I always say straightaway, "I'm hard of hearing" and so they tend to speak a bit more slowly and clearly, and I just always say "Pardon, pardon".

"What it is, I don't have a very loud voice, so I do have a real problem to get people to hear me because I don't have the power in my voice to shout."

The impact of environmental noise was not to be under-estimated as to the difficulty for hearing and understanding people with waiting room noise such as; other peoples' communications; noise of children; and noise emitted via a screen/television and background music creating extreme difficulty and increased strain. People would frequently position themselves to be able to try and read the lips of the person calling their name out for their appointment. It was recommended that a visual alert be present such as via a waiting room screen.

There was a feeling that more awareness was needed as to the potential prevalence of underlying conditions which in turn can increase difficulty in making oneself understood. Mobility issues were also raised as to difficulty when trying to write information down in order to communicate.

Other points raised included the experiences of difficulty in getting hearing loss diagnosed and finding/receiving the correct information about the help available to manage it.

There were issues experienced with the accuracy of medical records and feedback demonstrated a wish for a note to be placed on a deaf patients' file to show they are 'deaf' and the type of deafness and communication needed. This information should also follow through between services.

"I went to my GP surgery the other day and saw the nurse, she was facing the other way and I said, "I've got a hearing problem" and she said, "Oh, it's not on your file", - and I've been a problem patient now for 2 years. Some of the information had not been transferred across..."

In terms of time with a professional, there was a general feeling of being 'rushed', and a need to know that additional time could be given for the appointment, in order to effectively explain issues and understand responses.

2 Hospitals

Deaf sign language users' experiences

"A woman came up to me and said, "You've been here all afternoon" and then she realised I was Deaf and then said, "I'm ever so sorry" and walked off, but I'd given my name and said that I was Deaf, so if all hospitals do that, if they'd just had a bit of notification that we are Deaf, it would be clearer, people don't realise and then we are left there waiting."

"Hospitals have no awareness of boundaries – they would ask a child, a family member, support worker, [to interpret] and it's not their role to do that. It's not. They will just try anything really - and they have a responsibility."

"My daughter at that time was 8 years old, and the doctor actually said to her, "Tell him what I'm saying", but she is 8, she can't."

"The family are there for emotional support, not to interpret and not to relay the information."

There was an overall lack of interpreter provision and cases of medical professional requests to non- interpreting Specialists such as support/care workers and even a young child to interpret for the Deaf patient. It is essential to book registered qualified sign language interpreters [the National Register of Communication Professionals working with Deaf and Deafblind People, NRCPD].

"....that should NEVER NEVER happen. What if the family member is a child and....the doctor is exposing information, that's abuse you know, or, maybe that family member is not skilled enough or it's sensitive information, you know where the Doctor is saying this, you know your life is terminal and the child doesn't share that information. This is why you should NEVER EVER EVER use a family member EVER."

Examples were given of no interpreter provision for Urgent Care, and hospital discharge taking place without clear communication or information as to onward arrangements/transportation and medication procedures.

"I was trying IVF in the past and I thought I'd do it privately because it was quicker and they refused to provide me with an interpreter. So, I went through the NHS and they did provide me with an interpreter."

"....communication is important – some of them could learn basic sign language, simple things like how to say your name, just to be able to respond. You can't have an interpreter in an operating theatre, so if staff could learn some basic signs like 'Gas' for example so that I understand that I'm going to have to go under an anaesthetic, just some simple signs and they should speak clearly as well so that we can lip read them, and, speak to us face to face and understand not to have the light behind them [which puts the face in shadow], and not

to have beards and moustaches because we need to be able to see people's lips as well."

There is an urgent need for front line hospital staff to have Deaf Awareness and basic sign language training in order to know how to approach and begin to communicate at an introductory level with Deaf patients. Examples of patients being forced to try and read facial expressions/lip patterns on people with beards and moustaches, who may or may not have a spoken accent (altering lip pattern shape) and speaking with their back to a window, thus putting the face in darkness.

"...you just have to probably communicate with pen and paper. You know the old sort of way, sometimes they expect you to do that."

Whilst there was an appreciation of the flexibility of time frames with ward rounds, it was essential to have a fixed time with a Deaf patient and interpreter present.

"Sometimes they'll book an interpreter, but they'll only allow an hour. So, what if we needed more than an hour. They are sort of, "No they've only been booked for an hour" and that's it."

"One of my friends went for a heart bypass at [X] hospital and it was fantastic for him really. He had three days when interpreters were there. Three days, post operation, everything."

Interpreters being booked for fixed time frames and to ensure this has not expired thus rendering the patient without an interpreter when the medical professional arrives.

"I think in terms of the hospital as well, another issue with my father, is that he was there and when the doctors were doing their rounds, the times can be varied, they don't tend to stick to a time when they are coming and obviously there is a communication issue."

"If your appointment was delayed and the interpreter has to go because they've got another booking. It's a bit like, hold on, we haven't finished."

There was an overall lack of knowledge on 'Patient Choice' as to hospitals and consultants.

“...really, you can pick any option, locality and that?”

“I've never been given that information, no...”

“...[I am] just asking, if the GP withholds that information, what do I do then?”

It was felt strongly that the Audiology service needed to have far greater Deaf Awareness when dealing with Deaf patients who use British Sign Language, and needed to provide more visual alerts on screens and subtitles.

“About Audiology, they're the worst, the worst of all, you know, - they literally have no Deaf Awareness whatsoever and it is a bit ironic isn't it really?”

“It's sort of a negative experience of Audiology. I had an appointment where I needed to have an audiogram done. I went to Reception and Reception had NO Deaf Awareness whatsoever, so I asked, “Can I have a pen and paper please?” She didn't even understand, you know, I was gesturing pen and paper, but in the end, she eventually got it, put my name down but, I am here for an appointment and this is in the Audiology department, they should be Deaf aware. So I was in the waiting room, there was a TV, no subtitles on the TV, which I was really quite angry about that because, it's Audiology - they should know we are Deaf and we're not going to be able to watch TV whilst waiting because there's no subtitles, but I just think some places should know better.. they don't.

Hard of Hearing Peoples' experiences

It was acknowledged that this was a busy and generally noisy environment which naturally makes communication difficult. Again, background noise e.g., from other patients, music, and even the 'acoustic signature' of the room, was difficult to manage with a suggestion as to the possibility of having a 'quiet' or 'silent' room for hard of hearing patients.

“Well the background noise or the background music they play or anything like that, - it's the other things you can't control – and that's the noise of the other patients there and the acoustic signature of the room you are in. They can't control that, unless, they had a 'silent room', or a 'quiet room' – obviously not silent, in case you need to use your phone – you've got to know, but a 'quiet room' – for those who are hard of hearing, but that maybe more difficult....I don't know...”

Again, knowing when it was a person's turn to be called into a practitioner was difficult to know with people deliberately positioning themselves where they could see or thought they would be called from, in order to try and lip read. However, where several names were called at once, this was particularly difficult to understand. A visual screen would help with alerting as to when a turn was, and where to go.

"I do position myself, especially at the hospital ...to make sure I'm in the right position for where they come out so that I can see them when they are saying my name."

"Often in a GP surgery like ours, it [your name] goes up on a screen but in a hospital, often they come out and say 6 or 8 names and people coming out from different places – and presumably you have to watch, - to know what they've said, but again ...it depends if they speak clearly enough."

"...on the [display] screen, - an arrow would also help, a name and the room number and which direction to go. You think 'Where's that', everybody knows that works there and that's the thing, - if you're not sure where to go and you ask somebody and you can't hear, - they are going to answer you and you will think, 'I still don't know where to go', - particularly, everybody's busy in that environment in hospitals, - it's kind of difficult."

"The last time I was there and was struggling to understand who was calling, it was because I needed a piece of metal taken out of my eye, so, it had nothing to do with Audiology. Even people with hearing problems have other problems too."

There needs to be better Deaf Awareness of the needs of this group and cognisance that another medical condition, e.g. an eye injury further impacts upon the difficulty of a) not being able to hear easily or at all, b) visual loss.

There was a feeling of being patronised by medical staff as 'stupid' when not understanding communication and a perception that it was 'too much trouble' to repeat the information to the patient.

"I find that they can be patronising because you can't hear and you are having to say, "Pardon, pardon", and they are very patronising and they actually treat you as if you are stupid and you say, "I'm sorry can you say that again because I'm hard of hearing", and it's just like too much trouble."

Issues had been experienced with communication breakdowns between the GP and the hospital which resulted in protracted delays and the client eventually requesting private provision. Further issues existed with the Audiology department in terms of: the waiting time to receive an appointment; the persistence required to chase for an appointment; different medical professionals for each appointment (when consistency would be helpful for communication and understanding); and requests for an easier checking-in system via e.g. ticketing/number system; and a visual screen to alert for their turn. Far greater support was requested for the management of hearing aids and far greater clarity of medical information so that patients did not feel as if they were 'in the dark' in managing their condition. There was feedback that the experiences of the high street provision by 'SpecSavers' was far superior.

“So perhaps it's about information around it – is what we are really saying here, but you are in the dark. It is a medical condition like anything [else], you don't know what's out there and what you can do, you are floundering.”

“Certainly, my experience is never being told about any support groups, from when I was hard of hearing until now and getting hearing aids was very protracted because I initially went deaf when I was at University. I went deaf for 6 months following 3 viruses, and so, because I've got asymmetrical hearing and visual loss they sent me to a consultant because obviously, the worst case scenario was a brain tumour. So, they sent me to a consultant who never gave me a follow up interview, and so I started managing with my hearing loss and then, because I was going to meetings and it was really interfering with the quality of my life, I went back to the GP and they referred me to X Hospital who then said that I needed to go back to a consultant, and so, I was back at a consultant again, and because he said that I was so deaf he didn't think the hearing aids would work for me and that I would have to look at other options – not implants, but [another] option. So, I went to a consultant and this time I said, “Look you know, I've been 2 years before and I was just cast off, and I want to know that this is going to be followed up and he said, “It absolutely will, but how did you go deaf?” I explained it, and he said, “Oh, we've got no records of you and I want to start right from the beginning with an MRI [scan], etc.” So, I had an MRI, then I got a letter from the consultant saying, that because my neuro transmitter was within normal parameters – I was discharged. So, nothing happened again, and so then you carry on, because life goes on doesn't it? Then, another 2 years [later], I went to my Doctor's and said, “Look, forget about sorting all my hearing out because of whatever it is, this irregular thing, - please can I have some hearing aids? It doesn't matter if they don't work very well they've got to improve my [quality] of life and can I please be referred, not to X Hospital, can you refer me to 'SpecSavers' or somewhere OK”? So then my appointment came for West Park, so I contacted them again and said, “Can I please go, please, please, go to SpecSavers...” and, they finally referred me to SpecSavers... but it's taken years and years”

Hearing Aids: Hard of Hearing Peoples' experiences

“If I wanted an appointment with the same audiologist, to change the settings, that wasn't available, so I had to re-explain the situation every time I went in, - it took a while.”

“There was a self-checking system but that has been broken for about 18 months, - every time I go in I think, will it work this time?”

“I think in terms of a quiet room, the aspect of being seen as well, people might miss the hearing impaired in the hospital....that would be

particularly useful in the Audiology department then they could build these things into it."

"I do think there needs to be something done around hearing aids. You get the NHS ones, and for me, I got mine from Specsavers, but the guy from Specsavers was telling me that because they get so little money for providing the hearing aids, and it's decided geographically, so for an area like Wolverhampton, they could make it actually, to have an hearing aid, they are getting so little out of it that they could not provide that service anymore and then, your choices are West Park or paying – and then we are getting into paying for your hearing aids and having information about them and all, it's just, a minefield."

"So, this is one of the issues, when I had my hearing aids, he quickly showed me how to clean them, and then I wore them, but when it came to me trying to clean them – what do I do, twist this off? I was frightened of breaking it. The point is, when I went to Specsavers – they just did it for me. Where you are saying about your hearing aids you should usually have places, like in Tettenhall, it's the doctor's surgery, next to the Institute where you can go in with your hearing aids, and they'll clean it and give you batteries, and do all that....you know that little book they give you, you just take that with you."

3 Urgent Care/ NHS 111/999

Deaf sign language users' experiences

"The hospital on the first day I arrived there was no interpreter, on the second day I made them aware that for the appointments that I need you to book them [interpreter] but I was told that I have to book them. It is the hospital, it is their responsibility, they should book them."

"You need an emergency interpreting service really."

"Obviously, we can go to A & E, or I'll go to a Walk-In clinic without an interpreter if we have to, just so that we can get something."

Overall, there was little or no provision of interpreters for Urgent Care (including Walk-In centres) with a reliance on writing information down by the medical professional to a patient with variable abilities in English competence. These situations must have a registered qualified interpreter present [NRCPD].

"I was rushed up to hospital and one of my students interpreted for me actually."

"I think if it is a visible injury, you know like a cut on your head it is easy to point to [for] the Doctor if you haven't got an interpreter, but when

it's pains internally, it is vital you've got an interpreter to explain the pains and describe them."

An incident was cited of a patient being told to find an interpreter themselves. Some services would provide an interpreter, but with a minimum of a 2 hour wait.

"I arrived there and I said, "You need to book an interpreter, you've got information there on how to book an interpreter" and they said, "No, you've arrived on short notice, we need 2 hours' notice to book an interpreter", - it's not fair, hearing people have the access straight away, so it's not an issue for them."

"...at A & E, when you go in, is it like a minimum wait of 2 or 3 hours roughly? So, it's an emergency [setting] I've gone into, so there's enough time for them to phone up and arrange an interpreter to be booked. You're being denied this, being told, "No, no, no."

An interim solution suggested was the use of Video Relay Services/Video Remote Interpreting [VRS/VRI] which could provide initially, immediate access in these settings whilst waiting for an interpreter to arrive and which only needs computer access such as an iPad to connect to the remote interpreting service.

".... it's very difficult when you haven't got an interpreter and pen and paper is just not the right way to do it. It can very easily be solved by getting an iPad and getting a signed service [VRS/VRI] that can be there for emergency use and there won't be these issues. When you are zonked out and ill, how can you write things down when you are not communicating in your first language?"

"With emergencies, - you have online signing access [VRS /VRI] which goes through the weekend as well like 'Sign Video' that would work wouldn't it?"

"My mobile has got 'I.C.E.' on it, which is – 'in case of emergencies' so my brother's name is on there so if there is an emergency, they can sort of see that, and they are able to contact somebody, and they'll know there is an emergency going on."

There were protracted difficulties in contacting emergency services via text message and no direct access available. There were difficulties with registering 999 by phone for text messaging with too many questions which were not understandable. A lack of understanding about the difference between 999 and 111 services prevailed.

"I had 2 different stories; one said for emergency it is 999, but now you are saying 111..."

"What's 111? I don't know what 111 is."

"It's not clear information, whether it's 999 to phone or it's not clear...I don't know what 111 is..."

"...the NHS 111, there needs to be more education on it really. I don't use it personally, because it's a phone line, I'd need a minicom, a text phone, there is no access."

"I have an emergency text for 999 on my phone and you get these questions like, 'Which service do you want? But, lots of deaf people won't know how to use that though. If you want 999 you must register for that, with the Police, ambulance and so on. It's a lot of bother to set up a 999 text. You could improve that though by for example, press 1, for Fire, 2 for Police, 3 for Ambulance – that would improve it, to simplify it and improve it."

"We'd be in bed and my husband would fall in the night, - in the bedroom, because he was in a different room I'd have to check on him every now and again to make sure he hadn't fell, but, I literally wouldn't be able to get in sometimes because he'd fallen by the door, and he hadn't pressed the button or anything like that, so, I had to call 65999, to the Police, and the Police would then re-direct me to somewhere else where eventually, an ambulance would arrive, so basically, it was a process, it wasn't a simple call to 999. My husband would fall an awful lot and I'd have to dial this number several times, I can't remember – I would text this number and it would go to West Midlands Fire Service, or Police Service, and eventually it would come through with what you needed. The Care Link panic button, wasn't that good because you would have to press it and then they would speak to you – like a help line, but how can we communicate back? So, I would just sort of text back, and then we would eventually get the answer and it was very much back and forth – a long process and eventually, somebody would arrive. On average, we would have to wait about 2 hours until the ambulance turned up. It just wasn't easy."

Respondents found that systems such as Telecare/Care Link panic button was not 'Deaf friendly' due to the use of spoken language communication and responses.

"Oh yes, the ambulance, so I'd go in and initially they'd start writing things down [asking], "What's your name" and that sort of thing and an awful lot of questions and I was weak, and be asked your name, date of birth, address, and I didn't have the energy to do it, it was very much- yes/ no questions and answers. It's easy for a hearing person, they can just answer with ease, an awful lot of questions to answer."

Examples of difficulty in Ambulance services with mis-diagnosis of condition due to communication breakdown and staff 'shouting' to communicate with a Deaf patient.

"...the ambulance, they mis-diagnosed my father, saying he'd got mental health issues, but actually, the medication he was on was too strong, and they thought he had mental health issues and referred him to the wrong Specialist completely, and when the doctor assessed him and agreed that he didn't have mental health issues, it was his medication, which was incorrect and it made him hallucinate."

"...in February I had some pain here in my chest a bit like heartburn and went into the 'Walk-In centre' at four o'clock. I waited about half an hour and my name was called and I said, "I'm Deaf" and they said, "What's wrong?" and I said, "I've got pain in my chest like heartburn or something like that", so, she checked it and sent me straight off to hospital and I didn't know what was going on because of the communication and I said "Hospital?", and I said "What's wrong - Why do I have to go to hospital?" and the nurse said, "Calm down, calm down". I couldn't phone my husband because he was Deaf, my son was working, so I phoned my sister but she didn't pick up the phone so, I've got my mobile and took out my phone and the nurse said, "Put the phone away", but I said, "I have my phone there", and she said, "Put the phone away", so I showed her the phone and the number and she wrote it down and gave it to the ambulance man. When I was in the ambulance I was being asked questions and I didn't really understand e.g., my name, date of birth, did I smoke - I've never smoked, drinking - sometimes I drink, - asking me all these questions, quite in-depth questions, but there was no interpreter, no signing, and I was waiting in the queue in a corridor. There were so many people around and I didn't know if anyone was calling my name, so I was waiting there so I asked someone who was passing by that I needed the toilet, but I was told that I couldn't that I had to wait and that was very painful just waiting in the corridor. My son came at 7.00pm and asked me what had happened.....and my son had to check if my car was still in the car park [at the Walk-In centre]. He went to the reception and asked where his Mum was, and my son was told that I had gone to New Cross Hospital in an ambulance, so he had to drive to New Cross and he was really worried, and he asked me why I was in the Cancer room for he had seen my name on a screen. I wasn't in the Cancer ward [area] at all, but I had been left on a trolley in the corridor in a queue in the wrong place. It was very stressful because of that. In the end, the Doctor came over to me with my son, - I had a blood test and X-rays, and in the end, it was found that I had a heart problem [due to] stress. 7 hours I was in hospital. I was never asked if I needed an interpreter."

Hard of Hearing Peoples' experiences

There was a request that Hard of Hearing patients are taken seriously despite the difficulty during communication. Clear communication was essential and communication difficulties resulted in the perception and experience that medical professionals became agitated when the patient did not hear/understand. People felt a 'burden' when asking for information to be repeated. There was extreme difficulty in understanding lip patterns where accents existed and with those who spoke rapidly.

"I think with everything you just struggle, don't you? I recently had to go to Accident and Emergency, and it was just an absolute nightmare because what they do is they come out and they call your name and I can't hear when they call my name, umm, I find that really difficult. That's the advantage when you go to the GP because they've got the name, your name lights up [on a screen]."

"It's irritating for people around you when you are deaf, I mean, I irritate everybody because I keep on and on and on saying, "Can you say that again, can you say that again".

"In A & E the acoustics are really bad, its particularly bad."

"The acoustics are terrible, absolutely terrible. The sound goes upwards."

"The thing is about making a distinction, if you are totally deaf, well they may or may not put signers in there or whatever it is, when you are hard of hearing, it's not taken seriously but you still can't hear anything and so you spend your whole life just saying 'Pardon, pardon' and apologising as if you are stupid."

"It's just a case of having to repeat yourself lots of times. Going back to the thing you've just said as well when, if you're phoning up or speaking to somebody in Health services and they haven't got somebody where English is the first language, that makes it even more difficult, and communicating with consultants where they struggle with their English, it's really difficult when you can't hear and you can't understand each other."

"I recently went to A & E with my thumb and when I was speaking to the consultant, I haven't got a clue what he was saying. I was saying, "Look, I know it's not broken", because they speak quickly and they are wanting you in and out aren't they? It was really hard."

"Yes, it is lost in translation. I'm saying, "Look I'm sorry I'm hard of hearing, I don't really understand". It's a medical issue and they need to explain it more clearly."

"It's hard enough explaining it to somebody who has got full hearing and full understanding. You need to pick up on the nuances in what they are saying and I haven't got a clue, not a clue. I ended up

frustrated because I came out because I wanted to know what could happen. OK, it's not broken, it's not right, but what could I do and I go home and I'm there 3 weeks with a thumb that needs some sort of care and I don't know anything about it. There is a breakdown in communication. Very frustrated and thinking 4.5 hours of your life gone."

Requests were made that patients' names are not shouted out within this busy and noisy environment and a visual alerting system e.g. screen should be present in order to know when it was your turn and where to go. Suggestion was made that a ticketing/number system would provide far greater clarity.

There was a lack of information and knowledge about how to register for emergency services via a mobile phone, manual dexterity issues with using them and difficulty in phoning emergency services but not hearing the spoken response.

"Again, you see, if he needs to phone the Emergency services for anything he would have the same problem of not being to hear the other end."

"I don't have a mobile phone, I can't use it and I don't want to use it and that's typical of older people actually, there is a resistance around that and so texting would be brilliant but, my equivalent of texting is emails. To me I can be sitting at the computer and communicate by email and anyway, you have these other issues as well to deal with."

"[I am] short sighted – you've got to work on a small screen with your fingers and you can't see."

"I remember phoning for when my friend was having a stroke, the thing for me is that it is incredibly frustrating, because when you are hard of hearing you have to concentrate so hard on what people are saying, especially when it's important things. You can kind of switch off when it's just trivia, but, when you have to make notes, - it's when it's important what they are saying, it can be really, really, tiring, and it's frustrating when you mis-hear what they are saying and then they get agitated because you are not responding to what they are saying, and then you are getting frustrated because you are not getting the point over."

4 Dentist

Deaf sign language users' experiences

"My dentist doesn't book interpreters. I go in and I ask them to book interpreters and they [say] '.....We'll be making gestures.....don't worry when you are lying down I will gesture,put your hand up if you

want',I said I will need an interpreter and I've been told, 'No, no, you'll be fine, you'll be fine – you'll be in and out within half an hour', so again, they won't book interpreters."

There were overall difficulties with communication due to the lack of provision of a sign language interpreter with patients being told that they do not need one. Dentist's indicating to patients that 'gesture' alone will suffice and or writing communication down on paper.

"My dentist.....it's OK, I've known the lady a long time to be honest so you sort of get along with it don't you, but with the mask, that can be an issue because they have to wear it, but they don't always remember to take it down to talk to you and when she's sort of finished, she'll write it down on a piece of paper for me with instructions or whatnot, but whilst she's treating me, she does have to wear the mask, but we need that communication. They don't think about that."

Patients experienced significant issues in trying to lip read or read facial expressions of their Dentist due to a face mask being in place, and Dentists not pulling the mask down frequently enough.

"Well, a dentist wears a mask! Don't they! And I'm like, "I can't understand you", and, they sort of move the mask slightly, but it's just a pain. You can't communicate with them at all."

Patients were worried that if they booked an interpreter themselves that their Dentist would be annoyed and instead accepted that they would have to 'muddle through' communication.

"I went to the dentist recently and I said, "There is something hurting", and it's 100% hurting but they couldn't find anything and they said, "Do you want somebody who can sign?", and there was somebody upstairs and then they came down and actually pulled my hand out and started doing the Deafblind manual on me, NOT British Sign Language and I was, "Excuse me, I am not blind"! So yes, that was shocking really. I was a bit embarrassed, I think they were a bit embarrassed too. I mean, I used my 'Access to Work' interpreters from [work] to go to the dentist with me in office hours which helps me a lot, because I'm able to do that but, now I'm retired, I have no 'Access to Work' so, what would I do? Luckily my dentist knows how to communicate with me anyway so we just sort of get on with it."

"My dentist explained to me recently, something about my teeth and I literally had no idea what they were saying, because the jargon they used and the way they were doing it, I just didn't understand. They showed me the X-ray and they were pointing at things and I think they said there was something about the gum and sort of gesturing, and I

think they were saying something about age. But, because it was quite visual, because I had the X-ray, I sort of got a little bit of the information but, pretty much it is impossible to understand so, we should have interpreters at Dentist's appointments and I did say, "Hey look, next time I want an interpreter" and the receptionist said, "Oh don't worry, I'll explain for you" and I said, "No, no, I want a proper interpreter".

Within the waiting room, patient indication for next turn was an issue where no visual indication via a screen existed and patients being 'called' to their Dentist when they could not hear this.

It was generally found to be easier to book an appointment with their dentist, whose practice frequently operated more flexible methods of contact than GPs did.

*"My friend just said about private dentists, - it shouldn't matter whether it's private dentists or NHS dentists, you know, it shouldn't matter should it, you should still have an *interpreter*."*

Hard of Hearing Peoples' experiences

Effective communication needed to be established with examples of current practice frequently demonstrating the Dentist talking to the patient when sitting behind them, which therefore, could not be understood. An effective and agreed system for alerting to pain needs to be established between Dentist and patient, as frequently instructions for this, e.g. the patient putting their hand up, were not heard from the outset.

"How do you talk with all those things in your mouth?"

"I think when you have a procedure and they explain something to you, like during the procedure, as they are going along and they say "Oh, I'm just going to..." or, [they should] stop and walk around and take the mask off and explain. From my perspective of attending the Dentist, I don't really know what is going to happen, I just sit there because they have the mouth mask on and are sitting behind you and there is absolutely no chance. I can't hear."

"A problem for some people if you are lying down and they say, "Put your hand up or move your arm or something if it hurts", and if you don't hear them say that, it could be hurting and you are thinking what do I do – how do I let them know, you need to let them know – you need to speak up, to make sure you understand people."

It needs to be remembered that not all hard of hearing patients can lip read and Dentists need to have patience and the time to repeat information until understanding has been achieved. There was increased difficulty understanding information when spoken rapidly, and with an accent.

“When I was a child, I attended one dentist, and I’m not sure how health and safety appropriate this would be now, but he took his mask off and did the treatment so I could lip read him.”

“Is there such a thing as a transparent mask? Because, if they could make it transparent, like you see some of those dressings which are transparent – I don’t know, would you be able to see enough?”

“I try really hard, but I fail every time to lip read.”

“On the whole, not too bad, sometimes I have to ask them, “Sorry I didn’t hear you”, if there is a problem.”

“Do you think it’s something to do with a one to one at a dentist, where in a hospital it tends to be a lot bigger and even in a consultant’s room, the acoustics tend to be really bad in all hospital rooms.

“In a Dentist you depend a lot more on lipreading don’t you?”

Waiting rooms need a screen to alert patients as to when it is their turn to enter the dentist’s room, and loop systems need to be in place together with signage to indicate that they exist.

“At the dentist we go to, they had a screen, and it played a TV programme, except someone broke-in and stole it, it took over 6 months [to replace], - because it was 2 appointments before they replaced it, and now they’ve replaced it, they no longer put the names on. I don’t know if they haven’t connected the software....”

“Some places have loop systems but, if you’re not wearing a hearing aid, it doesn’t help at all and I don’t think they really understand that.”

“No, I’ve never been made aware of anything [loop system].”

Making appointments and returning telephone calls could be problematic where hearing the phone ring was a key issue.

“In terms of calling back can be an issue. Sometimes I miss a phone call say, if you’re chasing an enquiry, missing calls, that can be quite difficult.”

5 Opticians and Pharmacists

Deaf sign language users’ experiences

“I mean I’ve got a problem with my eye and there is a dot on my eye. I went to the doctors first and they said it would be best to go to the opticians. So, I went to my local opticians with an interpreter, luckily, I managed to get one to come with me and I said I need further checks on my eye, so if I could book an appointment and asked them to book an interpreter and they actually said, “No” and they said because they weren’t part of the NHS, they were private, that I couldn’t have an interpreter. I said, “but my eyes are literally so important, I am Deaf, my eyes are everything”, and they told me to go to Accident and

Emergency and so I did, but again luckily, I had an interpreter with me. So, I went to A & E and the interpreter didn't arrive, so I used the interpreter I'd got with me and in the end, the hospital actually said I needed to go back to the opticians to do a test, so I did, and I asked for an interpreter and they wouldn't do it, so literally, it was problem after problem. I went back to my GP, explained the whole thing to the GP and the GP was actually VERY angry and phoned the opticians and luckily, after a sort of big fight if you like, they provided me with an interpreter...."

Experiences of no interpreter being provided for NHS services with provision being reliant on writing information down. Even when requested, there was frequent refusal to provide an interpreter. The darkness of the opticians room created issues for understanding the process with clients not being able to see in order to try and lip read and see facial expression. People indicated that opticians need to explain the process first in a lit room before turning the lights off.

"I don't have an interpreter for it, I would prefer to have an interpreter, but when they put the lenses on you might not be able to see them, or if it's in the dark. I don't know, - obviously if they are doing a test you have to look at the interpreter and concentrate on the test – that would be quite difficult actually, impossible."

It was strongly communicated that opticians need to realise the elevated importance of eye sight for Deaf people as the only means of communication for profoundly Deaf sign language users.

"My experience with Specsavers was that my wife [who is also Deaf], goes online and books the interpreter, but recently that [provision] doesn't seem to be happening. I don't know whether they've changed their policy or their access, so we both [now] go to the opticians together, and sort of have to 'interpret' and support each other which, I don't feel is right. You know, she needs to focus on her information and her appointment [not on trying to understand without an interpreter]. I mean a lovely young girl was sort of conversing with us and I got my glasses OK and correct, but it shouldn't be like that. You know, there could have been an error in communication and information, I would have [received] different glasses that weren't appropriate. Again, I used to use an 'Access to Work' interpreter to go to the opticians and now I'm retired that's not an option, and really, you are not supposed to do that, it is supposed to be [use of Access to Work interpreter] in work hours, you know.....it's abusing 'Access to Work', because 'Access to Work' is for people who are in their job, but because we have no choice, we abuse the system, every now and again you know if there is an emergency, but it is not a normal thing to do."

"It's not the correct thing to do and like this gentleman just said...., I just sort of go out of work for 10 minutes you know, and the interpreter comes with me, or used to [now retired]."

An example was cited of excellent provision being arranged for a deaf client from Boots chemist the High street dispenser.

"Mine's quite positive actually, we go to Boots Opticians, and they book an interpreter – so that's fantastic. I know some opticians refuse to book an interpreter, but luckily, they've done it, so we still use Boots Opticians."

"For me, I tried to register our family with a new opticians, and I literally asked so many places if they would provide an interpreter, and they said "No". So, I approached Boots in Wolverhampton and they said 'Yes' and they said they would provide an interpreter for [the] family.... that was a positive experience."

Pharmacists:

"Well, if the GP has given me a prescription, I go to the pharmacist, hand it over, then I'm given it with printed information about the dosage, how often to take the medication and such, if it's one or two, and how many days and that, and then the leaflet contained within the medication box is obviously jargon to me, it goes over my head, but I just take the tablet and a brief explanation of what it is."

There were issues with understanding the Pharmacist due to no interpreter provision and subsequent communication difficulties with examples of Deaf clients using family to help them communicate.

"I did go into a [consultation] room once before as I had Shingles but I wasn't sure obviously at the time, [I] went in and luckily my brother came with me but he's a male and I'm a female. If I had a female interpreter, I would've felt a lot better, but this is what we have to use sometimes, - use family."

"Sometimes the medication itself - the tablets, the packets, the information on there, I don't understand that, so I might sometimes have to ask the pharmacist whether I can take this tablet with another tablet and they double check if I've got any other medication. That's vital for Deaf people to have access to that communication because that's such an important thing to know, it can be quite dangerous really."

There were consistent difficulties with understanding prescription information and medical guidance.

"I go the chemist myself and sort of write down what the issue is and communicate with them that way and they will provide me with whatever they think is appropriate and obviously, you have to pay for the medication you're having if for example, you've got an upset"

tummy or something. You write it down, you show them, they give you the appropriate medication."

A suggested requirement for Pharmacists is for them to have Deaf Awareness training and a clearer explanation for Deaf clients to be able to understand what the consultation room is for.

"I don't have a problem really [accessing pharmacists]."

"In terms of the private room, some Deaf people don't know what that's for, maybe they think it's for staff, so they wouldn't ask to go in there."

"My local Boots chemist, they've got a consultation room, and I didn't really know what that was for, - to be honest. I found out recently, that you can go into the room and talk about medication and things like that, so that's quite useful. Whether they provide an interpreter for that, I don't know."

Hard of Hearing Peoples' experiences

There were no issues stated in terms of dealing with pharmacies or with the staff therein, with flexible approaches to communication cited.

"My pharmacist is excellent anyway and would come to me and speaks one to one, and makes sure he is being understood."

There was however, experience of difficulty when communicating with opticians due to instructions being given when the lights had been turned off in the consulting room. Lip reading cannot take place in these conditions and information needs to be clearly explained to the client before eye/sight examination commences.

"So difficult when they turn the lights off, and I don't know which direction to look at and I can't lip read because the lights are off."

"What would help is an arrow showing which direction you ought to look."

"Look left first and then after so many seconds look right, [then] down – if they told you beforehand,... I don't know if that would work?"

6 Community Services

Deaf sign language users' experiences

"Once, I think I was at the health centre, with my husband for the Brain Clinic, - so we arrived and the deaf support worker was there, the interpreter never turned up, so the lady there asked the Support

Worker whether they could interpret and he said, "No", and she said, "How about we carry on the appointment and we can sort of write things down to each other", and I said, "No, I'm not going to do that", I need an interpreter, and she said, "Why not, we can do it, come on, we've got to do it now and get along with the appointment", and I said, "No", and then we couldn't continue with that appointment because the interpreter never turned up."

No interpreter provision was frequently cited and where services existed by way of 'Drop-In', there was no BSL access for this which forced alternative communication via writing down. Opportunities for Deaf parents to socialise with other parents in child based forums such as 'Stay and Play' provided no access via an interpreter and therefore were not inclusive.

There was a need cited for Deaf people who use BSL as a first or preferred language to work in community/support services in order for direct and effective communication and access to be achieved.

"A health visitor for the Deaf? If it's a hearing person who can only sign a little bit, that's not very good either. You need Deaf people to actually do that, to be the Support Worker, to work as carers - to do the shopping and medication. Hearing people apply for the job, but it's working with Deaf people, so it's kind of oppressive in a way for Deaf people. So, you need to encourage more Deaf people to be involved in health care and looking after older Deaf people because they are often alone."

"For me, the health visitor, normally they'll say I'll visit on this day between 9am and 5pm and I'm like, "Oh hold on, you know, I need an interpreter" and they're like, "Oh yes you're Deaf aren't you"? I say, "Yes, you can't just give me a vague 9 till 5". You need to book a specific time so that an interpreter can be provided. So, they need to obviously adapt their working routine, for me, which I understand is different for them, but that's the way it has to be because you can't sort of just say, 'we will come along sort of between 9 and 5'. That's what they tend to do. Just give you [a broad time frame] and then just drop in. For me and other Deaf people, you would have to say a specific time. Luckily, they did adapt."

In settings such as a GP surgery where noticeboards displayed and advertised a range of community services, e.g. bereavement, stopping/cutting down on alcohol, smoking, obesity etc, there was no way of accessing these via BSL due to no interpreter provision.

"Community services in terms of care, carer support, obviously a lot of us do care for a disabled person but, in terms of carer support and support groups, we can't attend because there's no interpreters, they don't have the budget for them. You know you've got Parkinson's UK

or a carers group, - we can't access them because of the interpreting issue and there's no support."

"There is also no interpreting provision for Dementia Cafes."

Variable provision of interpreters was reported for physiotherapy services with some receiving interpreters and some not.

"There is a physio at [X hospital] and they do provide an interpreter, and I've never had any problems with them."

"Yes, physio - I didn't have any interpreter for my physio."

"My wife and I both have had physio, but we do have an interpreter provided, that's [therefore] not a problem at all. They are booked, not a problem."

Regarding Council and Social Services provision; Wolverhampton Council appears to have removed specialist services for Deaf people with referral delays and no specialist support. Currently social workers appear to have no specialist knowledge about Deaf people, sign language ability, Deaf Awareness or specialist provision. Examples of clients receiving multiple social workers across different departments with a heavy reliance on the Deaf client to educate and inform each social worker on service provision specialism for Deaf people. There were issues with lack of funding for carer support or interpreting provision, and little in the way of community support.

"No skilled or experienced social worker for the Deaf, from Sept 2016 to Feb 2017 – we went through 10 different social workers. Not one of them knew anything about Deafness."

"My husband, with Wolverhampton Social Services, - the experience – Oh, it's just awful. I don't know if it's the Council strategy, they've literally removed Deaf Specialist services, to become more mainstream, they have these teams,the referral gets delayed, they get the wrong support, - there's no specialism within the Council. No Deaf professionals."

"We need Deaf specialist services, in the community, having that outreach service for Deaf people."

"There are no Deaf social workers, - it's the funding, isn't it? It's always the same, it's about the money, affecting us..."

"....my father is in a care home because there is literally no support for mum. Respite wise, mum would want to go out in the evening, so we'd be told, "Oh yeah, we've got respite support for you", and we'd ask, "Can they sign?" and it was always, "No, they can't". So, mum wasn't comfortable going out and leaving dad with someone who can't sign."

"There is carer support as well, so information and resources from local carers in the community but they don't support her, they haven't got the funding to pay for an interpreter."

Community Services Hard of Hearing people's views

There was general agreement and request for clearer information as to what is available in terms of service provision and technology to assist, e.g. environmental aids in the home such as the installation of a flashing light doorbell.

"[There are] Technology needs, e.g. a flashing [light,] doorbell, and access to this information."

7 Nursing Homes/Care Homes

Deaf sign language users' experiences

Deaf people report there is no Council or privately run Deaf Care Home in the Wolverhampton area.

"We need a care home for Deaf people, with communication, that's just what it is."

"I know for a fact, that there are no specialist care homes which have provision for Deaf people in Wolverhampton, the nearest one is in Blackpool or the Isle of Wight. Deaf people, older people that need care, nursing care - they've got an adult service in Walsall which is run by Action of Hearing Loss, but that's for Deaf adults with learning disabilities, but for Deaf older people, whom potentially need nursing care, as I said, the nearest one is Blackpool and [the] Isle of Wight."

"It's very, very, very important around the UK about the care of old people who are Deaf. I worked in a care home before, and they were all hearing people and there was only one Deaf person there, an elderly Deaf person and I was the only person who could communicate with that Deaf person and she relied on me an awful lot as she couldn't communicate with hearing people. You need an old peoples' home for Deaf people. It's very, very, isolating and unfair on a Deaf person to be the only Deaf person in a hearing home for Deaf people. If you had a Deaf care home that would be a lot better with staff who could sign, then you care for the Deaf person a lot better and people have the right qualifications and they will live longer that way. If a Deaf person is alone its very lonely and isolating and not fair on the Deaf person to be the only Deaf person in an old peoples' home."

There was evidence of inconsistency with medical and care home provision of interpreters, with professionals making decisions as to when an interpreter was required thus, creating difficulties for patients and their families. This often resulted in

forced communication for all concerned via written form which in turn raised the level of 'risk' for a patient via potential misunderstandings.

"Pen and paper – it isn't too bad you know, we can do it but, we are used to writing little bits down, and it's very much back and forth all the time."

It was uncertain as to who was responsible to pay for interpreter provision, with an example given of a private care home.

"In regard to the Council – would they pay? They pay the care home, they are responsible for my father so, shouldn't it be in the contract that it's their responsibility to provide interpreters? Whose responsibility is it? There's no boundaries. Social Services say "It's not me", the care home say, "It's not me", it's the Council because they are funding part of the payments", - so who is responsible?"

"The care home don't want to fund an interpreter because it's quite costly and I think that's the problem....."

"Ideally, I want a care home for Deaf people. I'd still visit him and that's why I visit him everyday because I don't want him to be even more on his own than he already is, because they all are hearing [people] in the care home. He's the only Deaf person and, as I've said, the nearest Deaf care home is in the Isle of Wight. The care home have provided a brief course for the staff and they've done that, but that's all they've done really. So, they kind of have a little bit of Deaf Awareness but it's not enough really. They don't have a conversation with him naturally and they sort of generally just do what they need to do with him. Whereas, with other people in the care home, they probably have more normal, day to day chats with the staff because they can communicate with them, whereas my husband has to rely upon us going to see him to have those normal conversations."

Care Home provision demonstrated little or no Deaf Awareness knowledge which is critical in order to maximise effective communication with the patient.

"...the care home doesn't have any Deaf Awareness..."

"In our old doctor's surgery, they booked interpreters and now he is in the care home it's a different surgery, they don't reinforce that and they don't do that. [X surgery] won't provide interpreters. The care home is responsible and the staff know what my husband's problem is but he can't hear what they are saying, he can't communicate – they say it's just not necessary, they say they'll get along, they'll explain for him but, my husband wants to know what the doctor is saying...."

Issues were raised over the quality of life and mental wellbeing/health for Deaf patients isolated within a care home made up of other hearing patients and staff. There was no local provision for a Deaf care home with the nearest being in the Isle of Wight.

"...he's actually in a care home, in Wolverhampton, but the process to get to that point was horrific and again we made a complaint about that. He's in a care home now, which is fantastic, but there's ongoing issues, because he's very much isolated, he's the only Deaf person. The staff can't communicate with him very well at all, if not at all. You know, he's now saying he wants to kill himself, he's got mental health issues. His mental and physical health has literally deteriorated because of this process. We've made formal complaints and again achieved nothing."

"[The] journey to the care home was a massive battle with social care professionals and health professionals, because they were adamant that he should stay at home and we said, "Well that's fine", but if we just had carers, he would have literally needed them 24 hours and the carers need to be able to sign and they [the professionals] were like, "No, no, you could use anybody". No! It's got to be, they've got to wash him, they've got to..., it's very intricate care isn't it you know. It doesn't work like that. If we managed to find somebody that was able to do that for 24 hours, it would be £125,000 a year for somebody to do that, which in a care home it's an awful lot cheaper. In the care home you obviously have got a better service, because you've got hospital beds, you've got everything there and staff who were trained but they wouldn't listen to us."

"....there's a woman here in Wolverhampton, who's 94, lives on her own, has no support whatsoever, but she's a very proud lady you know, she's like 'No I'm fine, I'm fine', and I'm actually thinking – ooh, you know? My wife and I are quite concerned about her, because we're just waiting for something to happen to her, a fall or something. At the moment, she's very much 'I'm fine' because, there's nowhere she could go to. A lot of elderly people don't want to go to a care home in Wolverhampton because of the isolation and the mental health issues, they don't want to, so they avoid it."

"I know one lady- she has to be over 90 by now, she had Dementia very badly and she's in a care home. Her daughter can't visit her own mum, because she's ill herself and it's quite a serious illness. My wife visits her and it's very emotional, but her mum has got nobody. There is only one Deaf person in the care home, so my wife will visit the daughter and her mum who is on her own with nobody who can communicate with her."

It was stressed that Deaf people in these settings need BSL using Deaf support staff too, as well as in their own homes and Day Centres.

“One of our friends, a local couple, both need carers who come to the home, but then the situation became worse and the woman who had health problems went to hospital and the male was on his own and he really wanted to visit her. They both ended up being in a [care] home and then some time later the elderly lady was I think, in hospital and then the male missed out on all the information, he didn't know what was going on he was like sort of where is my wife? What's going on? They didn't see each other and then the wife came back to the old peoples' home, but the husband still didn't get to go back, and nobody was sharing any information with him whatsoever. There was a massive breakdown of communication and they finally reunited of a sort, if you like, but then a couple of months later she passed away and then two months after that, he passed away. So, they [didn't have the opportunity to be] reunited for such a long time and I think that just didn't help. In terms of the couple - the wife doesn't really speak well; the husband spoke very well and he can communicate to another person but they wouldn't be able to communicate back. I think a lot of people thought because he could communicate via speech, that they could communicate back [via speech], but that wasn't the case. You know he had good speech but he hadn't got good receptive skills, but a lot of medical people need Deaf Awareness, that just goes back to what we originally said, all Deaf people are different in the way that they communicate.”

In terms of Hospice, terminal and respite care, it appears that currently, they have no budget to pay for interpreters which, in turn at a critical time, further isolates and causes distress to a Deaf patient and their family.

“There is an important thing about ‘hospices’ – for people with cancer, or people who will soon die. Lots of hospitals have a budget to pay for interpreters, but a hospice has a budget to pay for nursing care but there's no budget for interpreters. A lot of Deaf people would need to go to a hospice and they just give up on life and die very, very, quickly because there is no communication, so a hospice should be able to pay for an interpreter or a carer – a Deaf carer to work with Macmillan or palliative care, so I would like to see training for Deaf people to be carers to look after older Deaf people who are in a Hospice.”

Hard of Hearing Peoples' experiences

There appeared no basic Deaf Awareness knowledge within the experiences shared. Hard of hearing people felt isolated and communication was difficult. Shouting appeared the preferred means of communication, and a feeling that communication difficulties branded the individual as a 'trouble maker'. There was request for staff to learn the tactics of clear communication and some basic sign language.

“Communication problems brand you a 'trouble maker'.”

"I used to work as a senior care assistant in a care home, - it's amazing that there isn't any basic Deaf Awareness training in any care home that I've worked in or been into and I've worked in a few."

"There is no Deaf Awareness, people don't even know how to put a hearing aid in."

"Shouting is the preferred option [means of communication], from what I've seen."

"Talks on basic Deaf Awareness training, - not necessarily BSL [British Sign Language] the basics of what we do, e.g. no shouting."

There was a general consensus that care staff required far greater knowledge regarding the maintenance and fitting of hearing aids.

"Hearing aids as well, they don't know how to check them, and I was not in a position to talk to them about it."

"If I wasn't able to put my own hearing aids in correctly and someone put them in for me, then I was missing everything....so someone on shift should go round and check everyone's hearing aids are in properly instead of shouting."

It was felt that no appropriate provision for care, such as Sheltered Housing existed and concerns that maintenance for Telecare has been cut and therefore, there is no one to repair it should it break.

"I've been in sheltered accommodation, in Tipton and it deteriorated all the while."

"There was no care at all. Sheltered Housing – but there was nothing there. There was no support around, e.g., checking upon you at night. They used to call me in the morning, - but I gather there is practically no help at all."

"Summerfield – that was the worst of all".

"So, there was no supported care and there still isn't. The other people we spoke to that we used to know there, they said it's got worse, in fact I spoke to [someone] a few days ago."

"I'm on Telecare and you need to know what my concerns are there because they've cut the maintenance for Telecare, so if it goes wrong, I've got no one to repair it, because they've stopped the service."

8 Complaints about the NHS

Deaf sign language users' experiences

"My issue about the complaints procedure, - complaints to the hospital, I feel that they just brush them away. They say, "Oh, yes we admit, we admit this, we admit thatwe'd like the training" and

then that's it. That's all they do, and then it's done and dusted, and I say "Fine, you are admitting it, but then what - what are you going to do about it? How are you going to improve it?"

Many respondents felt they did not know how to make a formal complaint to for example; the NHS, GP, hospital.

"...complaints have had to be made, but, how do I make a formal complaint to my GP?"

There was confusion as to the different pathways to complain/feedback such as; PALS, PPG's as to what these services and processes actually do.

"I don't know, I don't know at all. I was told you were meant to write to PALS, you are meant to write to them. What is it? What is PALS? That is where we had to complain to eventually."

"I think the other issue with the complaints procedure, there's too many pathways, - you've got PALS Healthwatch, the Complaints Commission..."

"Where do you go to complain?"

This raises a key question as to how a Deaf person who uses British Sign Language as a first or preferred language presents a complaint when the procedure for doing so is based upon making a complaint in English? Deaf people need to be able to make their complaint and provide feedback using BSL, and there was a feeling that the NHS should provide a translation service or an interpreter for this. The implementation of Video Relay Services/Video Remote Interpreting (VRS/VRI) should be standard practice for immediate access and 'Sign Video' is a service which could be used to make complaints.

"The other problem obviously is that we don't know how to complain to the NHS and the process. Deaf people when they do complain to PALS, some people might be able to type and understand English, but not all of them will, so, will they use and accept 'Sign Video' [VRS/VRI] to complain? We could sign it, and send a video [digital BSL clip] to them. The staff could get an interpreter and understand it through sign language [English translation] - could they do that? Why shouldn't they?"

"With complaints, - for Deaf people their first language being British Sign Language, so for a complaints procedure which has to be in English, that's a barrier straight away for us. 'Sign Video', I really, really recommend them, I feel very confident, it meets our needs, that is very useful."

"[Making a complaint online] - But it's all in English - my English isn't too good, so would you understand it? My first language isn't English."

"I've been through the complaints procedure and they just never responded...about an operation about 10-15 years ago...there's been no response."

"In terms of complaints, the complaints procedure is awful. I mean we made a serious complaint to the NHS, they responded, but their response was unsatisfactory and we weren't happy with their response so we brought it up with the Health Ombudsman and the barriers we faced there - it was like, "Look we haven't got the time, we haven't got the resources we are completely worn out, we don't want to drag this on any longer, we want to move on with our lives", but it was just an awful experience."

Where a Deaf person had made a complaint, they felt that the hospital had brushed it away with platitudes and even where responsibility was admitted, the service did not improve, leaving an impression of, 'Why bother complaining'?

There was a serious example given of 'forced treatment' on an elderly Deaf patient but no method of recourse to this.

"...so my father was forced to have a catheter, and he said "No", he didn't want it, but they forced him, and he has the right to say 'No'. He did say 'No' but they forced it onto him – so where are the human rights there? Horrific. Really horrific."

It was essential to be provided with a registered qualified sign language interpreter [NRCPD] consistently and the NHS needed a Deaf expert on board to provide regular Deaf Awareness training. There was awareness as to the high staff turnover in such a large institution and the need for regular updating and inducting of new staff in Deaf Awareness.

"The professionals don't understand the barriers we face on a daily basis. We try and explain but they just don't get it and they always look down on us like Deafness is a second-class thing, thinking that Deaf people don't know anything, that we know better than you but actually I'd probably say I know a lot more about Deaf issues and Deaf barriers than them, but I have to fight all the time."

"We need to see more Deaf Awareness training for everybody. All medical people within hospitals, GPs, dentists, therapists, etc, rather than relying on interpreters only. I understand you know, yes, we do want an interpreter, but, they think by doing [providing that], that's it, we can just get on with it."

It was felt that posters needed to be displayed in services such as hospitals and GPs surgeries about how to communicate with Deaf people and for Deaf people to know how to make a complaint."

“Well this forum or this project, I feel like I have repeated myself for the last twenty years and nothing has improved. I am completely fed up with complaining to professionals and sharing information and giving feedback, and I just think any service in Wolverhampton you know, health and social care, education, whatever, the first point of contact is always by phone and if I email, sort of eventually find the address to email them, I never get a response and I am really, really, fed up with that.”

Hard of hearing peoples experience

Front line services do not understand the needs of Hard of Hearing people and do not respond to them using an effective method of communication.

9 Interpreting/Translation agency provision (CCG): Deaf sign language users' experiences

“For GPs, they use an agency and they won't use qualified interpreters because they want to use the cheapest option”

Service users raised concerns about the qualification levels of interpreters that they had been provided with and interpreters when they had been booked, not arriving for the appointment. They were left with the impression that due to the tendering process, the cheapest option was being favoured in place of 'safe' interpreting. They also found it difficult to understand that contracts were being awarded to non-local providers.

“Well, we want qualified interpreters, we prefer 'Communication Plus' “

“With GPs, sometimes they book interpreters for me, but when they actually do book an interpreter, they use an agency called 'Absolute Interpreting' which is a very poor service, - they sort of use cowboy interpreters unfortunately, the interpreters will come along and quite often they are not qualified and they are not experienced enough, so the information they are interpreting for me is incorrect, so that is very dangerous. The commissioners need to be aware that some interpreter agencies shouldn't be used, and they need to make sure they pick the correct and qualified interpreting agencies. They need to be qualified interpreters.”

“Obviously, they're doing the cheapest option, which is not the right option, but to be fair [in] Wolverhampton there are a lot of female interpreters, not many male interpreters and I accept that, you know, that can't be helped. If we needed [it] if we've got male problems, we would need a male interpreter and that's not easy. It's not easy to get one.... before I've had to have a female interpreter, we just must accept it. Can't say no, otherwise we wouldn't have anything. We wouldn't have any communication. Look away and then we can show our bits and then we can get on with whatever we need to do.”

Deaf people also reported that they were uncertain as to the current interpreting service provider and whether there were in fact multiple providers for different settings. When comparing the recent changes in interpreting service providers, there was greater dissatisfaction with a current agency provider in contrast to a previous provider.

"I don't know if the NHS contracts 'Communication Plus'? The contracts keep on changing, so therefore agencies [suppliers] keep on changing, and that's an issue".

"In the last 3 or 4 years, [X] was the main interpreting agency for the NHS, and recently it's changed, now we are very much confused as we don't know who is providing the interpreters. I think they still provide interpreters for the hospital but not for the GPs, but it's very confusing, it's not clear at all."

Deaf people stated that over the years they have experienced reduced choice in selecting a particular interpreter, and fail to understand, given there is a contract in place, why there is too often no interpreting provision.

"I'll say I want an interpreter – this [particular] interpreter, but no, we have got to use this [particular] agency, so obviously before when it was under the PCT, we could have a bit of a choice - we could recommend that."

"[there should be an on-call interpreter] - It should be 24 hours"

"I just want to clarify, before we used to use [X] and about 10-15 years ago, there was no 'on-call' interpreter, when another provider won the contract they would provide interpreters 24 hours, you would just phone and get an interpreter straight away. Now, thank (goodness) the new provider still has contracts but not with the GPs unfortunately and not with the dentists and opticians, so that's the problem really."

".... it was literally just like that. [The] contract ended, literally just the same day if you like it, you know, it just sort of it went.... I just completely disagree with that sort of agency."

"I didn't have any information to say that the interpreting agency contract had changed. I know that before, it was [X] agency, and then they [CCG] used a London agency. I did get an email to inform [about] the contract for the different agency.... but... I didn't know the PCT had finished and that they'd switched to somebody else...., we didn't get notified, but...when I'd said... I want this specific interpreter, because they work for 'that'[particular] agency, and they're like, "Oh no, no, we don't use that agency anymore."

In emergency cases, due to there being no 24hour provision and no short notice provision, Deaf people were faced with communication barriers. This results in some cases in people being forced to make their own arrangements, i.e. sourcing their own interpreter, and even feel forced to use them from other publicly funded sources such as 'Access to Work'.

"NO, no, no! I have never experienced, oh actually, maybe once but, I was lucky because you know I used to work at [X], so I knew which interpreters were not working because it was school holidays, so I would just text them and say could you come along, so that was a one off, and the Doctor was really quite angry with me that I asked sort of asked an interpreter to come along with me, but I knew they were under an agency and obviously interpreters work all through holidays, so they work for different people. So, I did that, I did happen to have an appointment on the same day with an interpreter, but the Doctors weren't happy because they said they needed to use an agency, but, I know this interpreter, they interpreted last year [for me]. I know who they are, but there is one agency that lost the contract, it was a London based agency and I was really angry. So, I wrote to the Health Commissioners here and said why are you giving [business to] a London based agency, you know, I thought you were promoting local economy, you know more local and they said, "Oh yea no, London promised to use local interpreters", but you know, the money is going to London isn't it? They lost the contract anyway luckily because of the poor service that they were providing and then it went to a local agency but then the PCT finished."

10 Mental Health services in Wolverhampton: Deaf sign language users' experiences

Generic mental health and therapeutic service professionals had a severe lack of understanding of the needs of Deaf patients and suggested suitable therapeutic methods of relaxation which are traditionally based upon being able to hear, were highly problematic and not an appropriate solution for Deaf BSL users.

An example cited was that of a local service not being able to cater specifically for Deaf people which exacerbated the condition.

"I think I don't know whether is it health counselling, but [my employer] supported me with that particular session and there was an interpreter, but they told you how to relax and listen to the radio, but I was like eh? I'm Deaf. Literally they didn't know what to do or what they could do to help a Deaf person relax, the only thing they could think of was TV and radio and things that you hear and I'm like 'hello', I can't hear. My ears are off all the time. So... no wonder my Mental Health condition went on a bit longer, you know, because I couldn't recover as quickly as anyone else because they didn't have any option for me."

"I mean I suffer from Vertigo, so, I actually went to [X] and had an interpreter and they said, "You're best to have therapy to help you relax, it will include music" and this that and the other. I was sort of like "Eh music? You know, I'm Deaf, so how's that going to help me?"

Statistics were given by participants showing the prevalence and opportunity for mental health incidence and deterioration to be much higher in the Deaf community with little recourse to supportive recovery with a direct impact upon professional and personal life. Opportunities for Specialist Support were limited to a few specific units around the country with long waiting list times to receive an initial appointment.

"In the hearing population there's 25% of hearing people who have mental health issues and depression, anxiety and all that sort of thing, but for the Deaf population it's 40-50%, which is very, very, high. Deaf people are two to three times more likely to be abused in comparison to hearing people. I mean there's a lot of statistics out there and there's and a lot of information, that's old information but I've been very much stressed through Social Services and health services, I've been off work ill, because of the situation. So, it's true."

"No, you just argue your rights constantly, you know, we want to access the same thing as what a hearing person could, you know, my hearing neighbour has got access to this, that, and the other, so why can't I? And the professionals would always say, 'Oh you know, it's like an Asian person or a hearing person', and I'm like, 'No an Asian or hearing person they can hear, they can learn English, but I literally can't hear, so it's completely different thing'.... and they'd say, 'Oh I do understand what you mean', and I'm like, 'No you don't', and it does make you very, very, cross as a Deaf person, it really does."

"...support [for] Deaf people with mental health illnesses or issues, there is one in Manchester, Norwich, Glasgow, London and there are only 4 or 5 Deaf CAMHS [Children and Adult Mental Health Services], so the nearest one here is Dudley and Walsall that fund. It doesn't cover Wolverhampton, it only covers people who go to specific schools or live in specific areas and for adults in terms of mental health services, the nearest one is in Birmingham and it is called the 'Jasmine Suite'. Northampton is for men only, but children's services, as I say, there's only 4 or 5 in England in terms of CAMHS".

"My child has been referred to CAMHS because of as I've said earlier on, they have additional needs and issues and I've been waiting and waiting and waiting on the waiting list, and it just hasn't - nothing has happened yet. I know that's the same as hearing CAMHS but you know.....?"

"...the initial appointment with CAMHS is [X] but I've been waiting for years, well it feels like it but, it has been a long time."

11 Other: Health and Social Care

Deaf and sign language users experience

Overall, there was overwhelming experience of constant barriers to access, resources and getting the correct professionals together with extreme difficulty in being understood and the resulting impact upon peoples' lives.

Hard of Hearing peoples experience

Experiences cited of: constant barriers to access; being understood; to resources; to the correct professionals; and the subsequent impact upon their lives.

Conclusion

This report highlights that some Deaf and Hard of Hearing people have positive experiences of local health and social care provision, but it also highlights the extent to which most participants have and continue to face significant challenges and barriers to access both health and social care services in Wolverhampton.

It is perhaps not surprising that the most common theme to emerge from this study is the lack of clear communication – with examples being given surrounding the issue of medication and misdiagnosis, raising questions of patient safety.

There was an overwhelming request for trained and qualified BSL interpreters to be more readily available across the entire health and social care scene in the city, as we heard of several examples where often, health and social care professionals assume that it is appropriate for a family member or friend to assume the role of interpreter. As well as an increased number of trained and qualified interpreters to be available, the provision of interpreters at Drop-In facilities, emergency departments, and outpatient appointments was also highlighted as an issue needing addressing, with many experiences being shared regarding having to wait several hours to be seen whilst an interpreter can be sourced.

It was widely reported that as patients, Deaf people feel that they are having to educate professionals about Deafness, as there is an overwhelming lack of Deaf Awareness amongst professionals. It was evident that appropriate Deaf Awareness training is needed for front of house staff, particularly receptionists and GP's as it is important for them to know the difference and communicative needs between Hard of Hearing people and profoundly Deaf sign language users.

There was overall, perception by both Deaf and Hard of Hearing people that the barriers they face in accessing health and social care services bring about a feeling of exclusion and discrimination. This extended past the traditional acute and primary care services into community services. Examples of barriers to inclusion included the lack of opportunities for Deaf parents to socialise with other parents in child-based forums such as "Stay and Play", as it provided no access via an interpreter.

Whilst people were keen to share their experiences and highlight the barriers that they face to accessing health and social care services, there was a degree of frustration that these concerns have been voiced for a considerable time with service providers and commissioners, yet there is a perception that very little has been done to remove these barriers and create equal access to services. This issue has been compounded by barriers to accessing complaints procedures, often leaving people with no recourse, even when a clear barrier has been identified.

We are hopeful that this report will provide an up to date and insightful picture of the access to services for Deaf and Hard of Hearing people in Wolverhampton which will drive forward service improvements, involve service users in how future services should be designed to avoid barriers being put in place, and remove existing barriers to improve accessibility to essential services throughout the city. We are committed to supporting this and will be continuing to work with local communities and ensure our recommendations are acted upon.

Recommendations

Emergent from the findings of the research, it is recommended that:

1. The patient should decide if an interpreter is required at hospital and community healthcare appointments and not the staff, as is current practice in some areas. It is the Deaf patient who understands their own communication needs.
2. The CCG and the Local Authority commission sufficient interpreters to meet demand, so that no Deaf person is denied access to an interpreter or has to wait an unreasonable length of time.
3. The CCG and the Local Authority commission interpreting services which employ staff with recognised qualifications and registered with the National Registers of Communication Professionals working with Deaf and Deafblind People (NRCPD www.nrcpd.org.uk)
4. The CCG and the Local Authority commission a 24-hour standby interpreting facility for emergency services, urgent care, out-of-hours services and crisis intervention teams. This may include provision of access to remote interpreting services, such as Video Relay Service (VRS) and Video Remote Interpreting (VRI), especially as a first point of communication whilst waiting for an interpreter to arrive on site. Remote access would also prove helpful in the case of delayed discharge from hospital. (SignVideo is mentioned in this report: <https://www.signvideo.co.uk>)

5. Deaf patients are involved in the commissioning process for interpreting services to ensure that these services are responsive to their needs.
6. Methods of communication, such as texting, are available to Deaf people as an alternative to spoken English by telephone. Examples of areas to which this would apply include making appointments, obtaining test results and improving communication with 999, 111 and Carelink.
7. All health and social care services with waiting areas have non-verbal communication methods in place. For example, display screens with visual alerts for calling patients/clients to their appointments and subtitles in different languages for information videos. Participants in the research felt that Audiology would be a priority area for providing access to information for those who cannot easily understand spoken English.
8. The facilities in place for hearing aid users, such as the loop system, be consistent across all buildings and at different locations within the same building. For example, there may be a loop system at reception, but not within the consulting room.
9. A programme of Deaf Awareness training be developed across all primary care and hospital services to ensure that the time is focused on the patients' health issues, rather than "educating" the healthcare professional about Deafness. Deaf Awareness training would apply equally to reception and other support staff who may be the first point of contact with the service for the Deaf person.
10. The previous recommendation also applies to training in hard of hearing awareness, so that staff understand the differences in communication needs between hard of hearing people, who may rely on lip reading for example, and profoundly Deaf sign language users.
11. Issues of confidentiality and privacy are implicit in Deaf Awareness training, so that inappropriate communication is not facilitated through a hearing relative or friend, particularly a child, without the consent of the patient/client.
12. The content and delivery of Deaf Awareness training be developed in collaboration with Deaf people to ensure accuracy of information and relevance to their needs.
13. All health and social care professionals are made aware of the need to allow extra time for appointments with Deaf people, to ensure that they fully understand what they are required to do as part of their own care. This is especially true for diagnosis and prescriptions, where patient safety is at risk, and to avoid repeat appointments or seeking help from inappropriate services.

14. The information on how to make a complaint about NHS and social care services be translated into formats suitable for Deaf people, such as BSL video, and that access to these be readily available on request.
15. The resources available for mental health patients be reviewed to include suitable options for Deaf people. For example, to include relaxation methods that are not dependent on hearing, such as music or audio tapes.
16. Community services have ready access to interpreters for their clients to enable them and their carers to fully engage in activities. Examples of services where this would be helpful were identified by the participants, including:
 - Child-based forums such as "Stay and Play" groups, where the child and/or the parent may be Deaf,
 - Dementia cafes,
 - Carer groups,
 - Carer support at other community groups, where the carer and/or the service user may be Deaf,
 - Drop-in facilities, where pre-booking of an interpreter is impractical.
17. Deaf clients be allocated to social workers and health visitors who, ideally, have BSL skills or, at least, have undertaken Deaf Awareness training. Where there are skills deficits within the workforce, it is recommended that training be provided for a critical mass of social workers and health visitors to prevent delays in client allocation or clients receiving Support Workers whom they cannot communicate with.
18. The previous recommendation also applies to support services for the carers of Deaf people to ensure that their needs are met, for example in accessing respite care knowing that their family member is being cared for.
19. Clear information in a range of accessible formats is made available to Deaf and hard of hearing people on assistive technology, such as doorbells with a flashing light, or alerting to a fire, to improve their ability to live independently in their own homes.
20. Residential and nursing care provision within Wolverhampton is reviewed to ensure that the needs of Deaf people are met. It can be socially isolating and deleterious to mental wellbeing to be the only Deaf person within a Care Home setting, especially if the staff have limited Deaf Awareness and communication skills.
21. The provision of end of life support for Deaf patients and patients with Deaf family members be reviewed, especially in a hospice setting where financing appears to be prohibitive. One suggestion, made by a participant in the research, was to train Deaf people as befrienders to provide this support.

22. Commissioners and large providers consider a recruitment campaign to encourage more Deaf people into the workplace to increase understanding of issues affecting Deaf people and to facilitate improved communication and information.
23. When services are conducting their own audits and internal reviews, that the requirements of the Accessible Information Standard are checked for compliance. The requirements include:
- Identifying the communication and information needs of service users,
 - Recording the communication and information needs they have identified clearly and consistently,
 - Having a consistent flagging system for communication or information needs,
 - Sharing the identified information and communication needs of the individual when appropriate,
 - Meeting the identified communication and information needs.

It is the view of Healthwatch Wolverhampton that these checks would be more effective and relevant to the users' needs if a Deaf and/or hard of hearing person were involved in the process.

Appendices

Appendix 1: Facilitator Question Prompts for Table Discussion/Feedback

GPs:

- Access to appointments – is it easy to get an appointment?
- Can you get an interpreter with a same day appointment?
- How do you book appointments?
- Waiting room notifications, - how are you notified of your appointment?
- BSL interpreters, - do they turn up on time if they are booked?
- Are you given additional time in your appointment? Is there enough time?
- Have you had to bring a family member with you to interpret at an appointment?
- Can you get an interpreter if you are there to see a Practice Nurse?
- Have you received a results letter that you did not understand?
- How do you get results following on from an appointment/test?
- Any other experiences/comments about GP's?

Hospitals:

- Outpatients: what are your experiences as an outpatient in hospital?
- Communication: how are you notified of your appointments?
- How long are the waiting times?

- Has it been easy to arrange an interpreter for your appointment? Did they turn up?
- Inpatients: what are your experiences whilst staying in hospital?
- Was an interpreter available to enable you to speak with the Doctors/Nurses/understand your care?
- Were you able to communicate your choice regarding meals?
- Was there provision made for an interpreter to speak with your family members if required?
- Informed consent: was an interpreter available to explain things to you?
- Discharge from hospital: was the process explained clearly; was an interpreter made available? Have you had experiences with Social Care and interpreters on the hand over from hospital?
- Have you got any other issues/experiences you want to share regarding hospitals?

Urgent Care:

- Ambulances/NHS111: what provision is made available to make contact? Is it effective?
- How do Ambulance staff communicate with a deaf patient?
- Emergency Department: have you attended and has an interpreter been made available? Did you have to wait long?
- Urgent Care Centre: Communication, availability of interpreters, timing – did it mean you had to wait longer so an interpreter was present?
- What is the follow through process for the provision of interpreters if you were admitted to hospital and transferred to another ward/discharged in the middle of the night?
- Any experiences/comments/suggestions for change/improvements?

Dentists:

- How easy is it to access a Dentist/make appointment/arrange for an interpreter to be present?
- Are staff aware of how to book an interpreter?
- Are your experiences about an NHS Dentist or private provision?
- Are you given more time in your appointment to communicate with an interpreter?
- What could be done to improve access to Dentists for the deaf community?

Opticians and Pharmacists:

- How do you communicate?
- Is it easy to access services?
- Are there provisions made to access an interpreter?
- What are your experiences?

Community Services:

- District Nurses
- Midwife appointments
- Health Visitors

- Occupational therapists
- Physiotherapists
- What are your views and experiences of accessing these services?

Nursing Homes/Care Homes

- What are your experiences and views?

Complaints about the NHS

- Have you had experiences of making a complaint?
- Was an interpreter made available?
- How was the process explained to you?
- What could be done to improve access to information on how to make a complaint?
- Were you offered advocacy support?

Do you have any other comments or views about any other NHS service or social care service that you would like to share?

Appendix 2 section A: Audio recordings of Deaf British Sign Language users' experiences via interpretation by sign language interpreters

Audio transcript feedback

1.0 GP:

GP Surgery [Y] - it's a female GP and I go in and communication is quite difficult. She has quite a stern looking face, there are no facial expressions that she expresses, so I tell her the issues, write it down, I try and explain to her, she's turning around, she's writing the prescription out already, I'm handed that and then I just leave.

I don't attend the GPs surgery on a regular basis, obviously over 50, things have occurred health wise... my ex-partner, she would phone, make an appointment for me, request to book an interpreter, and I would be told "No X, you can lip read well, so we can communicate fine", so she would explain how X can express details and issues, but they have refused to book interpreters. So, I'll attend, explain you don't have to pay for interpreters, it comes from the NHS budget, so there are no concerns there in regard to your budget, but again I'd be told, "But you can lip-read", and I'll explain [about the] difficulty explaining my health issues, [the] clarification of details, but we just continue how it was. A year ago, they gave me a telephone number for an appointment and it was for a blood pressure check, and my writing skills are not very good, so it was like communicating in 18th Century fashion in black ink, and I didn't understand what was being written, and they said, "if you have problems with your heart and cholesterol...", and that was that... So, I went to a deaf club service, and explained to the doctor and they then further gave me details and clarification if I had issues about my cholesterol and heart disease and stuff, and I've been given a telephone number – the detailed information that you should get from GPs – it is not good enough, it's limited. A month ago, I was poorly and I thought my tongue

was dry, no saliva and my mouth was dry and I went to the pharmacist and explained the issues I was having and I was given some tablets and a few days later it didn't make a difference and I went to a Drop-In Centre and explained that I was having ice lollies, ice creams and drinking water, and I was told to go to the hospital, so I attended there and requested an interpreter and you have to give 2 hours' notice to book an interpreter. So I said, "No, I need an interpreter now", and they responded, "No, no, no" and I had my eyes checked, my mouth checked and I was given medication, eye drops and a few days later that medication wasn't working and so I returned to my local GP and explained that my mouth was still dry and there was something to do with my throat and I my doctor's receptionist was told "No, no, you need an appointment" so I said, "Look I'm Deaf, I'm ill, I'm feeling so weak, I haven't got any energy, and I didn't know I needed an appointment", so I had to then go to [X] (the Walk-In Centre) so I went there and explained it and they said, "No, you shouldn't be here, you need to go to your GPs surgery", so, I was like 'Ahhh', so I returned back to my GPs surgery and explained to the receptionist that I needed to be seen and said, "Look, I'm definitely ill here". So, the next day on the Thursday, I had an appointment, was given medication, I was going to the toilet an awful lot, on the Friday, I returned on the morning, had a blood test taken and I asked about the results and how long they would take and was told about a week. I returned home, and in the afternoon, had a text for me to urgently go to the hospital to the Diabetic Centre. I arrived there, and I said, "You need to book an interpreter, you've got information there on how to book an interpreter" and they said, "No, you've arrived at short notice, we need 2 hours' notice to book an interpreter". It's not fair, hearing people have the access straight away, so it's not an issue for them. It was discovered that my blood sugar levels were too high, so I was given medication, but again, it's the communication, it's all typed, and my English isn't very good, and I can read, but you know, I need an interpreter, and everything was being typed out, but I really did need an interpreter. So, on the Friday, at last, an interpreter was booked, I was told what injections I needed, the diet I needed to follow as well, and I did complain about the [situation with booking interpreters] and I received an apology and since then, interpreters have been provided for appointments. They won't book the interpreters [though], I have to."

This is my Mum, so I'm just prompting questions and experiences really, -

In terms of my father, with the GP and home visits [they did not provide an interpreter]

So, we had home visits for my dad, and they never brought interpreters along. I told them to.... and I asked them to but it would depend what particular thing would need doing that day, but I did say that communication is important to the doctor and you need to bring an interpreter and they would say, "No, if you are really ill, then yes, we will bring an interpreter but if it's just a general medication or blood test then no it's not necessary", but if they are going to ask him any questions we need an interpreter there to be able to give him an answer. The doctors always said it wasn't necessary, the staff know what this patient needed for the routine, so GP Surgery [A] which is just around the corner from here, the doctor was from there.

Thorny Street, which is the old doctor's surgery they booked interpreters and now he is in the care home it's a different surgery, they don't reinforce that, and they don't do that. Thorny Street won't provide interpreters.

To be fair, they book an interpreter, so it is quite positive with Castle Croft surgery, they'll book the interpreter where needed and if for example, I have the appointment and the interpreter arrives late or if the interpreter hadn't arrived yet, I'd wait and let somebody else go in before me and wait for the interpreter to arrive. I would like to know that the interpreter is definitely booked because sometimes I am a bit wary like, have they booked one, haven't they? It depends on, - if it's just a small thing I don't know if one needs to be booked, but, if it's a big issue then yes, I would like an interpreter to be booked.

"Obviously being over 50 years old, I am having to attend more and I've got Gout now and, yeah, I suffer from Gout and that started in my feet swelling up on a regular basis and inflamed and feeling hot and I was given medication and I asked, "What's wrong, can you explain the details, what's happening?", and he [the doctor] said, "It just happens by itself" and I said, "Come on, give me the more detailed information " and I looked up the information, but then over the years..... I found out information not to eat red meat, eat less of certain things, but, I love red meat but I've taken on board.... what I should be doing, and this is what I've found out about what caused Gout in me, so since then, not eating fish, (and other things) but the doctor hasn't explained any of this information to me, I've just had to find it out for myself, and been told, "It's Gout, it happens". 8 years of that though, it's a waste, if she'd had told me the first year what foods to avoid I would have been ok.

The doctors have equipment which is a visual aid to alert you to when your appointment is, but it's constant like, looking up [at the screen]... whereas other people just rely on their hearing which comes over the speaker but for deaf people, somebody needs to come out to obviously get our attention to say "You are next in", and they come out and say your 'Name' and everybody looks at me and, I say "You know, they should know better, I'm Deaf", and they say, "Oh, I'm sorry, I'm sorry " and we carry on into the room.

In the waiting room, luckily there is a TV in my surgery where it says you know, "Mr Brown go through" or whoever, so that's useful because obviously you can see it but, it's quite nosey really knowing everyone's name (Laughter). I mean when we moved to Wolverhampton, my doctor used to come out of his room and call you in, that's what I think he used to do before but now, technology is so advanced isn't it, you got the screens, so that's good

When you have a blood test as well and you go to the doctors, we do have a screen so obviously you have to watch that all the time to make sure you catch your name if it comes up and I literally don't take my eyes off the screen, but if you are going for a blood test, they don't put your name on the screen, so every time someone comes out, you are thinking, "Oh is that me, is that me", because I can't understand them when they actually call your name, so that's an issue.

Sometimes, doctor's don't put on your file 'Deaf patient' but I think sometimes they don't look at the notes properly, and they forget that someone's deaf and just call

the name or do that sort of thing. In the past, they've actually called me in and it's not me! So, they need to check the notes properly, and make sure they are getting the right person in and knowing whether you are Deaf or not.

1.1: GP - Service Improvement?

Well, we want qualified interpreters, we prefer 'Communication Plus', and we want Deaf Awareness as well for all staff that work in the GP, Opticians, yes, and I'm saying, I'd like to see all the doctors and nurses – all the people involved in the medical services they should have a one-day course about Deaf Awareness.

..." maybe once a year they could have Deaf Awareness and that could be something that is ongoing, just some Deaf Awareness training that's ongoing rather than 'one off' and then nothing happens for 10 years. It should be something that's ongoing. Just to remind people about Deaf Awareness, we need more posters as well, how to deal with deaf people, just some posters up just to remind people and the staff about how to do that, about speaking slowly to make sure the deaf person understands, gestures, fingerspelling and, the importance of booking an interpreter as well.

My husbands had an argument with a doctor's receptionist, they were trying to [communicate by] write [ing] down... they banned my husband from going to the doctors because he was having an argument with the receptionist and through writing notes, so my husband was banned from the doctors. The doctor said – they got into an argument because communication was not going very well, and he got a letter through the post to say he had been banned from the doctors – and that was due to [poor] communication.

For me it is very easy to get there you know because the doctors are literally down the road from my house, so I can walk there. So, I'll book an appointment and they always book me an interpreter every time I see the doctor, because obviously I don't phone to make the appointment. So, I walk in and they can clearly see that I am Deaf...

...and that is the same with myself as well ...so they know to book an interpreter, that's never really a problem for me.

Yes, bereavement counselling, there is an awful lot of thing, you know, just the general sort of leaflets and information e.g., stop/cutting down alcohol, smoking or keep fit if you're overweight, they don't provide interpreters for that.

In relation to GP notice boards, in terms of health walks or bereavement counselling, you know there are lots of posters and information out there. Would they provide an interpreter for those sessions?

I had a letter sent to me, asking me to go to a meeting at the GP and that was because I'd given some feedback, I'd written on the feedback form my grievance

really with them refusing to text and so they'd asked me to go along to this meeting, but they didn't provide an interpreter!

I've noticed with my doctors, they'll say you know, all local people join this, like a local group, like a user group participation group, [Patient participation groups] but, I consider it a waste of my time, because nothing would happen would it, you know? To be fair, my doctors are very good with interpreter provision, I don't see the point in that with my particular surgery. When I moved to Wolverhampton, nearly 18 years ago, the hospitals had no Deaf Awareness whatsoever, but it just sort of happens over the years, they've become more and more familiar [with me/deafness] I've got to know people at the hospitals - the staff.

With our local GP it is in the South Staffordshire area, I can book an appointment but in terms of the interpreter it is very difficult because they won't allow you to book your appointment for the next day. It has to be sort of three to four days later because they need the time to get an interpreter, you know, it's very, very rare if you actually got an interpreter for the next day. So even if you are in pain then you need that appointment. I'd say that is very much a problem for me.

With GPs sometimes, they book interpreters for me, but when they actually do book an interpreter they use an agency called 'Absolute interpreting' which is a very poor service, - they sort of use cowboy interpreters unfortunately the interpreters will come along and quite often they are not qualified and they are not experienced enough, so the information they are interpreting for me, is incorrect, so that is very dangerous. So, the commissioners need to be aware that some interpreter agencies shouldn't be used, and they need to make sure they pick the correct and qualified interpreting agencies. They need to be qualified interpreters.

With my GP - so that was quite easy when it was under PCT because it was booked through one agency that covered all of the GPs in Wolverhampton, separate from the hospital bookings but it turned out to be the same interpreting agency that covered both aspects but now the doctors have their own budgets, the doctor's surgeries so I'll say I want an interpreter - this [particular] interpreter, but no we have got to use this [particular] agency, so obviously before when it was under the PCT, we could have a bit of a choice - we could recommend that, but now they have got their own budget and it is not an interpreter agency to be honest, it is a translation agency you know like spoken language interpreters and they just add the British Sign Language [provision], but luckily I know all the interpreters.

I am happy with my GP and how they book my interpreter, - I have got two Deaf sons and their partners and their children, so I am pleased to see that my GP does accept booking interpreters for my grandchildren's health, as they are hearing, but because their parents are deaf, they are still willing to book an interpreter for them which is fantastic. I am happy for that to happen because, it shouldn't matter you know, if it was a deaf parent with a hearing child, the GP should still book an interpreter, that's very important, because that reduces stress of you not knowing what is going on.

[It's not] just GPs I am talking about for example, nurses, health visitors, midwives. I feel half of the time I must educate them about Deafness and it is not my job, you know I am teaching them, it drags on my appointment time and they are asking me "What is Deafness?" and they are quite interested, which is lovely, but it is my time to focus on my child's medical [needs]. it is not my job to teach them. I mean for

example today my daughter had her immunisations. There was a nurse, there wasn't an interpreter there and she was like, "Oh you know..." and I said, "Well she is Deaf actually, my baby is Deaf, and her attitude wasn't appropriate, and I really wasn't happy with her attitude. So really.., I mean all the professionals vary. Some professionals say, "My God, I am so sorry she is Deaf, you know it is such a shame, it is awful to be Deaf". That is really not a nice thing to say. So, they need to be more aware, but it does vary with each professional you meet.

1.2 GP: 10-minute appointment times – are they enough?

I always double book to be honest, so yeah, that is quite good.

I didn't know you could do that, yeah, I like that.

Obviously, you have got to watch the interpreter haven't you, so sometimes that might not be enough, whereas hearing people can write and listen at the same time and do that sort of thing, so yeah, double booking would make more sense really.

1.3 GP: Booking appointments?

I receive a letter, and well sometimes you know I wait and wait and wait and I don't hear a thing at all, and I have to go to the doctor's surgery myself and say what's happened to my results. You know, I have been waiting all this time and I haven't heard anything

In the past, I have had an experience where I saw a GP, I asked them to book an interpreter, but they weren't sure whether the interpreter was available and whether they could get one, so they said they would let me know and they said they would phone me. I said, "Well you can't do that, you know, if you could text me" and they said "No, no, we can't, we can't offer that service". You'd have to come back.

I remember my daughter in-law wanted a doctor's appointment and she had to email for an appointment, - what is wrong with a mobile or a text [appointment]?

Sometimes the dentist can send you a text message, but Doctors are sort of thirty years behind aren't they. So, what's the problem?

With the dentist, I have never had a problem but, in terms of GPs yes, it's always a problem really.

1.4 GP: Same day/emergency appointment?

Normally you can book an interpreter, two weeks in advance, any closer than that is pretty much impossible I'd say, because there are not enough interpreters for the number of Deaf people in Wolverhampton. It is the same all over really.

So, my GP - I am really impressed with them to be honest, because they will NOT see me without an interpreter, you know, if there is a [funding] cut and I am adamant

we need to sort it out, - they are adamant they have to have an interpreter there. Which I think, is really good.

I also know a Deaf person who also goes to that same doctor and he got a bit annoyed with it really saying, "You know, I should be able to see [you] it is my right, but the doctor's response is, "No, you know, I need an interpreter with you it is very important".

For me, it is very easy to get there because I've got the doctors literally down the road from my house, so I can walk there. So, I'll book an appointment and they always book me an interpreter every time I see the doctor, because obviously, I don't phone to make the appointment. So, I walk in, and they can clearly see that I am Deaf.

That is the same with myself as well. They know to book an interpreter, that's never really a problem for me.

NO, no, no! I have never experienced, oh actually, maybe once but, I was lucky because you know I used to work at [X], so I knew which interpreters were not working because it was School holidays, so I would just text them and say could you come along, so that was a one off, and the doctor was really quite angry with me that I asked sort of asked an interpreter to come along with me, but I knew they were under an agency and obviously interpreters work all through holidays, so they work for different people. So, I did that, I did happen to have an appointment on the same day with an interpreter. But the doctors weren't happy because they said they needed to use a particular agency, but, I know this interpreter, they interpreted last year [for me]. I know who they are, but there is one agency that lost the contract, it was a London based agency and I was really angry. So, I wrote to the health commissioners here and said why are you giving [business to] a London based agency, you know, I thought you were promoting local economy, you know more local and they said, "Oh yea no, London promised to use local interpreters", but you know, the money is going to London isn't it? They lost the contract anyway luckily because of the poor service that they were providing and then it went to a local agency but then the PCT finished so....

It's not a problem they book interpreters.

2.0 Hospitals: Deaf sign language users' experiences

Sometimes they'll book an interpreter, but they'll only allow an hour. So, what if we needed more than an hour. They are sort of, "No they've only been booked for an hour" and that's it.

If your appointment was delayed and the interpreter has to go because they've got another booking. It's a bit like, hold on we haven't finished.

One of my friends went for a heart bypass at New Cross Hospital and it was fantastic for him really. He had three days when interpreters were there. Three days, post operation, everything. Absolutely everything all the way through [was good], and once he woke up, an interpreter was there. So that was fantastic for him. He's home

now, safe and well I think. He was in hospital for five days but for three days, it was a critical period but, he had a positive experience.

I returned back to my GPs surgery and explained to the receptionist that I needed to be seen and said, "Look, I'm definitely ill here". So, the next day on the Thursday, I had an appointment, was given medication, I was going to the toilet an awful lot, on the Friday, I returned on the morning, had a blood test taken and I asked about the results and how long they would take and was told about a week, - fine - I returned home, and in the afternoon, had a text informing me to urgently go to the hospital to the Diabetic Centre. I arrived there and I said, "You need to book an interpreter, you've got information there on how to book an interpreter" and they said, "No, you've arrived on short notice, we need 2 hours' notice to book an interpreter", - it's not fair, hearing people have the access straight away, so it's not an issue for them. It was discovered that my blood sugar levels were too high, so I was given medication, but again, it's the communication, it's all typed, and my English isn't very good, and I can read, but you know, I need an interpreter and everything was being typed out, but I really did need an interpreter. So, on the Friday, at last, an interpreter was booked, I was told which injections I need, the diet I needed to undertake as well, and I did complain about the interpreter (situation), and I had an apology and since then, interpreters have been provided for appointments. They won't however, book the interpreters, I have to.

Well, the GP says we don't need an interpreter because I can lip-read well which is stupid. The hospital on the first day I arrived there was no interpreter, on the second day I made them aware that for the appointments that I need you to book them [interpreter] but I was told that I have to book them. It is the hospital, it is their responsibility, they should book them. The hospital should learn some sign language - staff like receptionists, on the front line, in order to get professional interpreters there for appointments.

My experience with private healthcare agencies, they don't provide interpreters, e.g., I was trying IVF in the past and I thought I'd do it privately because it was quicker, and they refused to provide me with an interpreter. So, I went through the NHS and they did provide me with an interpreter.

Last year my husband was in hospital for 2 months and was discharged out of hospital and they had given me a massive bag of medication, - I didn't have a clue what it was, and they said that I was responsible to take my husband to the care home along with his medication, but, I thought the Ambulance service was responsible for that. Anyway, I had to do it and I took it all [the medication] along but they didn't explain to either me or my husband what the medication was for, but the care home staff said they would know what it was, but I couldn't ask them, [due to communication issues/no interpreter] but I'd still like to know. The care home were OK, if there is a hospital letter sent to the care home they should tell me if there is an appointment and sometimes they would forget, and I think it is the care home's responsibility to take my husband to hospital and not me because he's there isn't he, but they do expect me to do it sometimes.

I think in terms of the hospital as well, another issue with my father, is that he was there and when the doctors were doing their rounds, the times can be varied, they

don't tend to stick to a time when they are coming and obviously there is a communication issue. So, we made an agreement to book an interpreter just for an hour-2 hours at a particular time so that the doctor would know how to work his rounds so that he would come to my father at the same time. Doctors, I understand, can't guarantee that they can make it at that particular time but then if the doctor isn't there [in time], the interpreters says that they are sorry but they are only booked for an hour or two hours and they have to go and then 10 minutes later, the doctor turns up and I understand doctors are busy but it is important to have that communication where they [the patient] can understand the information so doctors need to ensure that they are there at that particular time and when the doctor has come, they ask me can you write this down and they sort of ask the deaf Support Worker who is sometimes there, if they could interpret and they say, "No, that's not my job," and then they would ask the Support Worker [the question], and they would say "Sorry that's not for me to answer", and they would take a bit of offence to that. Hospitals have no awareness of boundaries – they would ask a child, a family member, Support Worker, and it's not their role to do that. It's not. They will just try anything really - and they have a responsibility. The family are there for emotional support, not to interpret and not to relay the information. The Support Worker that we had, he is severely deaf, he can speak well, but it doesn't mean that he can 'translate' and interpret, it could be a mis-communication so you can't rely on people like that, and sometimes they [the Doctor/s] would be pestering until [he agreed] ...but he wouldn't do it. The support worker felt very, very uncomfortable and that's very wrong you know. There should be an interpreter there. My daughter at that time was 8 years old, and the doctor actually said to her, "Tell him what I'm saying", but she is 8, she can't

Before you go to the operating theatre, communication is important – some of them could learn basic sign language, simple things like how to say your name, just to be able to respond. You can't have an interpreter in an operating theatre, so if staff could learn some basic signs like 'Gas' for example so that I understand that I'm going to have to go under an anaesthetic, just some simple signs and they should speak clearly as well so that we can lip read them, and, speak to us face to face and understand not to have the light behind them [which puts the face in shadow], and not to have beards and moustaches because we need to be able to see people's lips as well.

Just talking about being able to lip read people clearly and I'd say 'shave off the beards' and moustaches, that's important and makes it easier as well.

[Without an interpreter] - you just have to probably communicate with pen and paper. You know the old sort of way, sometimes they expect you to do that.

Quite recently actually. Two different experiences within my family; so, my father in law stayed in hospital for a long time actually because he has got [X condition] and he's Deaf and he had an awful experience on his ward really, really, awful and we did make a complaint about that to you [Healthwatch] about the health care department but it was a horrific experience and procedure. For myself in hospital with my daughter, I had a caesarean, that was quite positive. I had an interpreter from Communication Plus [interpreting agency] and obviously at night time, the interpreter went home, and the staff were really supportive and wrote on a piece of piece of paper, we communicated that way and they were really lovely but, that's

a completely different experience to my father in law. I don't know whether that's because they were on a ward and that they are a lot older and it's quite a miserable thing, whereas having a baby is very cheerful, but it shouldn't be you know, it should be the same, we should be treated the same to be honest, we complained, and we achieved absolutely nothing.

A woman came up to me and said, "You've been here all afternoon" and then she realised I was Deaf and then said, "I'm ever so sorry" and walked off, but I'd given my name and said that I was Deaf, so if all hospitals do that, if they'd just had a bit of notification that we are Deaf, it would be clearer, people don't realise and then we are left there waiting.

It's sort of a negative experience of Audiology at West Park Hospital. I had an appointment where I needed to have an audiogram done. I went to reception and reception had NO Deaf Awareness whatsoever, so I asked, "Can I have a pen and paper please?" She didn't even understand, you know, I was gesturing pen and paper, but in the end, she eventually got it, put my name down but, I am here for an appointment and this is in the Audiology department, they should be Deaf aware. So, I was in the waiting room, there was a TV, no subtitles on the TV, which I was really quite angry about that because, it's Audiology - they should know we are Deaf and we're not going to be able to watch TV whilst waiting because there's no subtitles, but I just think some places should know better. They don't.

About Audiology, they're the worst, the worst of all, you know, they literally have no Deaf Awareness whatsoever and it is a bit ironic isn't it really?

I mean I suffer from Vertigo, so, I actually went to West Park Hospital and had an interpreter and they said, "You're best to have therapy to help you relax, it will include music" and this that and the other. I was sort of like "Eh music? You know, I'm Deaf, so how's that going to help me?"

3.0 Urgent Care: Deaf sign language users' experiences

You need an emergency interpreting service really.

Obviously, we can go to A & E, or I'll go to a Walk-In clinic without an interpreter if we have to, just so that we can get something. For example, I have been to a Walk-In clinic before because I fell from a ladder....and that was fine. I felt that the Walk-In clinic sort of treated me quicker than what a hospital would.

You know, it doesn't matter if it is an emergency interpreter if you are deaf or hard of hearing or another disability, it doesn't matter there should be one there available.

You'll laugh really in terms of what happened to me. I went to the theatre, here in Wolverhampton, and somebody threw a bottle and it smashed off my head, so I was rushed up to hospital and one of my students interpreted for me actually. You know it is very lucky that I worked [at X] and that I have so many students who are interpreters now.

I think if it is a visible injury, you know like a cut on your head it is easy to point to the Doctor if you haven't got an interpreter but, when it's pains internally, it is vital you've got an interpreter to explain the pains and describe them.

My mobile has got 'I.C.E.' on it, which is – 'in case of emergencies' so my brother's name is on there so if there is an emergency, they can sort of see that, and they are able to contact somebody, and they'll know there is an emergency going on.

With emergencies, - you have online signing access [VRI/VRS] which goes through the weekend as well like Sign Video that would work wouldn't it?

In the past in the 1980s ...you would type the information like at the railways...in the 1990s there was more access, out and about, more marketing in the communities and libraries, but with technology, the hospital should have a signed video provision there(minicom [text telephone] is a nightmare)...it [VRI/VRS] needs to be on display, ready to use.

Obviously if you haven't got a good understanding of English, that's a big problem to use a minicom.

3.1 NHS 111 & 999: Deaf sign language users' experiences

I had 2 different stories; one said for emergency it is 999, but now you are saying 111...

What's 111? I don't know what 111 is.

It's not clear information, whether it's 999 to phone or it's not clear...I don't know what 111 is...

We'd be in bed and my husband would fall in the night, - in the bedroom, because he was in a different room I'd have to check on him every now and again to make sure he hadn't fell, but, I literally wouldn't be able to get in sometimes because he'd fallen by the door, and he hadn't pressed the button or anything like that, so, I had to call 65999, to the Police, and the Police would then re-direct me to somewhere else where eventually, an ambulance would arrive, so basically, it was process, it wasn't a simple call to 999. My husband would fall an awful lot and I'd have to dial this number several times, I can't remember – I would text this number and it would go to West Midlands Fire Service, or Police Service, and eventually it would come through with what you needed. The Care Link [Line] panic button, wasn't that good because you would have to press it and then they would speak to you – like a help line, but how can we communicate back? So, I would just sort of text back, and then we would eventually get the answer and it was very much back and forth – a long process and eventually, somebody would arrive. On average, we would have to wait about 2 hours until the ambulance turned up. It just wasn't easy.

My mum has a Care Line pendant, that she presses to alert emergency systems, so why can't deaf people have that?

My husband had one, but they'd speak to you from the line, and I'd use this text service, but it was very delayed.

Before he had one that he wore on his wrist and he accidentally pressed it and somebody would turn up at the door and I was thinking, 'Whose that?', but obviously, it was just an accident, so we didn't use that one anymore because of the accidents of pressing it and the services turning up when it wasn't necessary. So, I think again, the NHS 111, there needs to be more education on it really. I don't use it personally, because it's a phone line, I'd need a minicom, a text phone, there is no access.

'TeleCare' [Care Link] is not Deaf friendly. Like you mentioned about the panic button, - there is no access to the service whatsoever, and the staff who work there have no Deaf Awareness. The systems are not Deaf friendly. There is just nothing.

We have Care Link for my husband, which was OK, but I was just shocked when they would just turn up and it was because he had accidentally pressed it or knocked the button. I can't hear anything from it, - it's ringing, what can I do, because obviously it does sort of make a noise sometimes. When it's pressed by accident, somebody will try and talk and because they can't hear the talking, they are like, "Hello, are you ok" - and they send the people [staff] over, but it's wasting their time isn't it? You could prevent that by maybe a text message....

Maybe you could press something and then 'Sign Video' could connect and maybe that could be a possibility in the future.

[In relation to 999] It's Automatic. I just registered on my phone

I never use 999 – but if it's something like a heart attack, she's lucky because her daughter can phone 999, but I live on my own I don't have anything like that To be honest, I don't have 999, I'm deaf. I have an emergency text for 999 on my phone and you get these questions like, 'Which service do you want? But, lots of deaf people won't know how to use that though. If you want 999 you have to register for that, with the Police, ambulance and so on. It's a lot of bother to set up a 999 text.

You could improve that though by for example, press 1, for Fire, 2 for Police, 3 for Ambulance – that would improve it, to simplify it and improve it.

3.2 Accident & Emergency department: Deaf sign language users' experiences

I was very, very ill with Shingles, so I went to the hospital and wrote down what was wrong with me, but I really felt very ill and I said that I needed an interpreter, I can't continue with this I was so weak and I needed to obviously tell them the information in depth and they wouldn't book an interpreter so I literally had to continue, writing it down which was a long process, but as I say, I was very weak, very ill, I needed an interpreter there, and if I did have an interpreter, I would feel very much more comfortable. Writing down is limited, so I couldn't share everything I wanted to share. You sort of go blank at the time, so, the communication just wasn't successful.

(I think it was last year, yeah, maybe – my son was on holiday, so yeah, that's right, - think I was in Devon.)

Can I ask at A & E, when you go in, is it like a minimum wait of 2 or 3 hours roughly? So, it's an emergency [setting] I've gone into, so there's enough time for them to phone up and arrange an interpreter to be booked. You're being denied this, being told, "No, no, no",

There are many times, many experiences, but I just can't think on the spot....

Oh yes, the ambulance, so I'd go in and initially they'd start writing things down [asking], "What's your name" and that sort of thing and an awful lot of questions and I was weak, and be asked your name, date of birth, address, and I didn't have the energy to do it, it was very much- yes/ no questions and answers. It's easy for a hearing person, they can just answer with ease, an awful lot of questions to answer. Also with the ambulance, they mis-diagnosed my father, saying he'd got Mental Health issues, but actually, the medication he was on was too strong, and they thought he had Mental Health issues and referred him to the wrong Specialist completely and when the doctor assessed him and agreed that he didn't have mental health issues, it was his medication, which was incorrect and it made him hallucinate. There were an awful lot of questions, and we tried to respond appropriately, but again, it's very difficult when you haven't got an interpreter and pen and paper is just not the right way to do it. It can very easily be solved by getting an iPad and getting a signed service [VRS/VRI] that can be there for emergency use and there won't be these issues. When you are zonked out and ill, how can you write things down when you are not communicating in your first language?

The ambulance men and women shout.

Last Christmas I was made redundant and lost my job, I felt upset and stressed and in February I had some pain here in my chest a bit like heartburn and went into the 'Walk -In Centre' at four o'clock. I waited about half an hour and my name was called and I said, "I'm Deaf" and they said "What's wrong?" and I said, "I've got pain in my chest like heartburn or something like that", so, she checked it and sent me straight off to hospital and I didn't know what was going on because of the communication and I said "Hospital?", and I said "What's wrong - Why do I have to go to hospital?" and the nurse said, "Calm down, calm down". I couldn't phone my husband because he was deaf, my son was working, so I phoned my sister but she didn't pick up the phone so, I've got my mobile and took out my phone and the nurse said, "Put the phone away", but I said, "I have my phone there", and she said, "Put the phone away", so I showed her the phone and the number and she wrote it down and gave it to the ambulance man. When I was in the ambulance I was being asked questions and I didn't really understand e.g. my name, date of birth, did I smoke - I've never smoked, drinking - sometimes I drink, - asking me all these questions, quite in-depth questions, but there was no interpreter, no signing, and I was waiting in the queue in a corridor. There were so many people around and I didn't know if anyone was calling my name, so I was waiting there so I asked someone who was passing by that I needed the toilet, but I was told that I couldn't that I had to wait and that was very painful just waiting in the corridor. My son came at 7.00pm and asked me what had happened.....and my son had to check if my car was still in the car park [at the Walk-In centre]. He went to the reception and asked where his Mum was, and my son was told that I had gone to New Cross Hospital in an ambulance, so he had to drive to New Cross and he was really

worried and he asked me why I was in the Cancer room for he had seen my name on a screen. I wasn't in the Cancer ward [area] at all, but I had been left on a trolley in the corridor in a queue in the wrong place. It was very stressful because of that. In the end, the doctor came over to me with my son, - I had a blood test and X-rays, and in the end, it was found that I had a heart problem and was because of the stress I had been through due to the redundancy. 7 hours I was in hospital.

No, no, they never asked, I was never asked if I needed an interpreter. That's the worst - in hospital isn't it? When I was in Accident and Emergency I said that I was deaf, and they should automatically phone for an interpreter because of the communication problem, you know. Even if people write things down for me sometimes I won't always understand the word because it is in English. If I ask for an interpreter, the receptionist will often ask me for a number to phone and I just say well go and look in the Yellow Pages.

No, never – they should really, it should be an emergency, they should bring in an interpreter. I go to Accident and Emergency and there is no interpreter...

Patient Choice: Deaf sign language users' experiences

...really, you can pick any option, locality and that?

I think that's good, but I know some people who prefer a better hospital if you like, but I've heard that the waiting lists, if I choose, 'this' particular hospital say for example, from the one here, there are 3 more waiting lists, but we don't get told that.

I've never been given that information, no...

I mean I, prefer a closer hospital obviously, you don't want to travel far, - if it was Birmingham.... but if the waiting list was a lot shorter, but then everyone's got to work it out and ...

just asking, if the GP withholds that information, what do I do then?

is it a maximum of 2 choices or can it be more than one choice? I was given 2 choices before...

4.0 Dentists: Deaf sign language users' experiences

Well, a dentist wears a mask! Don't they! And I'm like, "I can't understand you", and, they sort of move the mask slightly, but it's just a pain. You can't communicate with them at all.

My dentist doesn't book interpreters. I go in and I ask them to book interpreters and they [say] "We'll be making gestures.....don't worry when you are lying down I will gesture", "put your hand up if you want", but he said that my wisdom teeth ...that something is going on with them and I haven't felt anything for the last 8 years, and I've been told being over 50 I will do, and I said I will need an interpreter and I've been told, "No, no, you'll be fine, you'll be fine – you'll be in and out within half an hour", so they again won't book interpreters.

If I could text to an agency to book an interpreter to be there at the GP or dentist – are they going to be a bit annoyed? I don't know how they are going to react to that.

My dentist...it's OK, I've known the lady a long time to be honest so you sort of get along with it don't you, but with the mask, that can be an issue because they have to wear it, but they don't always remember to take it down to talk to you and when she's sort of finished, she'll write it down on a piece of paper for me with instructions or whatnot, but whilst she's treating me, she does have to wear the mask but we need that communication. They don't think about that.

I never have an interpreter for the dentist. I use pen and paper to communicate. We've never really had a problem with our teeth to be honest. Just so happens it is quite easy really.

I went to the dentist recently actually and I said, "There is something hurting", and it's 100% hurting but they couldn't find anything and they said, "Do you want somebody who can sign?", and there was somebody upstairs and then they came down and actually pulled my hand out and started doing the Deafblind manual on me, NOT British Sign Language and I was, "Excuse me, I am not blind"! So yes, that was shocking really. I was a bit embarrassed, I think they were a bit embarrassed too. I mean, I used my 'Access to Work' interpreters from [X], to go to the dentist with me in office hours which helps me a lot, because I'm able to do that, but now I'm retired I have no 'Access to Work' so, what would I do? Luckily my dentist knows how to communicate with me anyway, so we just sort of get on with it.

My dentist explained to me recently, something about my teeth and I literally had no idea what they were saying, because the jargon they used and the way they were doing it, I just didn't understand. They showed me the X-ray and they were pointing at things and I think they said there was something about the gum and sort of gesturing and I think they were saying something about age. But, because it was quite visual, because I had the x-ray, I sort of got a little bit of the information but pretty much it is impossible to understand so we should have interpreters at dentist's appointments and I did say "Hey look, next time I want an interpreter" and the receptionist said, "Oh don't worry, I'll explain for you". And I said, "No, no, I want a proper interpreter".

I think the big problem, is, I don't know if dentists have a budget to provide interpreters? I know Doctor's obviously have, but dentists? I have never come across that. opticians, I don't know, do they have budgets to do that? You know, you go to the Dentist twice a year don't you, opticians every two three years, so, are they able to do that?

My friend just said about private dentists, - it shouldn't matter whether it's private dentists or NHS dentists, you know, it shouldn't matter should it, you should still have an interpreter. I mean my son had a football injury and he had to go to the Nuffield hospital, and I was like 'Oh that's a private hospital', but luckily, he was able to go there, and they did provide an interpreter and that's obviously private so that's good. For me whether it's private or NHS it shouldn't matter you should have an interpreter.

5.0 Opticians and Pharmacists: Deaf sign language users' experiences

Mine's quite positive actually. We go to Boots Opticians, and they book an interpreter – so that's fantastic. I know some opticians refuse to book an interpreter, but luckily, they've done it, so we still use Boots Opticians.

Obviously, I've been going to the opticians for years, pretty simple, obviously the same as hearing people, put the lenses on, do the different tests, and they might at the end write down "You've got a slight loss", compared to last year, or that sort of thing. I don't have an interpreter for it, I would prefer to have an interpreter, but when they put the lenses on you might not be able to see them, or if it's in the dark. I don't know, - obviously if they are doing a test you have to look at the interpreter and concentrate on the test – that would be quite difficult actually, impossible.

I mean I've got a problem with my eye and there is a dot on my eye. I went to the doctors first and they said it would be best to go to the opticians. So, I went to my local opticians with an interpreter, luckily, I managed to get one to come with me and I said I need further checks on my eye, so if I could book an appointment and asked them to book an interpreter and they actually said, "No" and they said because they weren't part of the NHS, they were private, that I couldn't have an interpreter. I said, "but my eyes are literally so important, I am Deaf, my eyes are everything", and they told me to go to Accident and Emergency and so I did, but again luckily, I had an interpreter with me. So, I went to A & E and the interpreter didn't arrive, so I used the interpreter I'd got with me and in the end, the hospital actually said I needed to go back to the Opticians to do a test, so I did, and I asked for an interpreter and they wouldn't do it, so literally, it was problem after problem. I went back to my GP, explained the whole thing to the GP and the GP was actually VERY angry and phoned the opticians and luckily after a sort of big fight if you like, they provided me with an interpreter, but you know, if they had the funding or the NHS could fund, it wouldn't have been a problem and, it just caused a lot of stress really. In the end, an interpreter was provided finally, but it was a long process which I shouldn't have to deal with.

You know that X [person] has to fight for it and then it becomes a long process whereas hearing people get it just like that!

For me, I tried to register our family with a new opticians and I literally asked so many places if they would provide an interpreter and they said "No". So, I approached Boots in Wolverhampton and they said 'Yes' and they said they would provide an interpreter for [X] us in the family (not my baby) and they literally paid for it out of their own funding/budget which was really positive actually it was good. I think it is once a year that we go - the [X] of us, all at the same time so that was a positive experience.

My experience with Specsavers was my wife as she goes on line and books the interpreter, but recently that doesn't seem to be happening. I don't know whether they've changed their policy or their access, so we both go to the opticians, together and sort of have to 'interpret' and support each other, which I don't feel is right, you know she needs to focus on her information and her appointment [not on

trying to understand without an interpreter]. I mean a lovely young girl was sort of conversing with us and I got my glasses ok and correct but, it shouldn't be like that. You know, there could have been an error in communication and information, I would have different glasses that weren't appropriate. Again, I used to use an 'Access to Work' interpreter to go to the opticians before and now I'm retired that's not an option and really, you are not supposed to do that, it is supposed to be in work hours, you know.....

You know I mean 'workers' get 'Access to Work' [funding] support, but retired people, or unemployed people, haven't got an interpreter on call and to be honest, it's abusing 'Access to Work', because 'Access to Work' is for people who are in their job, but because we have no choice, we abuse the system, every now and again you know if there is an emergency, but it is not a normal thing to do.

It's not the correct thing to do and like this gentleman just said, within work hours but, sort of out of hours or when you're retired it's not possible, not possible. It's the same with the dentists and opticians I just sort of go out of work for 10 minutes you know and the interpreter comes with me, or used to.

Well, if the GP has given me a prescription, I go to the pharmacist, hand it over, then I'm given it with printed information about the dosage, how often to take the medication and such, if it's one or two, and how many days and that, and then the leaflet contained within the medication box is obviously jargon to me, it goes over my head, but I just take the tablet and a brief explanation of what it is. I'm diabetic so somebody at the pharmacy takes the needle test and then they will check my contact details, but they should know what they are and the information should automatically come up and but I get questioned, questions after questions, about the ...[dosage] and I reply, and then where's my nearest chemist – it's local, and that's [prescription] then sent to them and then I go there and no, they've run out of medication and thenthey call me back

I don't have a problem really [accessing Pharmacists].

I go the chemists myself and sort of write down what the issue is and communicate with them that way and they will provide me with whatever they think is appropriate and obviously, you must pay for the medication you're having if for example you've got an upset tummy or something. You write it down, you show them, they give you the appropriate medication.

Sometimes the medication itself - the tablets, the packets, the information on there, we I don't understand that, so I might sometimes have to ask the pharmacist whether I can take this tablet with another tablet and they double check if I've got any other medication. That's vital for Deaf people to have access to that communication because that's such an important thing to know, it can be quite dangerous really.

5.1 Pharmacists: Consultation rooms

In terms of the private room, some Deaf people don't know what that's for, maybe they think it's for staff, so they wouldn't ask to go in there.

My local Boots chemist, they've got a consultation room, and I didn't really know what that was for, - to be honest. I found out recently, that you can go into the room and talk about medication and things like that, so that's quite useful. Whether they provide an interpreter for that, I don't know.

I did go into a [consultation] room once before as I had Shingles but and I wasn't sure obviously at the time, went in and luckily my brother came with me but he's a male and I'm a female. If I had a female interpreter I would've felt a lot better, but this is what we have to use sometimes, - use family.

6.0 Community Services: Deaf sign language users' experiences

Once, I think I was at the Health Centre, with my husband for the Brain Clinic, - Brooklands Centre, so we arrived and the deaf Support Worker was there, the interpreter never turned up, so the lady there asked the Support Worker whether they could interpret and he said, "No", and she said, "How about we carry on the appointment and we can sort of write things down to each other", and I said, "No, I'm not going to do that", I need an interpreter, and she said, "Why not, we can do it, come on, we've got to do it now and get along with the appointment", and I said, "No", and then we couldn't continue with that appointment because the interpreter never turned up.

The Health Centre [booked the appointment]. Reception didn't apologise or anything like that, we tried to clarify if anyone was coming and it turned out who was responsible - I'm assuming it was the receptionist, but I don't know.

There is a physio at West Park Hospital and they do provide an interpreter, and I've never had any problems with them.

No skilled or experienced Social Worker for the deaf, from Sept 2016 to Feb 2017 - we went through 10 different Social Workers. Not one of them knew anything about Deafness. I'd give them a bit of brief Deaf Awareness [information] and we'd move on to the next one and different Social Workers and we'd do it all over again, and then when my father went to hospital, we'd have another new Social Worker and I'd have to explain the same to them and then [when he] came out of hospital and there was a different Social Worker, so literally, it was just again and again, and again and I would have to train them for my own father. Also, local community support for mum, and that is one of the main reasons why my father is in a care home because there is literally no support for mum.

Respite wise, mum would want to go out in the evening, so we'd be told, "Oh yeah, we've got Respite support for you", and we'd ask, "Can they sign?" and it was always, "No, they can't". So, mum wasn't comfortable going out and leaving Dad with someone who can't sign. Hearing people who've got a bit of respite have always got their options. No Support Workers, so we had to use external organisations to get someone who could sign. There is carer support as well, so information and resources from local carers in the community but they don't support her, they haven't got the funding to pay for an interpreter. They can't give her information because it's not Deaf friendly, it's not accessible and also, the Parkinson's Society, - because my father has Parkinson's, I'm involved with that because there is no funding for interpreters. The Parkinson's Society, obviously that's

a Charity, so, who is responsible to pay for the interpreters? So, it goes back and forth, and nobody will admit, with their hands up, who pays for it.

My husband, - with Wolverhampton Social Services, - the experience – Oh, it's just awful. I don't know if it's the Council strategy they've literally removed Deaf Specialist Services, to become more mainstream, they have these teams,the referral gets delayed, they get the wrong support, - there's no specialism within the Council. No Deaf professionals.

In my time, a long time ago, in the 1970s and 80s, the Social Worker for Deaf people was really good actually and now it's gone, but it was really good then...

In Wolverhampton, we had really good support from Social Services [in past]
We need Deaf Specialist Services, in the community, having that outreach service for Deaf people

There are no Deaf Social Workers, - it's the funding isn't it? It's always the same, it's about the money, affecting us...

For me, somebody who is an expert, has the knowledge to support, and I'm not saying you need a Deaf person in every single team, just one person on board who can give correct advice and the right information.

In meetings, I complain and rallied but when something is set up and then 2 years ago it closes because funding's finished again, and, 'Oh you know it's that cycle again' and campaigning since the millennium....

Somebody actually said to me that in the 80s, they feel like it's happening all over again. It's never better though. In my time, before I had my children and when they were very little, the barriers I faced were hard but we'd have a Social Worker and you could access things and now obviously you've got interpreters, or should have interpreters, but with the NHS and any services for Deaf people that is a massive problem, so, as you say, it's happening all over again. Yes, you have interpreters, if, they are booked, but something solely for Deaf people; a service for Deaf people, - there's nothing, it's just disappeared..

So before, in the past, you had the Missionary service [service provision run by Missioners] ...NHS, Social Workers, all in one [place], but, there's just not enough information for Deaf people, - what sort of service would you want? Is it general equipment, communication – all in one?

Just sort of Deaf professionals, Deaf experts on board, where they need to be.

People who can support everybody, - NHS, Social Services, all in one, - just pass on that information, what's needed, who've got the expertise.

You know, we had a Social Worker come along who didn't have our experience, didn't have a clue, so we had to teach them again, Ooo, it's just a nightmare. I mentioned earlier about training them, - training the Social Workers! But, it's their job to help us! I've got 3 children, sign for them, doing the Deaf Awareness, informing them of, "You can contact this agency, that Specialist team," policy, what agencies they can use for interpreters,...they don't know who to ask. I end up doing their job sometimes....

I think I remember around the year 2000, I went to New Cross [hospital] and all the nurses were learning BSL, and that was funded by the NHS, from within their budget. Cleaners, nurses, ...including Deaf Awareness training and it went on for 2 years, but the budget finished. You know, this is what nurses should receive, they should get Deaf Awareness training. To be able to approach Deaf people about how to book interpreters, about their service, the training you know, was for one day and then you'd get an evaluation, feedback from the training

A Health visitor for the Deaf? If it's a hearing person who can only sign a little bit, that's not very good either. You need Deaf people to actually do that, to be the Support Worker, to work as Carers - to do the shopping and medication. Hearing people apply for the job, but it's working with Deaf people, so it's kind of oppressive in a way for Deaf people. So, you need to encourage more Deaf people to be involved in Health care and looking after older Deaf people because they are often alone.

For me, the Health visitor, normally they'll say I'll visit on this day between 9am and 5pm and I'm like, "Oh hold on, you know, I need an interpreter" and they're like, "Oh yes you're Deaf aren't you"? I say, "Yes, you can't just give me a vague 9 till 5". You need to book a specific time so that an interpreter can be provided. So, they need to obviously adapt their working routine, for ME, which I understand is different for them, but that's the way it must be because you can't sort of just say, we will come along sort of between 9 and 5. That's what they tend to do. Just give you [a broad time frame] and then just drop in. For me and other Deaf people, you would have to say a specific time. Luckily, they did adapt.

Drop-ins [appointments], I can't attend those because I haven't got an interpreter. If it's my child, obviously then I would because their health comes first. With Health visitors, they organise play group, 'Stay and Play' - that sort of thing and I don't participate, because I'd ask, "Will you provide an interpreter for me?", and they'd say, "No", - but you know, but we're both Deaf, so we'd be very much excluded anyway.

7.0 Nursing Homes, Care Homes: Deaf sign language users' experiences

I know for a fact, that there are no Specialist Care Homes which have provision for Deaf people in Wolverhampton, the nearest one is in Blackpool or Isle of Wight. Deaf people, older people that need care, nursing care - they've got an Adult Service in Walsall which is run by Action of Hearing Loss, but that's for Deaf adults with learning disabilities, but for Deaf older people, whom potentially need nursing care, as I said the nearest one is Blackpool and Isle of Wight.

This is my mum, so I'm just prompting questions and experiences really, - in terms of my father, with the GP and home visits mum - did they bring an interpreter? Mum is saying, "No, so we had home visits for my dad, and they never brought interpreters along". I told them to mum is saying, and I asked them to but it would depend what particular thing would need doing that day, but I did say that communication is

important to the doctor and you need to bring an interpreter and they would say, "No, if you are really ill, then yes, we will bring an interpreter but if it's just a general medication or blood test then no it's not necessary", but if they are going to ask him any questions we need an interpreter there to be able to give him an answer. The doctors always said it wasn't necessary, the staff know what this patient needs for the routine, so ... X GP surgery which is just around the corner from here, the doctor was from there.

A bit of background information; my father has got Parkinson's and my mother can't care for him anymore, so we agreed for him to go into a care home with personal care because he needs 24 hour care and my mum needed support, so obviously the care home is responsible for my father and they phone the doctors and that sort of thing, not mum anymore but, the care home doesn't have any Deaf Awareness, - so everything is OK in case he falls or anything.

Castlecroft- which is the old doctor's surgery, they booked interpreters and now he is in the Care Home it's a different surgery, they don't reinforce that, and they don't do that. Thorny Street won't provide interpreters. The care home is responsible, and the staff know what my husband's problem is but he can't hear what they are saying, he can't communicate – they say it's just not necessary, they say they'll get along, they'll explain for him but, my husband wants to know what the doctor is saying...."

I visited one old lady and she will be 94 and had a fall and went into a [care] home and she wasn't very happy and was very upset. She didn't want to be horrible, but they were all hearing people, there are no subtitles on the television, so she was bored there and really hated it there and she wanted to go back home. She went back home but had to be careful and I had to visit her every two weeks just to check that she is OK and ask if she needed any help with the shopping and, I can do that for her if she needs help, and help with painting her room, so I can do that for her. She is quite old so, she wants to go to an older peoples' home for Deaf people but she didn't like being in a home for hearing people.

Deaf old people they like to be together and mix with other Deaf people and talk to each other. If it's just hearing people then there's no communication and it's socially isolating, you know, you need some carers who are Deaf and who can sign, and then they will live longer because they will be happier then. It can be very frustrating as well for a Deaf person if communication isn't working properly and it can be very lonely for a Deaf person if there's no communication so it's not fair for older Deaf people.

7.1: Communication between staff and patient/family

Pen and paper – it isn't too bad you know, we can do it but, we are used to writing little bits down, and it's very much back and forth all the time.

Obviously, when we get to the appointment there is an interpreter that turns up, but at the care home, I don't know if it's because it's private or....

In regard to the Council – would they pay? They pay the care home, they are responsible for my father so, shouldn't it be in the contract that it's their responsibility to provide interpreters? Whose responsibility is it? There's no boundaries. Social Services say "It's not me" the care home say, "It's not me, it's the Council because they are funding part of the payments", - so who is responsible?

The care home don't want to fund an interpreter because it's quite costly and I think that's the problem.....

Ideally, I want a care home for Deaf people. I'd still visit him and that's why I visit him everyday because I don't want him to be even more on his own than he already is, because they all are hearing [people] in the care home. He's the only Deaf person and, as I've said, the nearest Deaf care home is in the Isle of Wight. The care home have provided a brief course for the staff and they've done that, but that's all they've done really. So, they kind of have a little bit of Deaf Awareness but it's not enough really. They don't have a conversation with him naturally and they sort of generally just do what they need to do with him. Whereas, with other people in the care home, they probably have more normal, day to day chats with the staff because they can communicate with them, whereas my husband has to rely upon us going to see him to have those normal conversations.

It's a consideration for the future to actually set up proper care and carers

So, last year my husband was in hospital for 2 months and was discharged out of hospital and they had given me a massive bag of medication, - I didn't have a clue what that was, and they said that I was responsible to take my husband to the care home along with his medication, but I thought the ambulance was responsible for that, but anyway, I had to do it and I took it all along but they didn't explain to either me or my husband what the medication was for, but the care home staff said they would know what it was but I couldn't ask them, but I'd still like to know. The care home were OK, if there is a hospital letter sent to the care home they should tell me if there is an appointment and sometimes they would forget. I think it is the care home's responsibility to take my husband to hospital and not me because he's there isn't he, but they do expect me to do it sometimes.

Because they don't know how to communicate with my father I think they just automatically think that my mum should do it and that's why they try and pass all the responsibility to her in terms of appointments. So, if there is another appointment they say, "Yeah, yeah, you have to take him", but I really do think it should be the care home's responsibility, I really do. They know I'm going to because I visit him every day so I'm just expected to because I'm here, it's that 'you should do it' you know, 'you take him' sort of thing.

It's very, very, very important around the UK about the care of old people who are Deaf. I worked in a care home before, and they were all hearing people and there was only one Deaf person there, an elderly Deaf person and I was the only person who could communicate with that Deaf person and she relied on me an awful lot as she couldn't communicate with hearing people. You need an old peoples' home for Deaf people. It's very, very, isolating and unfair on a Deaf person to be the only Deaf person in a hearing home for Deaf people. If you had a Deaf care home that would be a lot better with staff who could sign, then you care for the Deaf person a

lot better and people have the right qualifications and they will live longer that way. If a Deaf person is alone its very lonely and isolating and not fair on the Deaf person to be the only Deaf person in an old peoples' home.

Maybe over the past year or two, it seems to have got worse. I don't want to go into an old people's home I want my friends to come and visit or stay with me and help with shopping and that sort of thing, - I don't want to go into an old peoples' home.

I want to set up a building – a home for Deaf people where they are cared for, maybe with 10 bedrooms in it – a Deaf care home because Deaf people would be much happier there. Like a Day Centre – you go to the Day Centre, it is quite easy to get to, have a conversation and then go home....

There is an important thing about 'Hospices' – for people with Cancer, or people who will soon die. Lots of hospitals have a budget to pay for interpreters, but a hospice has a budget to pay for nursing care but there's no budget for interpreters. A lot of Deaf people would need to go to a Hospice and they just give up on life and die very, very, quickly because there is no communication, so a hospice should be able to pay for an interpreter or a carer – a Deaf carer to work with Macmillan or palliative care, so I would like to see training for Deaf people to be carers to look after older Deaf people who are in a hospice. For example, if you have to give a Deaf person Morphine to explain to the Deaf person what is going on, for often a Deaf person won't understand what is happening, so they do need that, but at the moment a Hospice has no budget for interpreters or anything like that, so, we need to raise money for Deaf patients who are in hospices. Maybe charities need to raise money for that, maybe £20,000 or more. Hopefully the Government or the CCG will allocate some money to the hospices for interpreters. That's all really. So, in the future, plans need to be made for a Deaf care home. We had that before – a Deaf care home, and it was run by the RNID – now called 'Action on Hearing Loss', and also the British Deaf Association (BDA) – that was around 1990s, then there was change within Social Services, - they took over and the church or charity was closed down, and a lot of Deaf care homes closed because Social Services refused to pay for them, so, all the Deaf people had to go and live at home and a lot of them died quite quickly after that. So, we need to keep Deaf care homes going.

My [X] is in a care home in Wolverhampton, but the process to get to that point was horrific and again we made a complaint about that. He's in a care home now, which is fantastic, but there's ongoing issues, because he's very much isolated, he's the only Deaf person. The staff can't communicate with him very well at all, if not at all. You know, he's now saying he wants to kill himself, he's got mental health issues. His mental and physical health has literally deteriorated because of this process. We've made formal complaints and again achieved nothing. So that's a brief overview of our situation.

In Scotland ... they have a care home for elderly Deaf people that closed down, because more and more older Deaf people more physically able if you like and their view is that, 'I'm not going into a care home', so they continue to have support or home help. That sort of thing, taking them out shopping, so more community based and some of the workers are Deaf, so they can support the Deaf elderly people in their own home, in their own comfort and, there's a woman here in

Wolverhampton, who's 94, lives on her own, has no support whatsoever, and but she's a very proud lady you know, she's like 'no I'm fine, I'm fine', and I'm actually thinking – Oooh, you know? My wife and I are quite concerned about her, because we're just waiting for something to happen to her, a fall or something. At the moment, she's very much 'I'm fine' because, there's nowhere she could go to. A lot of elderly people don't want to go to a care home in Wolverhampton because of the isolation and the mental health issues, they don't want to, so they avoid it.

My father in law literally had to, we had no choice, you know he needs 24-hour care, we didn't want to put him there, but the physical needs he had meant we just had to do it, but the communication and isolation is horrific.

We need a care home for Deaf people, with communication, that's just what it is. There's a lot of research been done on this. In Birmingham - BID Services looked into extra care within housing provision and visited a home in Holland, to see the examples they've got there and in France, but here in England, it's just so poor, so poor. The Royal Association for the Deaf and SONUS which is a charity in Hampshire, had a project, where they compiled a report about care for elderly Deaf people and pretty much of what you mentioned and they visited the home in Holland, [for further] information and my friend was part of that group, who went to look around that home and there were six Deaf people and if they would like to move somewhere like that and their response was, "No, no, I'm going to stay in my own home". I think because they realised in Holland there are a lot of rented houses, so they weren't bothered in terms of sort of upping and going into a care home, whereas in Britain, there is a high percentage of home owners, so they don't want to leave their home.

One of our friends, a local couple, both need carers who come to the home, but then the situation became worse and the woman who had health problems went to hospital and the male was on his own and he really wanted to visit her. They both ended up being in a [care] home and then some time later the elderly lady was I think, in hospital and then the male missed out on all the information, he didn't know what was going on he was like sort of where is my wife? What's going on? They didn't see each other and then the wife came back to the Old Peoples' home, but the husband still didn't get to go back, and nobody was sharing any information with him whatsoever. There was a massive breakdown of communication and they finally reunited of a sort, if you like, but then a couple of months later she passed away and then two months after that, he passed away. So, they [didn't have the opportunity to be] reunited for such a long a long time and I think that just didn't help. In terms of the couple - the wife doesn't really speak well; the husband spoke very well, and he can communicate to another person but they wouldn't be able to communicate back. I think a lot of people thought because he could communicate via speech, that they could communicate back [via speech], but that wasn't the case. You know he had good speech, but he hadn't got good receptive skills, but a lot of medical people need Deaf Awareness, that just goes back to what we originally said, all Deaf people are different in the way that they communicate.

With my [relative], the journey to the care home was a massive battle with Social care professionals and Health professionals, because they were adamant that he should stay at home and we said, "Well that's fine", but if we just had carers, he

would have literally needed them 24 hours and the carers need to be able to sign and they [the professionals] were like, "No, no, you could use anybody". No! It's got to be, they've got to wash him, they've got to..., it's very intricate care isn't it you know. It doesn't work like that. If we managed to find somebody that was able to do that for 24 hours, it would be £125,000 a year for somebody to do that, which in a care home it's an awful lot cheaper. In the care home you obviously have got a better service, because you've got hospital beds, you've got everything there and staff who were trained but they wouldn't listen to us. You know, it's common sense, it's common sense, what he needs but, they were adamant that he should stay in the home, but not provide 24-hour care. My [relative], hasn't got any English understanding whatsoever. He has got a basic understanding like that of a primary age child, but he can't write because he's got Parkinson's disease anyway and the professionals just didn't understand that, they were like, "Oh you can try and write down on a piece of paper", but, he's Deaf and he's got Parkinson's! It's just so stupid, I mean I'm sorry to say, but a lot of professionals are stupid. It was ridiculous.

Community services in terms of care, carer support, obviously a lot of us do care for a disabled person but, in terms of carer support and support groups, we can't attend because there's no interpreters, they don't have the budget for them. You know you've got Parkinson's UK or a carers group, - we can't access them because of the interpreting issue and there's no support.

There is also no interpreting provision for Dementia Cafes.

Charity provision most of the time and they haven't got the resources and a lot of 'sorry we can't', but it's the same old thing isn't it?

I know one lady she has to be over 90 by now, she had Dementia very badly and she's in a care home and her daughter is very, very, ill. She can't visit her own mum, because she's ill herself and it's quite a serious illness that she has. My wife visits her and it's very emotional, but her mum has got nobody. There is only one Deaf person in the care home, so my wife will visit the daughter and her mum. The daughter isn't Deaf but she's ill in hospital herself, so she's in there for regular treatment and it's just so sad, because her mother is Deaf and in a care home on her own with no nobody that can communicate with her. I haven't seen them both recently but my wife's told me about it and my wife couldn't come here today because she's got commitments this afternoon.

8.0 Complaints about the NHS: Deaf sign language users' experiences

Qualified interpreters which is what we should have for medical appointments...

I have heard that Deaf people have arrived for their medical appointment at the GPs surgery and complaints have had to be made, but, how do I make a formal complaint to my GP?

With complaints, for Deaf people their first language being British Sign Language, so for a Complaints procedure which has to be in English, that's a barrier straight away

for us. 'Sign Video', I really, really recommend them, I feel very confident, it meets our needs, that is very useful.

My issue about the Complaints procedure, - complaints to the hospital, I feel that they just brush them away. They say, "Oh, yes we admit, we admit this, we admit thatwe'd like the training" and then that's it. That's all they do, and then it's done and dusted, and I say "Fine, you are admitting it, but then what - what are you going to do about it? How are you going to improve it? Ok, you've admitted it, but the next time I come to hospital I know it's going to happen again – 100%" and they say they are going to offer the training, but you don't get details. They asked Communication Plus to give 2 Deaf Awareness days and the people who went, were the people I complained to, but, not everyone. They need to employ a Deaf expert for regular training. This one wasn't through Healthwatch but Social Services direct and we complained to them and they said, "Oh, yes, this is upheld and this is part upheld and this is notso, I said, "Ok, this is upheld but then what? So, what does that mean? You've admitted something, but then what? It's always the same thing." So, I just feel, what is the point? Typing up all this information and complaining. I've spent a lot of time and effort writing this complaintyou know, with your colleague, back and forth – it's upheld and that's it! Just brushed off! I feel like, next time I've got a complaint, I'm not going to bother, I'm not going to bother, because I'm not being listened to. I don't know whether it's....., just brushed away so, I've got the letter, and then what? They are going to make the same mistake next year, 2 years' time, and it's going to happen all over again. A vicious circle.

So, I have raised this with you before actually, so my father was forced to have a catheter, and he said "No", he didn't want it, but they forced him, and he has the right to say no. He did say 'No' but they forced it onto him – so where are the human rights there? Horrific. Really horrific.

The hospital said that they are going to identify it through training, but, I know that the hospital have a high staff turnover, so the next person that comes along is not going to know. I just want to ask, - do you know how to complain to the NHS?

I don't know, I don't know at all. I was told you were meant to write to PALS, you are meant to write to them. What is it? What is PALS? That is where we had to complain to eventually.

Maybe if I complain in Wolverhampton it's the wrong thing – St. John's – the office there? On Temple Street. St John's office. (near the Greyhound Pub) – I've written a complaint to there, but there again, offices keep on moving.

Accident and Emergency – the PALS office is there. We never knew what it was before.

The other problem obviously is that we don't know how to complain to the NHS and the process. Deaf people when they do complain to PALS, some people might be able to type and understand English but, not all of them will, so, will they use and accept 'Sign Video' [VRS/VRI] to complain? We could sign it, and send a video to them. The staff could get an interpreter and understand it through sign language [translation] – could they do that? Why shouldn't they?

Have you heard of Healthwatch before? That's important information isn't it?

I know a lot of Deaf people don't understand – one person told me about Sickle Cell and when they were young they had a blood test. We had a reunion about 3 weeks ago, Ethnic minority people were talking about Sickle Cell, and I wished I was there. There was information on Facebook and such you know, I just wish you could get full information regarding Sickle Cell. Some Deaf people miss out on that information.

I think the other issue with the complaints procedure, there's too many pathways, - you've got PALS Healthwatch, the Complaints Commission...

Where do you go to complain?

It's on the form isn't it? Do we complain to you? [Healthwatch]

[Making a Complaint Online] - But it's all in English - my English isn't too good, so would you understand it? My first language isn't English.

I've been through the complaints procedure and they just never responded...about an operation about 10-15 years ago...there's been no response.

In terms of complaints, the complaints procedure is awful. I mean we made a serious complaint to the NHS, they responded, but their response was unsatisfactory and we weren't happy with their response so we brought it up with the Health Ombudsman and the barriers we faced there -it was like, "Look we haven't got the time, we haven't got the resources we are completely worn out, we don't want to drag this on any longer, we want to move on with our lives", but it was just an awful experience.

Well this forum or this project, I feel like I have repeated myself for the last twenty years and nothing has improved. I am completely fed up with complaining to professionals and sharing information and giving feedback to and I just think any service in Wolverhampton you know Health and Social care, education, whatever, the first point of contact is always by phone and if I email, sort of eventually find the address to email them, I never get a response and I am really, really, fed up with that.

I have got a lot of grievances, - there is no resources here, there is no Deaf Awareness. The professionals don't understand the barriers we face on a daily basis. We try and explain but they just don't get it and they always look down on us like Deafness is a second-class thing, thinking that Deaf people don't know anything, that we know better than you but actually I'd probably say I know a lot more about Deaf issues and Deaf barriers than them, but I have to fight all the time. I have got two Deaf children, one is Deaf with special needs, we adopted her and we have an awful lot of problems with social care linked to her. It's caused a big family breakdown and there is no support, so it is very, very, very frustrating and that's because they have no idea. My daughter here you can see is Deaf, she is three months old and there are already barriers. I want her to go to a nursery with support and they are only offering me an hour a week. She's Deaf, she needs more than an hour a week of support. So that makes me think, I can't go back to work as my daughter is not going to have enough support at nursery, but I have to go back to work.... nursery, education, social groups, parent and toddler groups, direct

payments. My daughter is not able to apply [receive] Direct Payments because she is too young. My other daughter with special needs, has got Direct Payments as she's twelve, but, we aren't allowed to use freelance interpreters for Direct Payments, because the Direct Payments won't accept freelance interpreters so then it is limiting my daughter's access to services. So, there's another barrier ... and I would just like to say I am fed up of going round in circles and repeating myself to professionals and they didn't know this, and they didn't know that, and to be honest it's very dangerous. There was a massive incident recently as I said with the family breakdown and that it because of the professionals not knowing about Deafness and Deaf culture. I have another daughter who is hearing. I have no support for her in terms of parents' evenings, you know, and schools are like, "Oh we have got no funding to support you and to provide an interpreter", but we need all of this. There is a lot of things [information] there I understand that. It's all facts.

It's the same old story, same old story and it makes her health deteriorate. You know, I have got to think about mental well-being for us. We need to see more Deaf Awareness training for everybody. All medical people within hospitals, GPs, dentists, therapists, etc, rather than relying on interpreters only. I understand you know, yes, we do want an interpreter, but, they think by doing [providing that], that's it, we can just get on with it.

I agree with X, I understand X's feelings and I mean before I moved to Wolverhampton... I was working for [X] and I was setting up forums for Deaf people, in terms of Health and Social Care,.. and you know, we are talking how many years later on, and it's the same thing that's still happening and, but there are no results, it's all talk. You know, all these reports get created and just chucked on the shelf and that's it.

It's the Council that's what they do, you know - It's true.

9.0 Interpreting/Translation agency provision (CCG): Deaf sign language users' experiences

It should be 24 hours [there should be an on-call interpreter]

I just want to clarify, before we used to use 'Communication Plus'- and about 10-15 years ago, before communication Plus there was no 'on-call' interpreter, when 'Communication Plus' won the contract they would provide interpreters 24 hours, you would just phone and get an interpreter straight away. Now, thank (goodness) 'Communication Plus' still have contractsbut not with the GPs unfortunately and not with the Dentists and Opticians, so that's the problem really.

Well, we want qualified interpreters, we prefer 'Communication Plus', and we want Deaf Awareness as well for all staff that work in the GP, opticians, yes, and I'm saying, I'd like to see all the Doctors and Nurses – all the people involved in the medical services they should have a one-day course about Deaf Awareness.

I don't know if the NHS contacts 'Communication Plus' - is it? But the contracts keep on changing, so therefore agencies [suppliers] keep on changing, and that's an issue.

In the last 3 or 4 years, 'Communication Plus' was the main interpreting agency for the NHS, and recently it's changed, and deaf people were used to 'Communication Plus' being the agency whereas now we are very much confused we don't know who is providing the interpreters. I think they still provide interpreters for the hospital but not for the GPs but it's very confusing, it's not clear at all.

For GPs, it's 'Absolute Interpreting', [agency] and they won't use qualified interpreters because they want to use the cheapest option

NO, no, no! I have never experienced, oh actually, maybe once but, I was lucky because you know I used to work [at X], so I knew which interpreters were not working because it was school holidays, so I would just text them and say could you come along, so that was a one off, and the doctor was really quite angry with me that I asked sort of asked an interpreter to come along with me, but I knew they were under an agency and obviously interpreters work all through holidays, so they work for different people. So, I did that, I did happen to have an appointment on the same day with an interpreter. But the doctors weren't happy because they said they needed to use a particular agency, but, I know this interpreter, they interpreted last year [for me]. I know who they are, but there is one agency that lost the contract, it was a London based agency and I was really angry. So, I wrote to the Health Commissioners here and said why are you giving [business to] a London based agency, you know, I thought you were promoting local economy, you know more local and they said "Oh yea no, London promised to use local interpreters", but you know, the money is going to London isn't it? They lost the contract anyway luckily because of the poor service that they were providing and then it went to a local agency but then the PCT finished so.....

10.0 Mental Health services in Wolverhampton: Deaf sign language users' experiences

Generic Mental Health Services/Therapy had a lack of understanding of the needs of Deaf patients and suitable therapeutic methods of relaxation which are traditionally based upon being able to hear which was highly problematic for Deaf BSL users.

An example cited was that of a local service not being able to cater specifically for Deaf people which exacerbated the condition.

"I think I don't know whether is it health counselling, but [my employer] supported me with that particular session and there was an interpreter but they told you how to relax and listen to the radio, but I was like eh? I'm Deaf. Literally they didn't know what to do or what they could do to help a Deaf person relax, the only thing they could think of was TV and radio and things that you hear and I'm like 'hello', I can't hear. My ears are off all the time. So... no wonder my Mental Health condition went on a bit longer, you know, because I couldn't recover as quickly as anyone else because they didn't have any option for me."

"I mean I suffer from Vertigo, so, I actually went to West Park and had an interpreter and they said, "You're best to have therapy to help you relax, it will include music" and this that and the other. I was sort of like "Eh music? You know, I'm Deaf, so how's that going to help me?"

Statistics were given by participants showing the prevalence and opportunity for Mental health incidence and deterioration to be much higher in the Deaf community with little recourse to supportive recovery with a direct impact upon professional and personal life. Opportunities for Specialist support were limited to a few specific units around the country with long waiting times to receive an appointment.

"In the hearing population there's 25% of hearing people who have mental health issues and depression, anxiety and all that sort of thing, but for the Deaf population it's 40-50%, which is very, very, high. Deaf people are two to three times more likely to be abused in comparison to hearing people. I mean there's a lot of statistics out there and there's a lot of information, that's old information but I've been very much stressed through Social Services and health services, I've been off work ill, because of the situation. So, it's true."

"No, you just argue your rights constantly, you know, we want to access the same thing as what a hearing person could, you know, my hearing neighbour has got access to this, that, and the other, so why can't I? And the professionals would always say, 'Oh you know, it's like an Asian person or a hearing person', and I'm like, 'No an Asian or hearing person they can hear, they can learn English, but I literally can't hear, so it's completely different thing' and they'd say, 'Oh I do understand what you mean', and I'm like, 'No you don't', and it does make you very, very, cross as a Deaf person, it really does."

"...support [for] Deaf people with mental health illnesses or issues, there is one in Manchester, Norwich, Glasgow, London and there are only 4 or 5 Deaf CAMHS [Children and Adult Mental Health Services], so the nearest one here is Dudley and Walsall that fund. It doesn't cover Wolverhampton, it only covers people who go to specific schools or live in specific areas and for adults in terms of mental health services, the nearest one is in Birmingham and it is called the 'Jasmine Suite'. Northampton is for men only, but Children's Services, as I say, there's only 4 or 5 in England in terms of CAMHS."

"My [child] has been referred to CAMHS because of as I've said earlier on, she has additional needs and issues and I've been waiting and waiting and waiting on the waiting list, and it just hasn't - nothing has happened yet. I know that's the same as hearing CAHMS but you know.....?"

"...the initial appointment with CAMHS is [date given]-but I've been waiting for years, well it feels like it but, it has been a long time."

Appendix 3 Section B: Experiences from Hard of Hearing People

1.0 GPs: Experiences from Hard of Hearing People

I went to my GP surgery the other day and saw the nurse, she was facing the other way and I said, "I've got a hearing problem" and she said, "Oh, it's not on your file" - and, I've been a problem patient now for 2 years. Some of the information had not been transferred across...

"I find, even when they say "There's a loop [system]" - there's not one.

The reception [has one], [but] not the doctor himself.

I do position myself, especially at the hospital to make sure I'm in the right position for where they come out, so that I can see them when they are saying my name.

Often in a GP surgery like ours, it goes up on a screen but in a hospital, often they come out and say 6 or 8 names and people coming out from different places - and presumably you have to watch, to know what they've said [lip read] ...but again, ...it depends if they speak clearly enough.

A GP or Receptionist is not going to think about background noise, or children playing around, people chatting, - they don't think of it but they need to be made aware.

It's worse in the hospital, it's not just background noise, it echoes.

When booking a GP - it's not an option to book via text, and I think that would be good.

I think there is access via the internet but, it's been a bit of a problem getting that access. I don't know why, so it's an issue for me being able to access the appointment, but then again, you are not always going to have internet access are you? So, I think text would be good access.

For me, people assume because you are deaf or hard of hearing if you speak louder you can hear, but, actually for me, it is a certain tone and pitch I can hear, so it wouldn't matter how loudly you say things, I wouldn't hear it. My receptionist at the GP is actually, quite patient - I always say straightaway, "I'm hard of hearing" and so they tend to speak a bit more slowly and clearly, and I just always say "Pardon, pardon".

What it is, I don't have a very low voice, so I do have a real problem to get people to hear me because I don't have the power in my voice to shout.

So, it's important that Receptionists have training in Deaf Awareness and understand the difference between somebody that is hard of hearing and somebody that actually has no hearing.

It's a big jump isn't it? It's a big jump to signing, - it's almost like accepting that you are not going to hear, and you've got to change your way of communicating. I depend on lip reading.

This is one of the difficulties, - people assume you know signing which is one way of communicating, but, when you are hard of hearing, you've got to find a way which might be writing on bits of paper which again, is fine if you can write on bits of papers but there will be people who are hard of hearing, especially with an increasing older population, who are going to become deaf or related to age, they are going to struggle more to communicate I think. They might have mobility issues or something with writing.

An issue that deaf people have [is] making themselves understood.

X has got hypersensitive hearing, so actually sometimes sound hurt. So actually, it is an issue that isn't picked up in hearing services – it's like an over-sensitivity.

I've never been allocated extra time [for GPs appointment] it's always rushed, 10 minutes maximum.

If you actually ask for it, then that's different. I never ask for it, I never say I'm hard of hearing, can you give me extra time, so, some of it is about the Patient's responsibility.

Well over the phone sometimes the [GP] receptionist's not very good, so you have problems.

You can get telephones with amplified sound, can't you? That's part of the thing about when you are diagnosed with hearing loss, - you are not told about what's available.

1.1 Contacting GPs:

Texts - since the stroke I can't use appliances.

Always by text [test results] and I told them not to because since the stroke, my brain doesn't know how to work appliances including phones so, texting is a real problem, not just for me but for other people I know who've got vascular dementia.

2.0 Hospitals: Experiences from Hard of Hearing People

I do position myself, especially at the hospital ...to make sure I'm in the right position for where they come out so that I can see them when they are saying my name

Often in a GP surgery like ours, it [your name] goes up on a screen but in a hospital, often they come out and say 6 or 8 names and people coming out from different places – and presumably you have to watch, - to know what they've said, but again ...it depends if they speak clearly enough

Audiology at West Park Hospital- Don't get me started...!

I think [an issue is] the waiting time, for appointments. I've been having to change my hearing aids recently and because the setting wasn't right on them, I've had to go back 3 times. The waiting time for appointments was 4 weeks and then after

that, there was no available appointment on the system, so I had to wait for an appointment. There wasn't any cancellation [appointments] or bookings for 3 months for the hearing aids to get sorted. I think it only actually took about a month and a half because I kept on phoning. They are that busy and haven't got any appointments. My friend works on the reception desk at Audiology and she said they've got nothing [available] ...

There was a self-checking system but that has been broken for about 18months, - every time I go in I think, will it work this time?

Can I mention, that on the [display] screen, - an arrow would also help, a name and the room number and which direction to go. You think 'Where's that', everybody knows that works there and that's the thing, - if you're not sure where to go and you ask somebody and you can't hear, - they are going to answer you and you will think, 'I still don't know where to go', - particularly, everybody's busy in that environment in hospitals, - it's kind of difficult.

Well the background noise or the background music they play or anything like that, - it's the other things you can't control - and that's the noise of the other Patient's there and the acoustic signature of the room you are in. They can't control that, unless, they had a 'silent room', or a 'quiet room' - obviously not silent, in case you need to use your phone - you've got to know, but a 'quiet room' - for those who are hard of hearing, but that maybe more difficult.... I don't know...

I think in terms of a quiet room, the aspect of being seen as well, people might miss the hearing impaired in the hospital.... that would be particularly useful in the Audiology department then they could build these things into it.

The last time I was there and was struggling to understand who was calling, it was because I needed a piece of metal taken out of my eye, so, it had nothing to do with Audiology. Even people with hearing problems have other problems too.

Certainly, my experience is never being told about any support groups, from when I was hard of hearing until now, getting hearing aids was very protracted because I initially went deaf when I was at University. I went deaf for 6 months following 3 viruses, and so, because I've got asymmetrical hearing and visual loss they sent me to a consultant because obviously, the worst-case scenario was a brain tumour. So, they sent me to a consultant who never gave me a follow up interview, and so I started managing with my hearing loss and then because I was going to meetings and it was really interfering with the quality of my life, I went back to the GP and they referred me to West Park Hospital who then said that I needed to go back to a consultant, and so, I was back at a consultant again, and because he said that I was so deaf that he didn't think the hearing aids would work for me and that I would have to look at other options - not implants, but [another] option. So, I went to a consultant and this time I said, "Look you know, I've been 2 years before and I was just cast off, and I want to know that this is going to be followed up and he said, "It absolutely will, but how did you go deaf?" I explained it, and he said, "Oh, we've got no records of you and I want to start right from the beginning with an MRI [scan], etc." So, I had an MRI, then I got a letter from the consultant saying, that because my neuro transmitter was within normal parameters - I was discharged. So, nothing

happened again, and so then you carry on, because life goes on doesn't it, and then another 2 years [later], I went to my doctor's and said, "Look, forget about sorting all my hearing out because of whatever it is, this irregular thing, - please can I have some hearing aids? It doesn't matter if they don't work very well they've got to improve my [quality] of life and can I please be referred, not to West Park, can you refer me to 'Specsavers' or somewhere OK"? So then my appointment came for West Park, so I contacted them again and said, "Can I please go, please, please go to Specsavers..." and, they finally referred me to Specsavers....but it's taken years and years....

I find that they can be patronising because you can't hear and you are having to say "Pardon, pardon", and they are very patronising and they actually treat you as if you are stupid and you say, "I'm sorry can you say that again because I'm hard of hearing", and it's just like too much trouble.

2.1 Hearing Aids:

If I wanted an appointment with the same audiologist, to change the settings, that wasn't available, so I had to re-explain the situation every time I went in, - it took a while.

I do think there needs to be something done around hearing aids. You get the NHS ones, and for me, I got mine from Specsavers, but the guy from Specsavers was telling me that because they get so little money for providing the hearing aids, and it's decided geographically, so for an area like Wolverhampton, they could make it actually, to have an hearing aid, they are getting so little out of it that they could not provide that service anymore and then, your choices are West Park or paying – and then we are getting into paying for your hearing aids and having information about them and all, it's just, a minefield.

So, this is one of the issues, when I had my hearing aids, he quickly showed me how to clean them, and then I wore them, but when it came to me trying to clean them – what do I do, twist this off? I was frightened of breaking it. The point is, when I went to Specsavers – they just did it for me. Where you are saying about your hearing aids you should usually have places, like in Tettenhall, it's the doctor's surgery, next to the Institute where you can go in with your hearing aids, and they'll clean it and give you batteries, and do all that....you know that little book they give you, you just take that with you.

So perhaps it's about information around it – is what we are really saying here, but you are in the dark. It is a medical condition like anything, like diabetes, or whatever, you don't know what's out there and what you can do, you are floundering.

3.0 Urgent Care: Experiences from Hard of Hearing People

I don't really attend [hospitals] that often, well I've been to A & E a couple of times and they are developing a new A & E – downstairs, and they tend to come out and shout your name.

They do have a screen, and when we went in, it was broken.

There should be a note at the registration desk saying that's there's a screen – with an arrow – that would help.

Something that would help, if they don't have a screen for everybody, if they know that someone is deaf/who has a hearing loss, - it wouldn't take much to just write in big letters their name and hold up when they come out to call somebody, so that we could see it and don't have to listen for the name – a strip of card or something, - like at the airport – [arrivals]. They should do it for everybody, because when you think about it, - some of the names they call out, they are not very clear - it might not sound like your name, but if it's written down on a piece of paper or a card, you can just read it and think, 'that's me'.

I think with everything you just struggle, don't you? I recently had to go to Accident and Emergency, and it was just an absolute nightmare because what they do is they come out and they call your name and I can't hear when they call my name, umm, I find that really difficult. That's the advantage when you go to the GP because they've got the name, your name lights up [on a screen].

Or a ticket system being a solution, if they could give you a ticket and your ticket number shows up on the board.

In A & E the acoustics are really bad, its particularly bad.

The acoustics are terrible, absolutely terrible. The sound goes upwards.

The thing is about making a distinction, if you are totally deaf, well they may or may not put signers in there or whatever it is, when you are hard of hearing, it's not taken seriously but you still can't hear anything and so you spend your whole life just saying 'Pardon, pardon' and apologising as if you are stupid.

It's just a case of having to repeat yourself lots of times. Going back to the thing you've just said as well when, if you're phoning up or speaking to somebody in health services and they haven't got somebody where English is the first language, that makes it even more difficult, and communicating with consultants where they struggle with their English, it's really difficult when you can't hear, and you can't understand each other.

I recently went to A & E with my thumb and when I was speaking to the consultant, I haven't got a clue what he was saying. I was saying "Look, I know it's not broken", because they speak quickly, and they are wanting you in and out aren't they? It was really hard.

Yes, it is lost in translation. I'm saying, "Look I'm sorry I'm hard of hearing, I don't really understand". It's a medical issue and they need to explain it more clearly.

It's hard enough explaining it to somebody who has got full hearing and full understanding. You need to pick up on the nuances in what they are saying, and I

haven't got a clue, not a clue. I ended up frustrated because I came out because I wanted to know what could happen. OK, it's not broken, it's not right, but what could I do, and I go home and I'm there 3 weeks with a thumb that needs some sort of care and I don't know anything about it. There is a breakdown in communication. Very frustrated and thinking 4.5 hours of your life gone.

Again, you see, if he needs to phone the Emergency Services for anything he would have the same problem of not being to hear the other end.

You don't hear anyway people over the other end of the phone.

I don't have a mobile phone, I can't use it and I don't want to use it and that's typical of older people actually, there is a resistance around that and so texting would be brilliant but, my equivalent of texting is emails. To me I can be sitting at the computer and communicate by email and anyway, you have these other issues as well to deal with.

Short sighted – you've got to work on a small screen with your fingers and you can't see.

I remember phoning for when my friend was having a stroke, the thing for me is that it is incredibly frustrating, because when you are hard of hearing you have to concentrate so hard on what people are saying, especially when it's important things. You can kind of switch off when it's just trivia, but, when you have to make notes, - it's when it's important what they are saying, it can be really, really, tiring, and it's frustrating when you mis-hear what they are saying and then they get agitated because you are not responding to what they are saying, and then you are getting frustrated because you are not getting the point over.

It's irritating for people around you when you are deaf, I mean, I irritate everybody because I keep on and on and on saying, "Can you say that again, can you say that again".

4.0 Dentists: Experiences from Hard of Hearing People

In terms of calling back can be an issue. Sometimes I miss a phone call say, if you're chasing an enquiry, missing calls, that can be quite difficult.

How do you talk with all those things in your mouth? I think when you have a procedure and they explain something to you, like during the procedure, as they are going along, and they say "Oh, I'm just going to...." or, [they should] stop and walk around and take the mask off and explain. From my perspective of attending the dentist, I don't really know what is going to happen, I just sit there because they have the mouth mask on and are sitting behind you and there is absolutely no chance. I can't hear.

At the dentist we go to, they had a screen, and it played a TV programme, except someone broke in and stole it, it took over 6 months [to replace], - because it was 2 appointments before they replaced it, and now they've replaced it, they no longer put the names on. I don't know if they haven't connected the software or what.

A problem for some people if you are lying down and they say, "Put your hand up or move your arm or something if it hurts", and if you don't hear them say that, it could be hurting and you are thinking what do I do – how do I let them know, you need to let them know – you need to speak up, to make sure you understand people

When I was a child, I attended one dentist, and I'm not sure how health and safety appropriate this would be now, but he took his mask off and did the treatment, so I could lip read him.

Is there such a thing as a transparent mask? Because, if they could make it transparent, like you see some of those dressings which are transparent – I don't know, would you be able to see enough?

I try really hard, but I fail every time to lip read.

On the whole, not too bad, sometimes I have to ask them, "Sorry I didn't hear you", if there is a problem.

Do you think it's something to do with a one to one at a dentist, where in a hospital it tends to be a lot bigger and even in a consultant's room, the acoustics tend to be really bad in all hospital rooms. In a dentist you depend a lot more on lipreading don't you?

Sometimes, I can't hear what the dentist says.

Some places have loop systems but, if you're not wearing a hearing aid, it doesn't help at all and I don't think they really understand that.

No, I've never been made aware of anything [loop system].

5.0 Opticians and Pharmacists: Experiences from Hard of Hearing People

My pharmacist is excellent anyway and would come to me and speaks one to one and makes sure he is being understood.

So difficult when they turn the lights off, and I don't know which direction to look at and I can't lip read because the lights are off.

What would help is an arrow showing which direction you ought to look.

Look left first and then after so many seconds look right, [then] down – if they told you beforehand, I don't know if that would work?

6.0 Community Services: Experiences from Hard of Hearing People

Technology needs, e.g. flashing doorbell, - access to this information.

7.0 Nursing, Care Homes: Experiences from Hard of Hearing People

I used to work as a senior care assistant in a care home, - it's amazing that there isn't any basic Deaf Awareness training in any care home that I've worked in or been into and I've worked in a few.

There is no Deaf Awareness, people don't even know how to put a hearing aid in.

Shouting is the preferred option [means of communication], from what I've seen. Hearing aids as well, they don't know how to check them, and I was not in a position to talk to them about it.

If I wasn't able to put my own hearing aids in correctly and someone put them in for me, then I was missing everything....so someone on shift should go around and check everyone's hearing aids are in properly instead of shouting.

Talks on basic Deaf Awareness training, - not necessarily BSL [British Sign Language] the basics of what we do, e.g. no shouting.

Communication problems brand you a 'trouble maker'.

I've been in Sheltered accommodation, in Tipton and it deteriorated all the while.

There was no care at all. Sheltered Housing – but there was nothing there.

There was not support around, e.g. checking upon you at night. They used to call me in the morning, - but I gather there is practically no help at all.

So, there was no supported care and there still isn't. The other people we spoke to that we used to know there, they said it's got worse, in fact I spoke to [someone] a few days ago.

I'm on Telecare and you need to know what my concerns are there because they've cut the maintenance for Telecare, so if it goes wrong, I've got no one to repair it, because they've stopped the service.

Complaints about NHS: Experiences from Hard of Hearing People (none stated in this section)

Appendix 4: Table of Key Issues – British Sign Language Users and Hard of Hearing People

Domain	Experience	Key Issue
GPs: BSL users		
	Lack of Deaf Awareness and need for training in this area for medical practitioners	Deaf Awareness training
	Variable attitude of staff towards 'Deafness' as a condition to be pitied	Attitude of staff
	Turning back on deaf patient (face not seen)	Body language

	Facial expressions of service providers e.g. stern	Facial expression
	Refused interpreter provision	Communication needs
	Communication difficulties due to no interpreter provision (expression/reception)	Communication needs
	No interpreter provision for emergency appointment. Deaf person has to wait until booked, or appointment delivered through other means, e.g. writing	Communication needs
	No interpreter provision for wider services, e.g. bereavement counselling, giving up smoking, obesity etc.	Communication needs
	Forced communication through writing	Forced communication
	Forced to lip read	Forced communication
	Medical practitioner deciding when and when not to provide an interpreter	Disempowered
	Will not see deaf person without an interpreter – even though Deaf person considers it their right to be seen	Disempowered
	Quality of interpreting provision: Should be providing Qualified interpreters	Quality of provision
	Deaf person not understanding written English	Forced communication
	Prescribing without clear communication established or understanding	Communication & Safety risk
	Repeat appointments due to lack of understanding	Resource issue
	Reliance on Deaf patient to find out own medical information via other methods/resources due to lack of interpreter provision	Displacing responsibility
	Safety/risk due to protracted time taken to receive clear medical information	Delayed information
	No awareness of 'Patient Choice' (e.g. GP, Hospital, Consultant)	No patient choice
	Waiting Room calling: Visual indicator (screen) preferred to calling out name	Visual modalities
	Patient files should be labelled as 'Deaf' and preferred means of communication	Patient file
	Unaware of ability to book double appointments in order to given additional time for effective communication and understanding to take place.	Patient Rights

	No interpreter provision in Walk-In Centres	Communication needs
	Chasing up test results	Delayed information
	Not being able to book appointments via text	Forced communication
GPs: Hard of Hearing Patients		
	Deaf Awareness training needed for Receptionists. Important to know difference/needs between profoundly deaf and hard of hearing patients.	Deaf Awareness
	Issue of accurate record keeping. There should be a note on a Patient's file that they are deaf (and type of deafness). Information not transferred between services/provision.	Patient File/records
	Loop system required in Reception areas and in GP room.	Technology
	Speaking with Receptionist by phone is difficult	Communication
	Positioning in order to see name called out – understanding depends on clarity of lip pattern	Waiting room
	Screens for visual alerting better	Technology
	Waiting room environmental noise difficulties; e.g. music, chatting, children's noise	Waiting room
	Booking methods: text option would be good; not all can access the internet; currently GPs only confirm/reminder via text.	Technology/ booking
	Assumption that speaking louder will help; tone and pitch is important	Communication
	Feeling rushed; need extra time and need to know that hard of hearing patients can ask for this. It takes longer to explain issues	Appointment duration
	Written communication preferred	Communication
	Hard of hearing do not necessarily want to learn British Sign Language. Assumptions that people will automatically use sign language are incorrect.	Communication
	Mobility issues for older people when writing down, using text phone.	Mobility and technology
	Need awareness that hard of hearing people may have other underlying	Communication & condition

	conditions which increase difficulty in making self-understood. Impact of environmental noise when using hearing aids	
	Hard of hearing can also have hypersensitivity to noise	Hearing loss
	Difficulty getting hearing loss diagnosis and getting correct information about the help available	Diagnosis
Hospitals: BSL users		
	Request for front line staff to have Deaf Awareness training and basic sign language knowledge.	Deaf Awareness
	Lack of interpreter provision	Communication
	No immediate interpreter provision for Urgent Care	Communication
	Hospital discharge without clear communication/information as to medication and onward transportation	Communication
	Request for non- interpreting personnel to communicate/interpret for patient e.g. care worker, child	Communication
	Essential to have registered qualified interpreters	Communication
	Ward rounds: essential to have a fixed time for deaf patients using an interpreter to ensure interpreter booking time has not expired.	Communication
	Issue in trying to read facial expressions/lip patterns on people with beards/moustaches/who have an accent/stand with back to window thus putting face in darkness.	Communication
	Re: Audiology – much more Deaf Awareness needed. Subtitles on tv screen	Deaf Awareness, technology
Hospitals: Hard of Hearing Patients		
	Positioning of patient in hospital in order to see who is calling out name and try to lip read	Communication
	A visual alert via a screen would be helpful	Technology

	Audiology department issues; protracted waiting time to receive an appointment; persistence needed to chase up; different medical professionals for each appointment (consistency would be helpful); self-checking in system (ticketing/numbers) would help and visual screen alert system;	Audiology provision & related issues
	Noisy and busy environment which makes communication difficult	Communication, environment
	Background noise difficult to manage; e.g. other patients, music, the acoustic signature of the room. Possible to have a 'quite/silent room' for hard of hearing patients?	Communication, environment
	Need medical [deaf] awareness that if cannot hear, and if for example have an eye condition then cannot see either!	Deaf Awareness
	Issue with communication breakdowns between GP and hospital which result in protracted delays and client requesting private provision eventually.	Medical information - consistency issue between services
	Feeling patronised by medical staff, - 'stupid' if do not hear and appears too much trouble for them to repeat themselves.	Attitude, communication
	Better service given in Specsavers for Audiology	Audiology service provision
	Support required for managing hearing aids.	Hearing aids
	Need clear medical information – hard of hearing feel as if in the dark.	Information clarity
Urgent Care: BSL users		
	Emergency situations must have a registered qualified interpreter	Communication
	2 hours minimum wait for interpreter provision	Communication
	Readily accessible provision of online interpreters via 'Sign Video' – Video Relay Interpreting/Video Remote Interpreting needed in hospital.	Communication, technology
	No interpreter provided and client told to find one in Yellow Pages	Communication

	Difficulties with contacting emergency services via text (protracted process). No direct access available.	Technology, Emergency services
	Use of writing information about condition when interpreter should be provided.	Communication
	Lack of understanding about difference between 999 & 111 services	Emergency services, information awareness
	Care Line/Link pendant not suitable for BSL users due to spoken responses.	Technology
	Mis-diagnosis of condition (ambulance) due to communication breakdown	Communication
	Medical practitioners 'shouting' to communicate with deaf patients (e.g. ambulance)	Communication
	Positioning of Deaf patients in hospital for visual alerts, e.g. waiting room	Communication
	Issues with registering 999 by phone for text. Too many questions – not understandable. System needs to be more user friendly for deaf BSL users.	Communication, technology
Urgent Care: Hard of Hearing Patients		
	Visual alerting system needed	Technology
	Do not shout name – environment is too busy/noisy to understand clearly	Communication
	Difficulty understanding staff with strong accents, those with rapid pace of speech	Communication
	Ticket number system which shows up on a screen would better	Technology
	Hard of hearing patients need to be taken seriously. Communication is very difficult	Communication
	Difficulty phoning emergency services but not hearing the spoken response	Communication
	Manual dexterity issues with using mobile phones	Technology
	Lack of information/knowledge on how to register for emergency services with mobile phone	Emergency services, information
	Medical professionals appear to become agitated with a hard of hearing patient does not understand/hear	Communication

	Burden felt by hard of hearing people when not understanding/asking for information to be repeated	Communication
Nursing Homes/Care Homes: BSL users		
	No or little Deaf Awareness training/knowledge held by staff in home	Deaf Awareness
	Inconsistent provision of interpreters	Communication
	Medical professionals deciding when one is required	Communication
	Inconsistency in Care Home provision of interpreters	Communication
	Isolation for deaf person in Care Home (only deaf person in home of hearing people)	Communication
	Communication difficulties for deaf family of deaf person in home with home/medical staff due to no interpreter provision	Communication
	Forced alternative means of communication i.e. written – paper/pen	Communication
	Risk with forced alternative communication due to misunderstanding	Communication
	No clarity over who is responsible to pay for interpreter provision (Care Home is private provision)	Resources
	No local provision & Geographical distance of deaf Care Home provision (i.e. Isle of Wight)	Service provision
	Mental health issues/risk for deaf people in isolation in a Care Home. Quality of life issue	
	Communication skills (e.g. Deaf Awareness/sign language usage) need to be improved/developed in Support Workers	Communication
	Deaf people need to be provided to support Deaf people in own home (for health care/ageing)	Community services
	Day Centre for Deaf people needed	Community services
	Hospices: No budget to pay for interpreters, isolation for deaf person, communication critical in this setting (condition, medication etc)	Communication

Care Home: Hard of Hearing Patients		
	No basic Deaf Awareness in the homes	Deaf Awareness
	Deaf people isolated in home	Communication
	Staff communicate by shouting	Communication
	Staff need to learn basic British Sign Language	Communication
	No knowledge by staff of how to deal with hearing aids/cleaning/fitting etc	Hearing aids
	Deaf person labelled as a 'problem' due to communication issues for staff	Communication
	Sheltered accommodation (e.g. Tipton), does not provide Care and no one checks at night.	Sheltered provision
	Cuts to TeleCare budgets – no one to repair if broken	Communication, technology
Dentists: BSL users		
	Deaf patient told they do not need a sign language interpreter	Communication
	Communication difficulties with dental mask – cannot see lips/mouth patterns/full facial expression. Dentist speaking with mask on – not pulling down	Communication
	Dentists think that 'gesture' is sufficient provision instead of a sign language interpreter	Communication
	Just muddling through with gesture between Dentist and Patient	Communication
	Patient thinking that if they booked an interpreter themselves, the practitioner would be annoyed	Communication
	Dentist writing instructions/information on paper in order to communicate	Communication
	Calling patient's name whilst in waiting room (deaf person cannot hear)	Communication
Dentists: Hard of Hearing Patients		
	Dentist sitting behind patient means that patient cannot hear what is being said	Communication
	Need large waiting room screen to alert to patient's turn to enter Dentist's room	Communication, technology

	Ineffective communication e.g. missing/not hearing instructions to alert if pain and not knowing what to do when pain occurs	Communication
	Could mask be removed so that deaf patient can lip read? Could there be a transparent mask?	Communication
	Not all deaf people can lip read	Communication
	Dentists need to make allowance to use repetition if the deaf patient cannot hear/understand.	Communication
	Difficulty understanding where there is accented speech	Communication
	Not being made aware of if a loop system exists	Technology

Opticians and Pharmacists: BSL users		
	Optician: Need sign language interpreter provided	Communication
	Some Optician's refusing to provide an interpreter	Communication
	Optician: Communication via writing	Communication
	Optician: Difficulty communicating in Opticians due to room dark, cannot lip read. Need to explain process first before turning lights off	Communication
	Optician's need to realise importance of eye sight for a deaf person – the only means of communication	Communication
	Pharmacist: deaf person not understanding medication prescription/information leaflet	Communication
	Pharmacist: communication difficult without interpreter	Communication
	Pharmacist: Need Deaf Awareness training	Deaf Awareness
	Pharmacist: Deaf person using family to interpret when needed	Communication
Opticians and Pharmacists: Hard of Hearing Patients		

	Optician: Difficulty communicating in Opticians due to room dark, cannot lip read. Need to explain process first before turning lights off	Communication
Community Services: BSL users		
	No interpreter provision Drop-In appointments not possible – need fixed time to book interpreter	Communication
	Forced to alternative means of communication e.g. writing	Communication
	Social Services: issue about Social Workers having no Specialist knowledge about deaf people (awareness)/service provision. Multiple Social Workers to deal with (turn-over/different departments) Reliance on deaf person to educate/inform social worker No funding for Carer support Difficulty finding Support Workers with BSL knowledge Funding responsibilities for support/interpreting unclear Little in the way of Community support TeleCare/Care Link panic button not deaf friendly provision due to spoken provision/communication	Social Services provision
	'Sign Video' – alternative and immediate method of communication. Who would fund this?	Communication, technology
	Wolverhampton Council: appears to have removed Specialist services for Deaf people. Referral delays, no Specialist support	Wolverhampton Council services
	Need Deaf people working in Community support services	Community service support & communication
	Re: Physiotherapy at home: Need fixed appointment time in order to book an interpreter.	Communication
	Re: Health Visitor provision, e.g. 'Stay and Play' for children – not accessible/inclusive for deaf parents as no interpreter provided	Communication
	No interpreter provided for range of community services as advertised e.g. on	Communication

	GP notice boards (bereavement, stopping/cutting down alcohol, smoking, obesity etc)	
	Re: generic mental health services/therapy – lack of understanding of needs of deaf patients, therapeutic methods of relaxation (based upon being able to hear)	Communication, service provision
Community Services: Hard of Hearing Patients		
	Technology requirements e.g. flashing doorbell etc. Need access to information	Technology
Complaints about the NHS: BSL Users		
	Need to know how to make a formal complaint to NHS - GP/Hospital	Communication
	Need to be able to complain in BSL not written English	Communication
	Need to be able to use Sign Video for access to this	Communication, technology
	Need to have consistent provision of qualified interpreters	Communication
	Hospitals brush away complaints with platitudes, and where do admit responsibility service does not improve. What is the point in complaining?	Service response
	NHS needs a deaf expert to provide regular Deaf Awareness training	Deaf Awareness, deaf provision
	Example of forced treatment on an elderly deaf patient but no recourse	Human rights
	What is PALS?	Information, communication
	NHS should provide interpreter for translation of complaint	Communication
	Appears too many pathways to complain/feedback – all confusing. Who does what e.g. complaints process, PALS, PPGs, etc	Information, communication
	Need posters displayed at hospitals, GPs etc about how to communicate with deaf people and for deaf people to know how to complain	Information, communication

Complaints about NHS: Hard of Hearing Patients	Front line services do not understand needs of deaf people/cannot respond appropriately and in correct method of communication	Deaf Awareness, communication
Other – Health and Social Care: BSL users' experiences	Constant barriers to access, being understood, to resources, to correct professionals and impact upon lives	Deaf Awareness, communication
Mental Health	Support for residents of Care Homes with Mental Health conditions required. Residents family members report their relatives are left feeling isolated.	Communication, Deaf Awareness, Dementia Friends training

BSL users' Other:

Facilitator question: Have people had to use family members? Before if there hadn't been an interpreter provided?

Yes, a long time ago yeah and yea I'd find now and again even still now if an interpreter is not available last resort. I don't like doing it but I do, but this lady is saying that should NEVER NEVER happen. What if the family member is a child and you are the Doctor is exposing information, that's abuse you know, or maybe that family member is not skilled enough or it's sensitive information, you know where the Doctor is saying this you know your life is terminal and the child doesn't share that information. This is why you should NEVER EVER EVER use a family member EVER.

Yeah, I mean I've heard that before you know they're sort of so upset with the information that's been shared, they don't want to tell them. That's quite interesting, I was a community advocate in Scotland and there were forums and they were training sort of people how to use interpreters. I'm talking 25 years ago now and eh and I would say would you use an interpreter and they were like no no I'd just bring my sister along and eh and I was like you know you can't do that, because the older generation they literally just used to using family members. Younger people accepted it more you know willing to use interpreters that they didn't know and that sort of thing, but a lot of the older people would just take family members along because that's what they are used to.

Facilitator Question: a few months ago, the contract changed for interpreters' provision between the City Council and the clinical commissioning group. Has anyone experienced like any drop-in standard of service in interpreters?

Yeah,
Yes,
Yeah,
Yes,

Absolutely! and it was literally just like that. Contract ended, literally just the same day if you like it, you know, it just sort of went. I mean my daughter was born in April and I know that's Absolute Interpreting and I just completely disagree with that sort of agency.

I didn't have any information to say that the interpreting agency the contract had changed. I know that before, it was Communication Plus, and then they used a London agency. I did get an email to inform that the contract for the different agency. But before I didn't know the PCT had finished and that they'd switched to somebody else like, we didn't get notified but I'd just realized when I'd said like I want this specific interpreter, because they work for that agency and they're like oh no, no, we don't use that agency any more

Obviously, they're doing the cheapest option, which is not the right option, but to be fair Wolverhampton there are a lot of female interpreters, not many male interpreters and I accept that, you know, that can't be helped. If we needed if we've got male problems, we would need a male interpreter and that's not easy. It's not easy to get one. And yeah before I've had to have a female interpreter, we just have to accept it. Can't say no, otherwise we wouldn't have anything. We wouldn't have any communication. Look away and then we can show our bits and then we can get on with whatever we need to do [laughter].

Appendix 5: Press release

NEWS RELEASE

Project seeks to improve healthcare services for Deaf people in Wolverhampton

A new research project to help improve health and social care services for Deaf people in Wolverhampton is urging people to share their experiences.

Healthwatch Wolverhampton and the University of Wolverhampton are looking at the experiences of the Deaf community in Wolverhampton to identify what problems currently exist when accessing healthcare services.

They are inviting people who are Deaf or hard of hearing to join them for afternoon tea and a chat at the University on Wednesday, 12 July 2017.

There will be two sessions in the Chancellor's Hall at the City Campus, from 2pm-4pm and 4.30pm-6.30pm, chaired by Mr Tanvir Ahmed, from Action on Hearing Loss.

Tracy Cresswell, from Healthwatch Wolverhampton, said: "We want to know about people's experiences of accessing health and social care services in Wolverhampton so we can build a city-wide picture of where things are working well, where problems exist, and what we can do to help improve access to services for the Deaf community.

"The sessions on 12 July will enable people to share their views and experiences of accessing healthcare so we can highlight where things need to change and improve for the Deaf community."

Sarah Bown, from the University's Faculty of Social Sciences, added: "The research project aims to identify how Healthwatch can support the Deaf community to highlight these problems to service providers and commissioners, make recommendations to tackle inequality and give Deaf people a stronger voice. As patients accessing health and social care services, we want Deaf people to have a visible impact on improving access to healthcare services throughout the city."

According to the NHS Information Centre, there are 1055 people registered as Deaf or hard of hearing in Wolverhampton.³ The Equality Act 2010, outlines responsibility for health providers to make reasonable adjustments for the way they provide services to Deaf and hard of hearing people. This is to ensure that Deaf patients are being given equitable provision to non- deaf users in accessing services. Achieving

³ Health and Social Care information Centre (HSCIC), People Registered as Deaf or Hard of Hearing – England, Year Ending 31 March 2010
<http://www.hscic.gov.uk/pubs/regdeaf10>

this in health services locally is crucial, as people often seek access to health provision in times of need.

To book a place at the event, please contact:

tracy.cresswell@healthwatchwolverhampton.co.uk

Text: 07506 754 791

ENDS

For media inquiries, please contact the University's Media Relations Office on 01902 32 2736 or 01902 518647.

<http://www.healthwatchwolverhampton.co.uk/homepage/press-release-project-seeks-to-improve-healthcare-services-for-deaf-people-in-Wolverhampton/>

British Sign Language Video link (event publicity):

<https://www.youtube.com/watch?v=8VAf-VheJ8&feature=youtu.be>

<https://www.wlv.ac.uk/about-us/our-schools-and-institutes/faculty-of-social-sciences/school-of-social-historical-and-political-studies/news-and-events/project-seeks-to-improve-healthcare-services-for-deaf-people-in-wolverhampton/>