Health and Wellbeing for Deaf Communities in Wales

Scoping for a Wales-Wide Survey

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1. Executive summary

Over 4000 people in Wales use British Sign Language (BSL) as their first or preferred language.

Few studies have examined the health behaviours and factors that may help or hinder the d/Deaf population's ability to maintain health in the UK, and none specifically in Wales. In view of the reported inequalities, a better understanding of what helps and hinders d/Deaf individuals' ability to be healthy is needed. This work will help inform actions towards a healthier, cohesive and more equal Wales, addressing the aspirations of the Wellbeing of Future Generations Act.

Researchers at Bangor University, Wales, and the University of Graz, Austria, were commissioned by Public Health Wales to complete a literature review on the health and care needs of the d/Deaf[1] communities in the UK and Wales; and undertake a qualitative pilot study to explore (1) the barriers and enablers to staying healthy in d/Deaf communities, and (2) potential actions for different professional groups (e.g. local authority, planning, health promotion materials, health service (pharmacy, GPs, hospital care). The pilot study involved three group interviews, one in North Wales and two in South Wales, with a total of 13 participants.

The results from the literature review suggest that Deaf people have **similar health behaviours** to the general UK population, but **report being less healthy**. The group interviews confirmed that Deaf people are generally aware of the health benefits of physical activity, healthy eating and avoiding cigarettes, alcohol and drugs.

The literature review revealed that Deaf people overall have **poor health literacy**. The group interviews revealed that a major problem is that there is still **relatively little health information available in British Sign Language (BSL)**. Furthermore, not all interview participants were aware of the information that is available, for example through online services such as Sign Health.

A further problem was that many interview participants reported that they are given **written English health information to take home** at doctor's appointments. This is **not a reasonable adjustment** (see Equality Act 2010: guidance) because many Deaf patients, whose first language is BSL and who often have a low or limited proficiency in written English, cannot understand this information. Instead, they may ask a friend or family member to explain the information to them, which is problematic from a privacy and confidentiality perspective. The results also emphasised the extent to which Deaf patients **rely on the, sometimes anecdotal, knowledge of friends, family and other Deaf community members for health information**.

Accessing health care services was identified as a problem in both the literature review and the group interviews. As mentioned in both the literature and by interview participants, many patients needed to **go to the GP practice in person to make an appointment** or needed someone else to call the GP practice for them. Another issue mentioned in both the literature and interview participants is the availability of interpreters. This is currently not a reliable service in Wales, with interview participants reporting that **interpreters come late, do not come at all, or are not booked**, causing mistrust of the current interpreter booking system. A further issue that came up in both the literature and interview participants is not having enough time during appointments. Participants reported doctors not having enough time to explain their condition or the medication to them. Some participants reported leaving an appointment, **neither knowing what their condition was nor what the medication they had been prescribed was for**.

Numerous studies have reported inequalities in health among d/Deaf communities, including lower levels of health literacy, difficulties in accessing healthcare, and poorer health than the general population, including mental health.

Members of the d/Deaf community are also potentially at greater risk of underdiagnoses and under-treatment of chronic diseases.

[1] We have adopted the nomenclature d/Deaf developed within the deaf community to acknowledge the in-group cultural distinction made between deaf individuals who may have been born with some hearing but lost it over time, who may use hearing aids, who may be able to lip read, and may have English as their first language (i.e. lower case d) and those who were born deaf, strongly culturally identify as Deaf and use a signed language as their 1st or preferred language (i.e. upper case D).

Results regarding contacting and communicating with staff and medical personnel at hospitals and emergency services mostly come from the group interviews and suggest that most participants have poor experiences with these services. Participants report **poor experiences with texting 999**, with two participants independently suggesting to not text 999 at all, but instead phone 999 and put the phone down so that someone will come. In addition, participants report that interpreter availability is especially poor in hospital settings. **Interpreters are often not available**, especially in the case of an emergency.

Many of the issues and/or problems raised with respect to finding linguistically appropriate health care materials, receiving understandable health care information with respect to prescriptions and GP's instructions / directives, and accessing health care and emergency services suggests that many Deaf patient's rights in Wales (see Equality Act 2010: guidance) are not being met.

The literature on mental health suggests that there is a **much higher prevalence of poor mental health among Deaf populations** than among the rest of society. Despite this, mental health services for Deaf patients are often not adequate with a majority of Deaf patients in the UK not completing awarded sessions either because their therapist did not understand Deaf culture or due to communication problems.

Both the literature and interviews suggest that mental health services, however, are in an area where **remote services may prove to function as an enabler**. Interview participants clearly did not want to receive mental health support from a local BSL-proficient therapist, due to privacy and confidentiality issues. Despite strong initial reluctance and scepticism within Deaf communities in the UK, a UK telepsychiatry service has been successful in providing remote mental health services through BSL-proficient therapists across the UK.

Both the literature and the interview participants report the following problems with the doctor-patient relationship: Many Deaf patients do not trust health care professionals, and many health care professionals show **little to no Deaf awareness**. A major problem is that health care professionals overestimate Deaf patients' English skills and thus how successful their communication with the patient was. Doctors also tend to not schedule enough time for an appointment with Deaf patients and tend to not be aware of the importance of interpreters.

Both the literature and the interview groups paint a **mixed picture regarding the use of technologies**. It is clear that **technologies should be available in addition to face-to-face services**, and that patients' preferences should be considered. There is potential in using remote online services to provide mental health care

directly through BSL-proficient therapists. However, **internet connectivity and equipment failure seem to be a recurrent issue, especially in rural areas**.

Overall, it seems that although the Equality Act 2010 is in place to ensure equality for Deaf people, provisions to ensure equality are **not implemented satisfactorily** or providers do not know how to implement them.

To summarise, the main barriers to health care for Deaf patients are a lack of Deaf cultural and linguistic awareness, inadequate access to services, inconsistent interpreting services and poor communication during consultations, resulting in Deaf patients often either not receiving treatment or not receiving adequate treatment. Enablers for Deaf patients include Deaf awareness training for all staff, improved booking options for appointments, access to skilled interpreters for all appointments, an increase in Deaf health professionals, as well as telemedicine, health information and mental health assessments being available in BSL.

2. Introduction

Background and goals

In Wales, there are over 600,000 people living with sensory loss, of which the largest group are people who are d/Deaf or hard of hearing at an estimated 575,000 (Action on Hearing Loss, 2019a). There is, however, no reliable information about the number of d/Deaf people in Wales or the UK who use BSL. Extrapolating from estimates for the UK, BSL is the first or preferred language of over 4000 people in Wales (BDA, 2019; Sign Health, 2019) and over 7000 people in Wales use BSL in the home (BDA, 2013).

There are a number of studies that have reported inequalities in health amongst the d/Deaf community including lower levels of health literacy, difficulties in accessing healthcare, and poorer health than the general population, including mental health (Sign Health, 2013, 2014; BDA, 2012, 2014, 2016).

Deaf people are potentially at greater risk of underdiagnoses and under-treatment of chronic diseases (Emond, 2015b).

In 2010/11, Ipsos Mori completed an online survey of health and lifestyles amongst the Deaf population in the UK 1266 respondents from the "deaf community" including 583 Deaf BSL users; (Sign Health, 2013, 2014) and found that, although the respondents self-reported similar levels of health related behaviours (e.g. smoking, physical activity, eating habits) compared to the general population, they self-reported lower overall health and comparable levels of self-reported chronic ill health.

Few studies have examined the health behaviours and factors, which help or hinder the Deaf population's ability to maintain health in the UK, and none specifically in Wales.

Deaf communities around the world are linguistic and cultural minority groups and a better understanding of the needs of this population is essential to help inform actions towards a healthier, more cohesive and more equal Wales addressing the aspirations of the Wellbeing of Future Generations Act (Welsh Government, 2015).

This report focuses on Deaf people who use and prefer to use a sign language, in this case BSL, and who see themselves as belonging to a Deaf community (i.e. those whose preference is to communicate in BSL and share similar life experiences as a Deaf member of Welsh society).

Specifically, this report highlights themes from a scoping review exploring focus on:

- the health and health behaviours of the Deaf population

- the barriers and enablers to staying healthy in the Deaf population

- potential actions, adjustments and accommodations

Alongside the views from a small number of members of the Deaf Community in Wales (n=13), collated through focus groups.

The findings whilst not representative of the Deaf population in Wales, provide some valuable insights to shape actions.

3. Methods

The methods for this report comprise a review of the available literature and a small pilot study involving focus groups with members of Deaf communities in Wales.

Review of the available literature and methodology

Due to a lack of literature focused solely on Wales, we consulted literature to identify health and health behaviours and barriers to healthcare of the Deaf population in the UK as a whole. The review also considered services and programmes that have served as enablers in other larger Deaf communities, drawing on evidence from American, Irish, Canadian, Australian and New Zealand Deaf communities.

The search strategy, selection criteria and methodology used in this section used the following procedures. We searched ProQuest, Web of Science, ScienceDirect, Cog-prints and Google Scholar for reports published in English between 1 January, 1980 and 1 October, 2018.

We used the search terms "deaf" or "deafness" together with the following search terms to identify relevant peer reviewed articles and published reports : "health", "health literacy", "health services", "health education", "health disparities", "health communication", "access to services", "barriers", "facilitators", "mental health", "health policy", "telepsychiatry", "video conferencing", "health care delivery" and "health outcomes".

The initial search results and scanning process, based on article titles, yielded more than 250 papers from all over the world. We then excluded research and reports that did not deal with the following English-speaking countries: the United Kingdom, United States, Ireland, Canada, Australia and New Zealand.

We further excluded articles that did not speak to our primary topic of healthcare barriers and enablers affecting the d/Deaf community in the following seven categories: general health, health information, accessing health services / primary and secondary care, hospitals and emergencies, mental health, doctor / patient relationship and technology.

The remaining articles were subsequently analysed. The seven categories also formed the framework for the focus groups questions conducted as part of the pilot study. This process resulted in a total of 104 published papers and reports being analysed and included in this report.

Group interviews

Three group interviews with questions that guided participants through the discussion were conducted. The participants were individually recruited and invited to participate in the interview sessions by the staff at Centre of Sign-Sight-Sound in Colwyn Bay and the Wales Council for Deaf People in Pontypridd, Wales.

The first group interview was conducted in North Wales in March 2019. Seven members of the North Wales Deaf community participated. The second and third group interviews were conducted in South Wales in May 2019, both with three participants. All group discussions lasted about two and a half hours. Guiding questions were asked in English and interpreted into BSL for participants.

All participants responded in BSL, and their responses were interpreted back into English. Finally, ethical review and approval for this study (Reference Number: CAHB08) was provided by Bangor University's College of Arts, Humanities and Business Research Ethic Committee on 8 March, 2019.

Diversity in Deaf communities

We will be talking about Deaf communities and Deaf people in this report. However, it is important to note that Deaf people are individuals with different backgrounds, different preferences and different needs. This means that the responses from group interviews with Deaf

community members may not be representative of the entire Deaf community in Wales. While there are themes that have emerged in the group interviews, it is important to realise that an individual approach to healthcare is especially important when working with Deaf patients.

Deaf patients form a very heterogeneous group, including diverse communication needs, and there is no one-size-fits-all solution when it comes to properly supporting Deaf people to stay healthy and successfully navigate the health care system.

4. Results and discussion

There is a wealth of literature on the barriers that Deaf people in the UK and around the world face in accessing health care.

(see BDA 2016; et al., 2015b; Kyle et al., 2013; Sign Health, 2013; Sign Health, 2014 for overviews referring to the UK).

The following sections provide a summary of the main issues and recurring themes that Deaf individuals face in accessing health care. Briefly, Deaf people's access to health services, to health providers and to health information is extremely poor (Emond et al., 2015b; Sign Health, 2014).

Poor communication mostly causes this lack of access (Sign Health, 2013; Sign Health, 2014; Kyle et al., 2013). As a result, Deaf people are often underdiagnosed and undertreated (Emond et al., 2015b; Sign Health, 2014).

Deaf people also have substantially limited access to health information and rely mostly on family members or other community members for their health information (BDA, 2016; Sign Health, 2014). Poor mental health, such as depression, are more prevalent in Deaf individuals than in the general population (Department of Health, 2002, 2005; Hindley & Kitson, 2000; Kyle et al., 2013; Sign Health, 2014).

However, access to mental health services tailored to the needs of Deaf people are lacking (Department of Health, 2002).

As already mentioned, much less information is available about health care enablers for Deaf patients. We will therefore mention a selection of quite simple and easily implemented services that are in line with best practice guidelines (Action on Hearing Loss, 2018, 2019b; Department of Health, 2005). We will also provide examples that have served as enablers in terms of Deaf patients' access to health care and quality of care.

Deaf people's access to health services, to health providers and to health information is extremely poor.

Barnett et al. (2011) identified four issues underlying health inequities for Deaf individuals. These are the paucity of data on the health of Deaf people, low health literacy in the deaf community, language barriers faced by Deaf signed language users and that Deaf person may have a biologic basis for some health differences. With respect to the first issue, the data on the health of Deaf people is sparse. This situation has recently improved in the UK as recent large-scale studies (BDA, 2016; Emond et al., 2015a; Kyle et al., 2013; Sign Health, 2013; 2014) have documented in detail the health of Deaf people in England and Scotland (but not in Wales or Northern Ireland). The results from these studies show that Deaf individuals generally have poorer self-reported as well as clinically assessed health despite self-reported lifestyles that are comparable to the respective hearing populations (Emond et al., 2015a; Sign Health 2013, 2014).

Specifically, Deaf people in the UK report being less healthy than the general UK population: while 69% of the general population report their health as "good" or above (Department for Communities and Local Government, 2011), only 56% of Deaf people do so (Sign Health, 2013, 2014). This occurs even though Deaf people do not systematically report less healthy lifestyles than the general population.

Sign Health (2013, 2014) report that most of their 533 Deaf respondents did at least some regular physical activity, consumed similar amounts of fruit juice, and ate slightly more vegetables, but also more fried food than respondents in the Health Survey for England (Office for National Statistics, no year). The latter is in line with Emond et al's. (2015a) finding of high rates of obesity in their sample of the Deaf population. Deaf respondents also smoke slightly less and drink less alcohol than the general population (Sign Health, 2013, 2014, Emond et al., 2015a).

Deaf people are also more likely to be unaware of health problems. For example, Emond et al. (2015a) found that 29% of their participants were unaware that they had high blood pressure, compared to 6% in the Health Survey for England (Office for National Statistics, no year). In addition, 77% of Deaf participants were unaware that their blood sugar was at prediabetic levels. Emond et al. (2015a, p. 1) conclude that "Deaf people's health is poorer than that of the general population, with probable underdiagnosis and undertreatment of chronic conditions putting them at risk of preventable ill health." In other words, it is likely that Deaf people's poorer health is not due to an unhealthy lifestyle, but to poorer diagnosis, treatment and management of illnesses.

These problems most likely occur because Deaf individuals have poor access to health information, poor access to health services, and poor communication with their health care providers.

Views from the focus groups in Wales

The group interviews yielded quite varied results in terms of lifestyle and suggested that personal circumstances may have been driving some of the differences and changes in lifestyles:

"Sometimes, you know, I eat what my mum cooks. I love my chocolates. You know, it depends, sometimes when it's there in the fridge. I work part-time. I'd rather work full-time, so that's one reason I eat. Say at work, we have a coffee break, there's free food there. And the problem is, I'll eat there and then I'll go home, and I really need to not… you know, I need to avoid it."
(man, South Wales)

In line with Emond et al.'s (2015a) conclusion, we found some evidence in the group interviews that misdiagnoses and wrong treatment may quite easily occur due to miscommunication, especially in the absence of an interpreter. For example, some participants mentioned not knowing what the tablets they had been given were for:

"Sometimes you don't have an interpreter, they give you some tablets and I haven't got a clue what they're for"
(woman, South Wales).

Others worried that they may have been given the wrong tablets:

"I was with the doctor's. They gave me some tablets, and I said, 'Why are you giving me these tablets?' I didn't have an interpreter with me. So, the following week I went back to the doctor's again, but this time with an interpreter, and actually realised they had given me the wrong medication. […] I've learned from this. I check all the time and I make sure that I've got an interpreter before I go to the doctor's, and I go to the Wales Council for Deaf People, and I check with them."
(woman, South Wales)

I used to be a healthy eater, but since my husband passed away, I don't want to eat. […] My family support me. They're trying to make sure that I have meals. But when I am on my own, I throw a lot away. When I am with my daughter [inaudible], I eat better. You know, I'm trying to be more positive, but I am up and down.

(woman, South Wales)

Barriers and enablers

In the following, we will present barriers and enablers for Deaf people in terms of staying healthy and receiving good health care when needed.

Health information

Health literacy is often defined as the degree to which individuals have the ability, access or capacity to find, process and understand basic health and well-being information and to then be able to make appropriate health and healthcare decisions (CDC - Centres for Disease Control and Prevention, 2019) . Poor health literacy among Deaf people constitutes a barrier to allowing Deaf individuals to be proactive about their health and health care (McKee et al., 2014). One solution is to provide health information in BSL. Slowly, more health information has become available through BSL. Notably, Sign Health provides health advice in BSL, a growing library of BSL health videos (**www. signhealth.org.uk/health- information/health-advice**).

As of May 2019, the library contains 26 videos of physical health issues, 18 videos covering mental health and 14 videos on first aid. These videos include mostly information about conditions and diseases, but also cover topics related to staying healthy, such as "Quit smoking" or "Calories".

Finally, the BDA Scotland also provides a number of British Deaf Association (BDA) videos on health-related issues ranging from bipolar disorder to stroke (**http://old-bda.org. uk/What_We_Do/Health_-_ Scotland**). The response to the BDA Scotland's videos has been positive with 79% of 259 respondents being aware of the videos and 25% of 259 respondents having watched the videos and finding them useful (BDA, 2016).

Overall, health information is available in BSL format, but it is not comprehensive.

Views from the focus groups in Wales

While BDA (2016) received generally positive feedback and a large amount of awareness for their health information videos, this is not always echoed in our focus groups. For example, one participant pointed out that while videos are there, they may not be as clear as needed:

"So, they have something called SignHealth, which is an online resource. And I have watched some videos, and they are ok. Sometimes they are not very clear. Maybe you need some more information. Face-to-face information is usually better because there are lots of people who don't check the videos on SignHealth."
(woman, North Wales)

However, in addition to a need for health information to be available in BSL, it is also important that both doctors and the Deaf communities know about this information and the above resources. Our group interviews suggest that, overall, this is currently not the case in Wales. **Few participants knew about the resources available**, for example, through SignHealth.

As so little health information is available through BSL, and if it is available, not many Deaf people and even fewer doctors know about it, **most participants reported getting their health information informally through their social network**. When asked where she got her health information on heart disease, one participant responded:

"Well, my mother told me. It's passed down through the females in the family. And also diabetes, especially for those over sixty. So, my mother has explained this to me."
(woman, South Wales)

In response to the question of where he would learn about health issues, one man stated:

"My father had cancer. My father explained everything to make sure I understand" and "I know gout because my father had gout."
(man, South Wales)

Another woman also mentions getting health information from family members:

"I look on the internet or ask somebody in the family. Say, I've got pain in my tummy. I might ask them to help because they tend to know more than us Deaf people. My sister, she's a nurse, so she knows everything about health. I know my sister will know, so I can ask her."
(woman, South Wales)

Participants also emphasised helping each other in the community when it comes to health information:

"We try to help each other, talk about how to improve each other's health"
(woman, South Wales)

"We always ask people. And we work as a team, we help each other. We're like 'Oh, what does that mean?' And somebody who knows will explain it. And sometimes my children will explain it to me. I prefer to get it from Deaf people because I know they're fluent signers, they can explain it more clearly through BSL."
(woman, South Wales)

> Well normally we ask other Deaf people. What do they know? As a community, we say to each other 'do you know what this means?' So, we check with each other.
>
> (woman, South Wales)

It would be lovely if I could take information away in BSL. I'd really like that.

(woman, North Wales)

Deaf patients often receive additional health information in written form, for example, through English-language leaflets. In addition, NHS Choices (**www.nhs.uk**) has a vast amount of information about health and medicines available in English, but not BSL. Deaf individuals are lawfully entitled to reasonable adjustments under the Equality Act (UK Government, 2010), **and neither written information nor lip reading are reasonable adjustments. Many Deaf people have English as a second language and often have low English literacy rates** (cf. Strong & Prinz, 1997). Lip-reading involves a substantial amount of guesswork and accuracy rates are typically low, even in adults with only moderate hearing impairment (cf. Dodd et al., 1989). Nevertheless, a common misunderstanding by health professionals is that Deaf people can read English, and therefore providing written information is wrongly considered a reasonable adjustment. These problems fall under Barnett et al.'s (2011) second and third issues that Deaf adults often have low English literacy and that there are barriers to health care for sign language users.

Views from the focus groups in Wales

This was also a common theme in the group interviews with participants reporting that they would receive written information to take home, but that they could not access this information. This is illustrated in the following quotes:

"When you go to the doctor [...] there's information around the room. And hearing people with a good level of English are able to read that book. For Deaf people there is a need for something else, maybe videos, information on diabetes, on drugs, on alcohol, on weight gain, on healthy weight, healthy eating. That would be useful [...] because you are given written information to take home and then you can't read it when you get there." (woman, North Wales)

"The doctor gives you this information and then you take it away and you can't access it. That's the problem that I have. You have the information there and you just can't access it." (woman, North Wales)

"They all think that Deaf people can read, but they don't realise, for a lot of us, we don't understand English and it's really difficult. If I am about to open a letter and there's information about an appointment, you're thinking, I don't really understand the letter. So, you have to ask a friend or family member and it's private and that's the problem." (man, South Wales)

Accessing Health Services

Barriers to accessing health care services can be seen at every step of the health care journey. They begin with making an appointment. Almost half of Deaf patients have to go in person to their GP practice to book an appointment (Sign Health, 2014). There are also numerous reports of relatives who had to phone GP practices to make appointments for Deaf individuals as well as GP practices refusing to book appointments for Deaf patients who came to the practice in person as the practice only accepted bookings over the phone (cf. BDA, 2016).

This difficulty in accessing services causes up to 70% of Deaf individuals not seeing a health care provider even though they wanted to (Sign Health, 2014).

Views from the focus groups in Wales

Some in the focus groups highlighted challenges in booking an appointment, and an interpreter:

"So, if I want to book an appointment, I physically have to go to the health centre to say that I need an appointment to see the doctor and that I need an interpreter." (woman, South Wales)

Or having to rely on family members to call a practice for them to make an appointment:

"My mum will phone for me. I say, 'Please book an appointment and book an interpreter'. And then half the time they say, it's not available" (man, South Wales)

I can't text them. I would love to be able to text them. It would be so much easier for me. But I can't. I've got to literally walk there and say, 'can I make an appointment for a week or two weeks' time?'

(woman, South Wales)

Texting was suggested by one as a suitable alternative, and other participants mentioned there are services available to them that they can text or call so that a service provider can book an appointment for them:

"I text the interpreter, and the interpreter phones in, and the interpreter texts me back with the date."
(woman, North Wales)

"If you are unable to walk and you can't phone, through accessible health, which is a service that the Centre of Sign-Sight-Sound has, they're able to phone for you. And I've had no problems. I think I did it twice for an audiology. It was really good."
(woman, North Wales)

Once Deaf people have made an appointment, they often do not have sufficient access to services at the appointment itself. This relates mostly to communication during appointments often not being satisfactory. Specifically, 80% of Deaf individuals preferred to use BSL during doctor's appointments, but only 30% were actually able to do so (Sign Health, 2014). Reeves et al. (2004) report that BSL interpreters were present at just 17% of GP and 7% of A&E appointments. A recurring problem is that BSL interpreters are not automatically booked, are only reluctantly booked, not booked at all, or do not come to an appointment.

As a result, 56% of Deaf patients reported not using health services because no interpreter would be available. Many patients who did see their health care provider had to use spoken English and lip-reading or written notes during appointments (BDA, 2016; Sign Health, 2014). Even when an interpreter was present, he or she was often not qualified. The use of family members, often children, as interpreters was also widespread. The issue is not just one of interpreters not being booked, but of a general shortage of accredited interpreters (cf. Department of Health, 2005). An additional issue in the case of Wales is the complete absence of any interpreters accredited to interpret from Welsh to BSL or vice versa.

Views from the focus groups in Wales

Insufficient and inconsistent access to interpreters was probably the most common and pertinent issue raised by participants across the three focus groups. This is in line with a somewhat recent report on BSL interpreting provision in Scotland, which emphasises a shortage of interpreters, especially in rural areas, and found that there was no consistency across health boards in terms of sourcing interpreters (BDA and Scottish Government, 2012). The following quote illustrates the importance for Deaf patients of having an interpreter present at all appointments:

"We always say 'Make sure that you've booked an interpreter. Don't let me down. Don't let me down. Make sure you've booked an interpreter. I don't want to be going through this again."
(woman, South Wales)

One participant's recollection of going to the doctor's before interpreters were available also highlights the importance of access to interpreters:

[About her teenage years]
"It was quite intimidating, going to the doctor's […] Because the communication wasn't there at that time, so I didn't like that. I always used to try and bring mum with me. Because there were no interpreters at that time. It was very difficult."
(woman, North Wales)

Participants also emphasised the importance of having enough time during appointments and with the interpreter:

"Sometimes when I go to the doctor, I'm waiting for the interpreter to arrive. So, they'll try and sort of rush the appointment through. But I have to be quite firm and say 'no, I need to wait for the interpreter to come before we can go in'."
(woman, North Wales)

"It's not the same as it used to be now. They don't have the patience to sit down and to talk through things properly."
(woman, North Wales)

It can be difficult when there is no interpreter. It makes you very anxious.
(woman, North Wales)

They should be there a little bit early, so that we can talk about things. So that sort of anxiety is relieved before you go in to the doctor's.
(woman, North Wales)

Having enough time includes having the interpreter available a little before the appointment and also after the appointment, in line with findings by BDA and the Scottish Government (2012):

"Sometimes when we have an interpreter, we go out of the waiting room, and I say to the interpreter 'Can you just clarify again what the doctor was saying?' So, the interpreter has got more time then to go through what was there."
(woman, South Wales)

A few participants mentioned having family members with them to interpret for them:

"Sometimes I ask for an interpreter, but I don't have one. So, I use my brother. He can sign so that's not a problem."
(man, South Wales)

One participant clearly pointed out the privacy issues associated with this:

"I don't want my daughters with me to interpret. It's a private appointment."
(woman, North Wales)

Importantly, BDA and the Scottish Government (2012) found that while Deaf patients were concerned about confidentiality when using interpreters (who may be part of the close-knit Deaf community), none of the Scottish health boards had any confidentiality concerns related to interpreter use.

It is not readily apparent what the source of the problems with interpreter availability is. One participant mentions problems with an interpreting service:

"I don't like having interpreters from another agency […] because they have let us down so many times. They've said 'Yeah, yeah, we'll get you an interpreter', and they don't. I go to the nurse and she says 'No, no interpreter'. And that's made me feel worse, made me feel down. And I've got to talk to the nurse by writing everything down, and this is happening all the time. So, in the end I said, 'I don't want an interpreter from the agency, I want one from the Wales Council for Deaf People because I know that they will let me know that they have booked an interpreter and who the interpreter is."
(woman, South Wales)

However, a member of staff at the Centre of Sign-Sight-Sound mentioned that agencies may call all interpreters in the area, but nobody is willing to come, for example, if it is raining or during a weekend (personal communication, interpreter coordinator, South Wales, 2019). This is in line with one participant's observation:

"Yeah most are never available."
(man, South Wales)

There is also mistrust in GPs and hospitals actually booking interpreters:

"They tell us, yeah, we'll try to find one, but when I ask an interpreter directly, they say 'they never contacted me'."
(man, South Wales)

Finally, it can be difficult to find interpreters on short notice (see also section on hospitals and emergency services below), in the evening or during weekends, as the following quotes illustrate:

"So, they might say you haven't given us enough notice to get interpreters. There aren't enough interpreters here. You have to wait for over two weeks to get one."
(man, South Wales)

"There are no interpreters over the weekend. It's not 24 hours a day."
(woman, North Wales)

The access and communication issues for BSL users have profound implications, with one third of Deaf patients leaving appointments unclear about their condition and another one third not knowing how to take their medication (Sign Health, 2014). Many patients also reported not knowing what they were taking their medications for (Sign Health, 2014; also see section on health information above). As a result, many Deaf patients did not have their condition under control (Sign Health, 2014).

This also raises issues about Deaf patients' ability to give informed consent to treatment and surgery as it is likely that some Deaf patients may not understand that they need surgery or what surgery they are undergoing. This does not meet the requirements of the NHS Constitution (Department of Health and Social Care, 2015) or the Equality Act (UK Government, 2010) and seriously risks harming Deaf patients. Sign Health estimates that this risk costs the NHS an unnecessary amount of £30m per year (Sign Health, 2014).

A number of basic provisions can improve services for Deaf patients. Health care facilities should allow patients to make appointments through various different means (cf. NHS Wales Centre for Equality and Human Rights, 2018). They should also be aware of their patients' preferred language or their preferred method of communication (BDA, 2012). Deaf patients may prefer to make appointments via email, text messaging, via videophone, or over the phone with a remote interpreting service. This process has been made easier in recent years as "online access to interpreters via computers and webcams has improved availability, particularly at short notice. Some services now provide 24 h cover" (Alexander et al., 2017, p. 979).

One example of these expanded provisions is the Centre of Sign-Sight-Sound's (**www.centreofsignsightsound.org.uk**) Digital Access Interpreting System (DAISY) and InterpreterNow (**https://interpreternow.co.uk**). Both offer secure remote interpreting services for businesses and individuals. To book a doctor's appointment, the interpreter would call the health care provider and relay the conversation via videoconference to the patient (see also section of the use of technologies).

In addition, My Health Online (**www.myhealthonline-inps2.wales.nhs.uk/welcome**) allows patients to book and cancel GP appointments and request repeat prescriptions online. The website is only available in English and Welsh, not in BSL, but may be an option for Deaf patients with sufficient English or Welsh reading and writing skills.

Health care facilities should also routinely have information about Deaf patients' communication preferences in their records (BDA, 2012). This should now be the case in Wales: The Accessible Information Standard (2018) requires general practices to collect, record, alert and share Deaf patients' different communication and information needs. The information can then be transferred automatically when patients are referred on to secondary healthcare.

All general practices in Wales have the functionality to record different communication and information needs using coded data. In December 2018, all practices were now able to share this information via the electronic referral process. If a Deaf patient who prefers to communicate in BSL books an appointment, a qualified interpreter should be automatically booked (BDA, 2012). That is, it should not be the responsibility of the Deaf individual to remind the health care provider to book an interpreter. Due to communication often taking longer when going through an interpreter, a double appointment should also routinely be booked for Deaf patients (Sign Health, 2014).

In spite of these requirements; however, these best and required practices are apparently not being utilised which is one reason why the exact figures of the number of Deaf people in Wales still remains unknown in 2019.

In addition to improving the booking, logistical and communicative aspects of healthcare services, other administrative adjustments and infrastructure modifications can also greatly improve Deaf patients' satisfaction and awareness of health-related issues.

For example, encouraging healthcare staff to know who their Deaf patients are, and then to accommodate them in culturally and linguistically appropriate ways helps to generate a sense of respect and dignity for the Deaf patient. The use of video screens in waiting areas or vibrating buzzers to summon patients to doctors' offices (Emond, 2015a) has also been found to be an effective alternative to traditional public address / loudspeaker systems and is, again, respectful of Deaf patient's needs.

Participants in the group interviews mentioned that video screens are now common in GP waiting areas and that this does indeed help them to know when it is their turn to see the doctor. However, video screens seem to be less common at hospitals (see next section on hospitals and emergency services).

Deaf patients generally have poor access to hospitals and emergency services. For example, one study found that BSL interpreters were present at only 17% of GP consultations. This number went down even further with interpreters present at only 7% of hospital emergency consultations (Reeves et al., 2004). Considering the additional stress in an emergency situation, these numbers are clearly too low.

Views from the focus groups in Wales

In line with these results, participants in the focus groups have reported major difficulties in interacting with emergency services and hospitals. This starts with contacting emergency services, such as 999. One woman recalls a situation where she texted 999 and:

"They were asking me all these questions, and I didn't understand what they were asking", "they asked me all these questions, we waited and waited and waited for an ambulance, it took ages to get here", "and they came and checked his heart, and I said 'What do you mean his heart was fine?' Because it wasn't", "my husband said, 'I can't take anymore', and we didn't want to text 999 because of what happened before. So, I texted my daughter and said, 'Your dad's not well.' And she said, 'Do you want me to call 999 for you?' I said 'fine' and within ten minutes the ambulance came"; "I had my daughter on the phone signing, so I could use her as an interpreter for when the paramedics came. And then he said 'Yeah, he needs to go to hospital'"
(woman, South Wales)

It turned out that the woman's husband had a serious heart condition, which went undetected the first time the ambulance came.

Another participant echoed the difficulties in texting 999:

"There are all these questions that they are asking you. It's not fair for us because hearing people, they're on the phone, they're asked questions, and they quickly answer them. Whereas us, we need to read the question, type the answer, and there's all these questions. And all that we want to be able to say is 'We need an ambulance. My partner is having a heart attack. Just something short and sweet. Because what's happening is, we're panicking, we don't understand the English, there are all these questions being texted to us, it's hard enough for us to understand it anyway without panicking at the same time."
(woman, South Wales)

The problem may be a lack of Deaf awareness on the part of the ambulance service. Both women reported telling the ambulance service that they were Deaf and could not understand them, to little effect:

"I already said to them 'I don't understand your words'. And they kept texting the same questions again. And I kept saying to them 'I don't understand you. I'm Deaf.' [...] They just refused to accept that I couldn't understand them."
(woman, South Wales)

A solution that some participants suggested was to dial 999 and just leave the phone:

"The best way to do this is just dial 999 and just leave your phone because suddenly everyone comes to your doorstep wanting to know what's wrong. That's easier for us. That's what I would do. [...] As a Deaf person, you can say 'Well, I'm sorry, I can't ring you. I can't understand your texts'."
(man, South Wales)

"You can just dial 999 and leave it. And they will recognise my mobile."
(man, South Wales)

These comments suggest that communication with emergency services is poor, and that ambulance services can benefit from Deaf awareness training and communication training.

In addition to issues in interacting with ambulance services, participant also reported more problems managing to see a health care provider than they did for interactions with their GP.

For example, while many GP practices have screens that show patients' names and room numbers when it is a patient's turn to see the nurse or doctor, hospitals often don't have such screens and staff are not sufficiently Deaf aware. As a result, Deaf patients are worried that they will miss their name being called to see the nurse or doctor, or report having missed their name being called:

"I mean it's stressful enough going to the hospital if you've got a health problem, but with the added stress of just waiting for your name to be called out and you know you'll probably miss it because they're not aware. I usually try 'I'm Deaf. Can you make sure that the nurse comes out and [illustrates tapping herself on the shoulder] and says, 'It's your turn'? But it doesn't always work."
(woman, North Wales)

Unlike GP practices, hospitals are also more difficult to navigate, which can pose additional difficulties for Deaf patients:

"In hospital, as you walk in, they're massive big places, aren't they? The staff should maybe help a Deaf person, show them to where the department is, because the directions can be quite confusing in hospitals. They should maybe be shown to waiting rooms because they can be such massive big mazes of buildings."
(woman, North Wales)

As mentioned above, interpreter availability is a problem especially in a hospital setting, where interpreters are often needed on short notice and outside of normal working hours.

But if there isn't an interpreter when you arrive, you'll be sitting there waiting, you know, and the appointment is at 3 o'clock. And you're thinking, oh, it's half three now. Is the interpreter there? […] And then they say 'oh, I've already shouted your name'. Well I can't hear my name being called.

(woman, North Wales)

> **My husband went up to hospital and nobody came at all. And it was offered as 24-7 support and I had nothing. My son, he texted me at two, half two, and asked 'is the interpreter there?' And I said 'no'. My son was in London at the time. He was fuming. He came straight from London to say, 'where is the interpreter?' I had nobody to help, no one came at all.**
>
> (woman, South Wales)

Some participants reported hospital staff trying to get an interpreter without success:

"I went into the hospital, part of the crisis team. They said, 'We can't get an interpreter', so they googled on the internet to find a 24-hour seven-days-a-week service. So, they found the number, rang it. It rang, and rang, and rang, and rang. The office wasn't open because it was in the evening. Nobody got back to them, nobody answered the phone. So, what's the point in them advertising a 24-hour seven-day-a-week service when there's nobody to answer the phone? And we were like 'Where are they?' [...] I was really disappointed with that."
(woman, South Wales)

However, a number of participants do not trust hospitals to make a proper attempt at getting an interpreter to come in:

"The hospital will swear blind that they have tried to find an interpreter and then I am like 'Really?' I will then contact an interpreter and they will say 'No, they never contacted me'. And then on the usual websites. They have the contacts. Nothing's been posted on there saying an interpreter is needed."
(man, South Wales)

"My husband wasn't responding, so I said to the nurse 'Could you please get an interpreter urgently?', and she said 'Okay, I'll find one.' And luckily, I've got a few interpreters' numbers on my phone. So, I text some of them. Many of them did not get back to me, but one did, and she

was angry because the hospital didn't contact her, and they told me that they had contacted the interpreters, but they obviously hadn't."
(woman, South Wales)

"They all say that. We tried but couldn't find anyone."
(man, South Wales)

Participants agree that interpreter availability is a recurring issue, which is especially important in emergency situations:

"In a hospital emergency, we need them to be able to get an interpreter on short notice. That is what we need."
(man, South Wales)

As part of the conversation about the lack of interpreters at hospitals, one participant reported on the difficulties of getting this to change:

"I went to a meeting to talk about the ambulance service, hospitals, and everything is still the same. [...] Nothing has changed, no matter what you tell them. Things are still the same. It doesn't make any difference."
(woman, South Wales)

Overall, it can be said that participants' interactions with emergency services were poor, often due to an inability to get interpreters on short notice or a lack of awareness of Deaf patients' needs in an emergency situation.

Mental Health

Mental health problems arise from differences in individual vulnerability, resilience, environmental risk, and environmental protection, as well as adverse life conditions (cf. Øhre et al., 2011). Deaf adults and adolescents have a higher incidence of mental health problems than the general population (cf. Bridgman et al., 2000; Brown & Cornes, 2015; De Graaf & Bijl, 2002; Department of Health, 2005, Fellinger et al., 2005; Kvam et al., 2007, see Fellinger et al., 2012 for an overview) irrespective of degree of hearing loss (cf. Fellinger et al., 2008; Dammeyer, 2010; Stevenson et al., 2010; Hintermair, 2007).

Most of these are common mental health problems, but impulse control disorders, learning and intellectual disabilities, attention deficit hyperactivity disorder, and pervasive developmental disorder are also more common in Deaf compared to hearing individuals (Diaz et al., 2013; Landsberger & Diaz, 2010). As English language mental health assessments are not adequate for a majority of Deaf patients, there is also probably a high incidence of Deaf patients being misdiagnosed (cf. Klein, 2011).

The higher prevalence of poor mental health and wellbeing in Deaf individuals relates to social exclusion as well as low educational and employment opportunities (Department of Health, 2005).

Being part of a Deaf community seems to decrease these risks as members of the Deaf community report similar quality of life than the general population. In contrast, members of the hard-of-hearing community report lower quality of life (Fellinger et al., 2007). In addition, individuals with post-lingual deafness report more mental distress than those with prelingual deafness. Communication problems, low self-esteem and low acceptance of hearing loss also contribute to mental distress (De Graaf & Bijl, 2002).

Mental health problems are also more common in Deaf children compared to hearing children (cf. Walker, 2013). Deaf children are about twice as likely to have emotional or behavioural problems as hearing children (cf. Hindley, 2000; Van Gent et al., 2007; Fellinger et al., 2008, 2009; Dammeyer, 2010; Stevenson et al., 2011). Again, language and communication seem to be an important factor. For example, Deaf children with poor sign language and oral abilities experience increased psychosocial difficulties, whereas children with high signed or spoken language abilities do not (Dammeyer, 2010; Stevenson et al., 2010). Poor spoken language abilities have also been linked to impulsive behaviour in Deaf children (Barker et al., 2009; Stevenson et al., 2010).

Children who have difficulties communicating within the family are four times more likely to develop mental health disorders than children who communicate successfully with their families. Similarly, adverse experiences at school increase the prevalence of mental health disorders in Deaf children (Fellinger et al., 2009).

Despite the higher prevalence of mental health problems in Deaf adults and children, appropriate care is often not available or not accessible. The latter problem goes back to the above-mentioned barriers in accessing primary care services, which manage and treat most mental health problems and refer patients to specialist services (Department of Health, 2005).

Successful communication is even more important in treating poor mental health, especially when "talk therapy" approaches, such as cognitive behavioural therapy or psychodynamic therapy have proven to be effective treatments. Access to sufficiently trained interpreters is lacking even in primary care settings, and this problem is exacerbated in the case of treatment for mental health problems. Specifically, there is a lack of available specialist training for interpreters wishing to work with mental health patients (Department of Health, 2005). In mental health settings, it is also especially important to keep in mind the communication preferences, needs, and abilities of the individual patient (Silvester, 2013).

A survey conducted by Deaf4Deaf Counselling & Psychotherapy (**www. deaf4deaf.com**) found that 76% of Deaf patients who were awarded face to face counselling, did not complete the awarded sessions. The main reasons for not completing sessions was that the counsellor did not understand Deaf culture (47%) and that patients could not understand the counsellor (24%). Overall, 53% rated their counselling experience as poor, with another 26% saying it could have been better.

Importantly, there is a lack of Deaf mental health professionals, "who have the language and empathy of being a member of the same culture and community" (Klein, 2011, p. 65). The Department of Health (2005) also notes the striking scarcity of Deaf people employed in mental health services. Access to Deaf BSL-using mental health professionals is crucial in communication-based mental health treatments, but there are still few education and employment opportunities for aspiring Deaf mental health professionals (cf. Klein, 2011; Department of Health, 2005).

Having Deaf mental health professionals is important because the presence of an interpreter alters the dynamics between the patient and the health care professional.

Wales is currently the only country in the UK with no specialised Deaf mental health service.

In situations where patient and health care professional need to develop a sense of trust and understanding or where highly personal or sensitive information is being discussed, the presence of an interpreter can be a hindrance. In any situation that uses an interpreter, neither patient nor professional know whether what they have said has been conveyed as intended to the other. This is especially the case if interpreters who are not sufficiently trained are used. It needs to be mentioned though that Deaf mental health patients typically do not want a local counsellor as this person will be part of their tight-knit local Deaf community.

Patients are worried that word about their counselling may be spread throughout the local Deaf community. Deaf4Deaf Counselling & Psychotherapy has had success with online counselling, where Deaf patients in the UK can be connected with a Deaf counsellor in a different part of the country to preserve confidentiality and avoid that patient and counsellor are part of the same local Deaf community. Interestingly, Deaf communities in the UK were initially opposed to online counselling, but patients started using the service once available and many are happy with the service (p.c. Simon Lloyd, 29 January 2019).

As in the case of primary care, there are also reports of family members being used as interpreters in mental health settings (Halder, 2012). This raises issues of confidentiality and can have profound consequences (cf. Halder, 2012, for an example). Having Deaf mental health professionals is also important as they function as positive role models for Deaf patients and Deaf people in general (Department of Health, 2005).

Another issue is the lack of specialised care facilities for Deaf adults and children. In 2005 the Department of Health noted that unless "Deaf service users live in Birmingham, Manchester or London, the main responsibility for their care rests with a local team who are unlikely to have either significant experience of working with Deaf people or the necessary communication skills" (Department of Health, 2005, p. 13). In addition, in 2005 there was only one in-patient service for Deaf children needing specialised care (in London) and few outpatient services (Department of Health, 2005). This is especially problematic in mental health emergencies.

Support for carers of Deaf people with mental health problems is also insufficient, and mostly only available through Deaf Clubs and voluntary organisations (Department of Health, 2005). Wales is currently the only country in the UK with no specialised Deaf mental health service.

Carers therefore often do not know who to turn to in crisis, especially as access to specialised care is often far away from patients' homes (Department of Health, 2005). Access to specialised services is a particular issue for Deaf patients in Wales. Three NHS mental health services in the UK provide specialised services for Deaf people, but all three of them are in England (London, Birmingham, Manchester; NHS England, 2013).

Mental health services for Deaf patients are also vulnerable to departures, such that services may rely on one particular member of staff and may cease to be available completely should that person leave (Department of Health, 2005). Few mental health professionals have sufficient BSL skills to carry out their work in BSL, and retention is an issue (Department of Health, 2005). One view is that mental health services with adequate provisions for Deaf patients do so because one professional who has an specific professional interest in mental health amongst Deaf patients, or who has signing skills (U. Gotthardt, p.c., 15.10.2018). This means that where adequate provisions for Deaf mental health patients can be found is often random and may change with the departure of only one professional.

Successful engagement and communication are especially important in the case of mental health services. Deaf adults, especially older Deaf adults, overwhelmingly prefer to engage in mental health services with sign-proficient mental health providers rather than through an interpreter (Feldman & Gum, 2007). This means that more so than in other health settings, there is a need for qualified Deaf mental health professionals (cf. Crowe et al., 2016). There is a tendency for Deaf people working in mental health to work in unqualified positions (Sharples, 2013).

This is slowly changing, with the first Deaf person qualified in the UK as a clinical psychologist in 2003, the first Deaf Chartered Counselling Psychologist in the UK in 2008, and the first Deaf psychoanalytic psychotherapist in the UK in 2009 (Klein, 2011). The mental health-nursing programme for Deaf students at the University of Salford, which started in 2000, can also be seen as an enabler in this respect (cf. Department of Health, 2005). By 2012, ten Deaf qualified nurses had graduated from the programme with more currently in training. A Disabled Students Allowance that covers interpreters and note-takers in all classes and in hearing settings while on placement supports Deaf students in the programme (Sharples, 2013) and overcomes some of the barriers in access to education for Deaf students.

A slowly growing number of areas in the UK also have a Community Psychiatric Nurse for Deaf people. These include South Yorkshire, Newcastle and Nottingham (cf. Department of Health, 2005).

For Deaf patients in London, the National Deaf Services at St. George's Hospital provide comprehensive mental health services for Deaf adults, children and their families. Services include a Deaf Enhanced Support Team, which helps patients with anxiety, depression, psychotic episodes and schizophrenia, as well as an Assertive Community Treatment service for Deaf people, which provides 24/7 support for Deaf people with mental illness (cf. Department of Health, 2005; **www.swlstg.nhs.uk/our-services/specialist-services/national-deaf-services**).

While support is generally available for Deaf patients with poor mental health in London and some other urban areas, Deaf patients in rural areas often do not have access to Deaf or sign-proficient mental health professionals. Wales is no exception in this respect, with less than a handful of sign-proficient mental health professionals across Wales. Here, telepsychiatry can serve as an enabler, especially because many Deaf people already have expertise in videoconferencing (Austen & McGrath, 2006).

Diagnosis is another issue in working with Deaf patients with poor mental health, with a number of patients being misdiagnosed.

One issue is that standardised mental health assessments are not available in sign language, so that adequate assessment is often not possible. This problem is starting to be addressed in both the UK and Australia. In the UK, the BSL Verbal Learning and Memory Test (BSL-VLMT; Denmark et al., 2016) and the BSL Cognitive Screening Test (BSL-CST; Atkinson et al., 2015) were developed.

The BSL-VLMT is modelled on the English-language Hopkins Verbal Learning Test Revised. Both tests require no knowledge of English, use video-presentations and presents all instructions in BSL. Studies with over 200 healthy older Deaf signers and between 12 and 14. In Australia, Australian Sign Language (Auslan) versions of the Youth Self-Report (YSR; Achenbach, 1991) questionnaire and the self-report version of the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) have been developed (Cornes & Brown, 2012; Cornes et al., 2006). The Auslan version of the YSR allows for administration through an interactive CD-ROM, which is less likely to underestimate adolescents' level of disturbance than a written version of the questionnaire (Cornes et al., 2006). The Auslan version of the SDQ was rigorously translated and has good test–retest reliability and internal consistency (Cornes & Brown, 2012).

It should be noted (personal communication) that a range of mental health assessment tools have been translated into BSL by Deaf research teams, however, there is unfortunately no evidence of any of these being used in Wales at the present time.

Views from the focus groups in Wales

Participants of the focus groups agree that they would not want a Deaf counsellor from their local Deaf community and would rather have a hearing counsellor with an interpreter or engage online with a Deaf counsellor who is not part of the local Deaf community. Several comments reflect this:

"I would never have a Deaf person counsel me because the community is so small." (woman, South Wales)

"Yeah you want your privacy. You don't want […] to have other people know what's going on." (man, South Wales)

One woman also recalls a mental health emergency, where she needed access to an interpreter, but no interpreter was available:

"What would have been perfect is to have a mental health service, where you have got an interpreter available online, like a remote relay interpreter, so that we can access interpreting services." (woman, South Wales)

Overall, the responses from the group interviews reflect patients' wishes to avoid gossip and a wish to engage with mental health service providers that are not part of their local Deaf community.

I'm happy to see a counsellor that is hearing with an interpreter. They did offer me a Deaf person who was a counsellor, but I refused. I refused it because the Deaf community is too small. I didn't want them to gossip.

(woman, South Wales)

Doctor-Patient Relationship

When Deaf individuals do see a health care provider, the interaction is often not satisfactory and Deaf patients experience fear, mistrust, and frustration in health care settings (Steinberg et al., 2006). A minority of health care providers allow enough time to see Deaf patients and come across as good listeners to Deaf patients. As a result, only about one quarter of Deaf patients have trust and confidence in their health care provider (Sign Health, 2014). It is both noteworthy and surprising that audiology and Ear Nose Throat (ENT) departments, who see more Deaf patients than many other kinds of providers, performed especially low in terms of access and Deaf awareness (Sign Health, 2014).

Access to services and patient satisfaction can be improved substantially by increasing healthcare providers' general awareness of Deaf culture and by providing better means of communicating with Deaf individuals in health care settings. Of importance are highly proficient and medically skilled interpreters, but especially health care providers proficient in sign language (Steinberg et al., 2006; Middleton et al., 2010a; Kuenburg, et al. 2016; Breen 2015; Witko et al., 2017; Dykes, 2016 Finger Lakes Health Systems Agency, 2004; Steinberg, 1998; BDA, 2012; Earis, 2009).

Effective interaction with signing professionals or interpreters improves patient satisfaction and increases the use of preventive services among Deaf people (MacKinney et al., 1995; Breen 2015; Witko et al., 2017; Dykes, 2016; Finger Lakes Health Systems Agency, 2004) as does providing accessible links and means of communicating problems, complaints and suggestions on how to improve healthcare services (Levine, 2014).

Deaf awareness training, especially for front line staff, should be standard (cf. Department of Health, 2005), especially as the receptionist was often seen by Deaf people as the biggest barrier to accessing health care (cf. NHS Wales Centre for Equality and Human Rights, 2018). Currently, all NHS Wales staff receive the mandatory equality training 'Treat me fairly', but an available e-learning module on sensory loss is not yet mandatory. Middleton et al. (2010b) mention the need for Deaf awareness training to increase understanding and empathy towards Deaf patients. Implementing such measures across the board or at least more widely is likely to improve Deaf patients' engagement with health care services, interactions with health care providers, and outcomes for Deaf patients.

It is important that health care providers recognise and understand that linguistic and cultural differences are an important part of healthcare and that this applies to sign language communities as much as to other minority language groups. Witko et al. (2017, p. 10) write that "when Deaf people perceive this recognition, they describe feeling more satisfied with a health consultation even without an interpreter". In addition, there are clear advantages to working with the Deaf community to identify and try to find solutions to health and healthcare related issues. There are clear indications that "community-engaged research with deaf populations identifies strengths and priorities, providing essential information otherwise missing from existing public health surveillance, and forming a foundation for collaborative translation and dissemination of accessible public health programs to facilitate broader inclusion of Deaf communities" (Barnett, 2016, p. 15).

Views from the focus groups in Wales

Overall, comments from the focus groups echo the need for Deaf awareness training among medical professionals. Many comments relate to a lack of awareness in terms of Deaf patients' communication needs.

They included the following:

"Also, with the hospital, we've got the fact that we're Deaf on our records, but the nurses and doctors need to learn a bit more about Deaf awareness, so that should be part of their training. It's important that everybody has it, all members of staff, so they know if there's a Deaf patient – just something basic, so that they know how to sign 'How can I help you?' Just basic signs. It would be so easy for them and then we could say that we need an interpreter."
(woman, South Wales)

"But if you haven't got an interpreter, how are you supposed to chat and talk to a doctor? And sometimes you turn up at the doctor's and there's no interpreter, so everything is written down. I keep that paperwork and then I show my family."
(woman, South Wales)

"At a minimum, they should know the alphabet, and that would be a massive help."
(woman, North Wales)

"I don't think they understand Deaf identity."
(woman, South Wales)

"I want more people to have awareness of us as Deaf people."
(man, South Wales)

"I want them to learn BSL. Nurses and doctors."
(woman, South Wales)

"For them to research more about Deaf identity, what it means to be Deaf, our culture, to have more awareness of deafness. And are there different types of deafness such as hard of hearing, deafened? You know, I was born profoundly Deaf. Maybe somebody else was born hearing and became Deaf later. We are all different."
(woman, South Wales)

Several participants also voiced that medical professionals had a lack of understanding about their level of English skills:

"Hearing people have got a better understanding of English than Deaf people, so that is putting Deaf people at a disadvantage."
(woman, South Wales)

"We need our English to be brief and short. […] Big words like confidential or confidence, when you read those, you're like 'What does that mean?'"
(man, South Wales)

In addition to lack of knowledge and awareness, many patients also feel that doctors' and medical staff's attitude is an issue:

"Sometimes you feel like you are easily ignored being a Deaf person."
(woman, North Wales)

(About doctors)
"They can be a bit patronising at times."
(woman, North Wales)

(About doctors)
"Sometimes the attitude can be difficult."
(woman, North Wales)

"I always feel like Deaf people are put last."
(woman, South Wales)

> "
> Doctors aren't Deaf aware and they can't sign.
>
> (man, South Wales)

Use of Technologies

The use of technologies to improve Deaf patients' access to health care services has been explored in the literature. The Deaf community is spread across the country so that there are comparatively few Deaf patients in any one area of the country. As a result, services that Deaf patients require may be far from their homes. For this reason, various remote online services have been explored.

One such service is secure remote interpreting services. These can be used during the consultation for certain kinds of health appointments. Using such services would reduce the need for interpreters to travel long distances, as is often the case in rural areas. Similarly, remote interpreting services can be used in a hospital or GP setting (NHS England, 2018). For example, the Royal United Hospital Bath has computers on wheels (COWS), which can easily be transported to different departments at the hospital. Patients can access online BSL interpreters through the COWS system. In addition, the computers provide video clips of 500 medical phrases in BSL (cf. Middleton, 2010b). At present 'Interpreter Now' and 'Interpreter Online' remote interpreting services are available to the Deaf Welsh community.

It is important to note though that remote interpreting services should not replace but supplement face-to-face interpreting services for those interactions where face-to-face support is not needed or not available, as may be the case in emergency situations.

Specifically, Deaf patients in Wales have indicated that appointments with an online interpreter are not suitable for more in-depth appointments or appointments of a serious nature (Hilgart, 2018). Another issue concerning rural areas, such as Wales, is internet connectivity. Hilgart (2018) mentions issues with internet connections and computer equipment in using online interpreter services. Specifically, the Wi-Fi set up in many health care facilities was not adequate for good quality online communication, which negatively impacted the usefulness of the service.

Another such service is telepsychiatry using secure videoconferencing, which has mostly been explored in the literature in a US context (e.g. Rash, 2014), but which is available in the UK through Deaf4Deaf Counselling & Psychotherapy (**www.deaf4deaf. com**). Crowe et al. (2016) found that telepsychiatry sessions with a therapist fluent in American Sign Language (ASL) were as effective as face-to-face therapy sessions with a therapist fluent in ASL for Deaf patients with serious mental illness.

This was a relatively small pilot study, but the results are promising and suggest that telepsychiatry with a BSL-proficient therapist could also serve as an enabler in the UK. Telepsychiatry may be a good option especially for Deaf patients in rural areas like Wales and for Deaf patients with chronic mental health issues, who may otherwise have to travel far on a weekly or biweekly basis to see a therapist in person. In line with this, the Department of Health (2005) proposes a wider use of telemedicine in appropriate situations.

In the UK, the Deaf community was initially highly sceptical if not outright hostile towards the idea of telepsychiatry (p.c. Simon Lloyd, 29 January 2019). This is in line with results from Hilgart (2018) that patients in Wales thought that online interpreter services were not suitable for mental health appointments. After the launch of the Deaf4Deaf Counselling & Psychotherapy service, however, those patients who used this service have been positive about it (p.c. Simon Lloyd, 29 January 2019).

Thus, Deaf patients may prefer telepsychiatry with a BSL-proficient therapist over face-to-face mental health support for privacy and confidentiality reasons.

Telepsychiatry allows connecting a Deaf patient in Wales with, for example, a BSL-proficient therapist in Scotland, thus ensuring privacy and confidentiality and providing an environment in which the patient can safely open up to the therapist without worrying about gossip in the local Deaf community. As with online interpreting, the uptake of telepsychiatry with a BSL-proficient therapist may be limited by the quality of the internet connections and computer equipment available.

One further issue to consider in this context is the patient's individual preferences. Some patients are quite happy to use technologies, other are not. The Deaf community is no exception here. Online services should therefore, whenever possible, be offered in addition to face-to-face services in order to give patients options. Online services are also useful as a back-up, for example, in situations when face-to-face services are not available on short notice.

Views from the focus groups in Wales

Some participants in the group interviews reported to be open towards online services but said that their doctors were not using these services or were not aware of these services. Other participants had themselves not heard about these services.

It is thus important that both doctors and Deaf patients are aware of the online options that are available for interpreting and for mental health services. The following quotes illustrate this:

"I've asked the doctor's for an interpreter on screen, but they said there's nobody for it." (woman, North Wales)

(Responses to the question of whether their GP made use of online interpreting services)

"No, they don't know anything." (woman, North Wales)

"No, they've not tried it." (woman, North Wales)

Finally, some participants emphasised that patients' individual preferences should be kept in mind:

"Maybe some people don't use the computer. I prefer something visual in a physical format." (woman, North Wales)

I'm not very good with the computer. I prefer face-to-face with an interpreter.

(woman, North Wales)

So, when you go to the GP and an interpreter hasn't been booked, you can […] say 'I need an interpreter please'. […] And you can talk to the interpreter, who is on the screen. […] So, the interpreter can be on the screen, and the doctor and patient can be in the room at the same time. […] I think it was about five years ago when that started.

(woman, South Wales)

5. Key considerations and potential actions for different professional groups

The following key considerations are based on the interview findings. Several limitations must be taken into account when interpreting results. The findings only present the patients' viewpoints, but not the health care providers' or other professionals' viewpoints.

Furthermore, this was a small-scale qualitative pilot study

with three interview groups in two general locations (North Wales and South Wales) with altogether 13 interview participants. Thus, this was not a representative sample of the population as participants were self-selected and too small in number.

While the results may not reflect the national context, they are overall in line with the previous literature.

Specifically, the results provide interesting insights, useful information to inform public health practice and offer potential direction for larger studies to explore health and health care in the Deaf population in Wales.

In this section, we briefly present potential actions and key considerations for different professional groups.

Health information

- Increase awareness of current programmes, and provide more health information, including health promotion information, in BSL, online via specifically designed and targeted websites. These resources should be developed with the target population so that they meet patients' needs and are useful.

- Both health and care professionals and Deaf communities need to be made aware of health related information developed specifically for Deaf patients, and where to find it.

- Practitioners need to be aware that many Deaf patients cannot read English written information material. When possible, links to health information in BSL should be provided.

Health care

- All staff should undergo Deaf awareness training, select staff members should have basic BSL skills, and all staff should be aware that BSL is not a signed form of English.

- Patients should be able to make appointments through various means, not just over the phone. Online and texting services are already available but should be made more accessible to Deaf patients. Online interpreter services to book appointments also

exist, but awareness of these services in Deaf communities needs to be increased.

- Health care services should have patients' communication needs on record and automatically book an interpreter for all appointments for patients who communicate in BSL, including exploring different options for interpreters (e.g. online interpreting services).

- All health care facilities should have screens that show patients' names and the room number when it is a patient's turn. If a facility does not have a screen, a receptionist should approach Deaf patients and make them aware that it is their turn.

- Interpreters should be present for all appointments for all patients whose primary or preferred language is BSL.

- Hospitals should be aware of 24/7 online interpreting services and know how to contact these in emergency situations.

- Deaf patients may need help navigating hospitals or other large health care facilities and should be brought to the waiting room rather than given directions.

Interpreters

- More Registered Sign Language Interpreters (RSLI) are needed, especially those trained in specialised health care settings.

- Reliable and consistent access to interpreters needs to be 24/7/365, for example, through an on-call system similar to that for doctors.

6. Future directions
Recommendations for assessing, addressing and supporting the health needs of the Deaf community in Wales

The Wellbeing of Future Generations (Wales) Act 2015 includes goals for a healthier Wales, a more equal Wales, and a resilient Wales (Welsh Government, 2015).

A healthier Wales involves maximising people's physical and mental wellbeing and understanding healthy choices. A more equal Wales involves enabling all people to fulfil their full potential. A resilient Wales includes social resilience. The reviewed literature as well as the responses from the focus groups suggest that the goals of the Wellbeing of Future Generations (Wales) Act are far from being accomplished in the case of the Deaf communities. The Wellbeing of Future Generations (Wales) Act established that each public service board, which includes local health boards, must improve the well-being of its area by assessing the current state of well-being and settings objectives for future wellbeing. This report presents a small step in the direction to assess the wellbeing of Deaf people and communities in Wales.

Both the literature and the focus groups suggest that Deaf people face barriers that do not allow them to fulfil their full potential and that do not allow then to maximise their physical and mental wellbeing.

However, there is no recent comprehensive survey on the health and wellbeing of the Deaf community in Wales. Our focus groups represented experiences and impressions from a small number of members of the Deaf communities in North & South Wales; however, the responses, reflections and experiences conveyed by the pilot study participants paralleled and often concurred with many of the issues faced by Deaf communities in the UK, USA, Ireland, Canada, Australia and New Zealand. These findings clearly suggest that a more detailed population specific survey is needed to assess how members of the Welsh Deaf community specifically interact with their particular health care services, within their respective communities, and what the state of their wellbeing is.

The literature cited in this report reinforced the fact that all Deaf communities have different cultural, logistical, and support related needs which depend on a number of factors such as geography, infrastructure and accessibility, population density, employability, accessibility to support services and technology, legal provisions / protections or the lack thereof, and the type of health care and health insurance systems (i.e. state, national and/or private) that are provided.

The Deaf community in Wales, not surprisingly, is unique in a number of important ways, including but not limited to its cultural identity and history, geographical dispersion and accessibility and population size; therefore, we believe that a more comprehensive follow-up survey is needed to identify and address issues specific to the Welsh context and environment as well as to assess the impact that recent provisions in Wales, intended to improve Deaf access to health care, have actually had upon this community.

7. The next step: Importance of co-production

Working with the Deaf community in Wales, in support of a language minority group, was challenging but highlighted the importance of engagement and building personal relationships with the staff of d/Deaf and Hard of Hearing support / service agencies (i.e. the Centre of Sign-Sight-Sound in Colwyn Bay and the Wales Council for Deaf People in Pontypridd), with BSL interpreters and with members of Welsh Deaf communities.

A network of informed contacts and supporting organisations is critical to the success of any follow up survey. Furthermore, persons associated with the British Deaf Association, Action on Hearing Loss, the National Deaf Children's Society (NDCS), and Deafblind Cymru also provided invaluable advice, feedback and/or support for the initial pilot project and it is recommended that the groups and individuals as consulting partner and/or potential collaborators for any future research projects.

In addition to working with knowledgeable support and service agencies it is also imperative that the study participants themselves and their feedback, input, suggestions and responses are also taken into consideration when designing the study's questions, the study's supporting documentation (i.e. demographic forms, instructions and ethics guidelines etc.) and when carrying out the actual data

collection. It is critical when working with marginalised language and cultural minority communities that the participants feel valued and listened to, that the time they spend is seen as being a worthwhile investment, and that they can trust the research team's goals and objectives. This is considered to be a 'best practice' principle in ethnographic research and a step that should be maintained throughout the course of any follow-up research.

The pilot study also demonstrated that it is possible to use social media and related social apps, for example the Facebook pages of Centre of Sign-Sight-Sound or the Wales Council for Deaf People or other privately run Deaf social / activity sites and webpages, to contact, successfully recruit and engage with many Deaf individuals in Wales.

The combination of on-line and in person recruitment and internet-based communication

also allowed for the goals of this project, its intentions and proposed outcomes to be clearly articulated at every stage of the process so that any questions and concerns were answered promptly.

The result was that the participants' feedback and suggestions informed and/or guided every aspect of the pilot study, which improved both the quality of the questions being asked and the depth and detail of the responses we received. The feedback also included suggestions for future consideration, such as the use of BSL videos to help set up and explain the goals and objectives of the pilot study, a BSL medium website version of the survey to reach Deaf people living in more remote areas, and finally an app-based version of the survey. These suggestions and others that came from our participants should be used to inform any new studies with this community.

8. Conclusion

The review of the literature conducted in support of this project identified a number of remarkably common issues, problems and challenges faced by Deaf communities around the world with respect to health care literacy, living healthy lifestyles, accessing health care services, and doctor or healthcare provider / patient interactions and relationships.

Many countries, including the UK have enacted laws prohibiting discrimination based upon 'disability' and legally ensure that all qualifying citizens have appropriate and supported access to healthcare services; however, it is clear from the focus groups' responses and experiences that these mandated requirements are often not being met for members of the Welsh Deaf community. The pilot study that we conducted as part of this project revealed that, in spite of legal rights and protections as defined by the UK Equality Act 2010, the Deaf community in Wales is also beset by a number of cultural, linguistic, logistical and institutional issues that continue to have a negative impact on this community's health, wellbeing and quality of life.

The findings outlined in this report and the suggestions made regarding how to improve current practices is a good start; however, as a pilot project it provided a view limited to two locations situated in North and South Wales. We believe that a more comprehensive follow-up study is therefore warranted to identify the barriers and enablers affecting the Deaf community across all of Wales, so that current practices and policies can be adjusted and/or improved to better serve this important minority community.

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