Deaf Health

Analysis of the current health and access to health care of Deaf people in the UK

Part 1: Health Assessment and Quantitative Data

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Acknowledgements

November 2013

Summary

Deaf people are known to have difficulties in accessing health services, but there is a lack of research evidence as to whether their health is any different from hearing people of the same age, and gender. A study of Deaf Health in the UK was commissioned by Sign Health between 2010-13 from researchers at the University of Bristol. The study was funded by the Big Lottery.

The purpose of the Deaf Health data collection was to assess the current health of the Deaf BSL-using community in the UK, and to determine the link between their health status and the issues they face in communication and thereby their access to health care.

The original project aim was set out to:
> …. identify common health conditions where health inequalities between Deaf and mainstream (hearing) populations are particularly pronounced, e.g. diabetes, cardio-vascular disease, hypertension. Comparisons will be made with data from the hearing population. The study will suggest reasons for inequalities and identify practical measures which could reduce these. – (submission to the Big Lottery)

An indicative sample of 300 was planned, stratified by age and gender and ethnicity to reflect the overall UK population at the 2011 census. Recruitment of BSL-using Deaf adults to this sampling frame was undertaken in two ways: a) by approaching those respondents (who had given consent to be contacted) in a previous online survey of deaf people carried out by Ipsos MORI and b) by direct contact with the Deaf community via Deaf clubs and networks. The final sample for the study consisted of 298 participants aged from 20 to 82 years old, made up of 139 men and 159 women, with 11% from ethnic minorities.

These Deaf sign language users completed health assessments at Bupa centres in Bristol, London, Brighton, Solihull, Cardiff, Manchester and Glasgow. In each session they were accompanied by BSL signing Deaf advisers and interpreters. The structured health assessment consisted of the standard health check provided by Bupa and an interview with a Deaf adviser (to collect data on use of GP services), which would allow direct comparison with health survey data for the general population, using routinely collected GP data in England (eg the GP Patient Survey).

The sample of Deaf sign language users were initially asked about their medical history during the health assessment. Compared to general practice data from England (the Quality Outcomes framework – the QOF) and the Health Survey of England (2011), the Deaf respondents reported higher rates than the general population of hypertension, asthma, epilepsy and depression. The only major gender difference was in the reported history of depression, which was much higher in Deaf women (31%) than in Deaf men (14%).

The Deaf participants also reported high rates of early heart disease in their family history. Participants were asked about their medication use. Self reported rates of smoking (8%) and weekly intake of alcohol (averages between 2 and 8 units/week) were considerably lower than published rates in the general population in the UK.

The medical examination in of the health check calculated the BMI, and revealed high rates of overweight and obesity. Among the Deaf participants, 90% of those over 65 years were classed as overweight or obese. Deaf women seemed to have a greater problem with moderate and severe obesity, compared to men. The obesity trends were also reflected in the results of the body fat analysis, which concluded that 50% of participants had high levels of body fat. The study did not collect data on activity levels or diet.

One third of Deaf participants had elevated levels of cholesterol, higher in women (41.4%) than men (22.5%). The levels of LDL and the cholesterol/HDL ratio were also high, but the gender differences were less marked.

Almost all participants had their blood pressure (BP) measured, and 25% were seen to be high and 12% very high. However, there was poor correlation between the measured BP and the self-reported awareness of hypertension, or the taking of anti hypertensive medication.

The reported rate of chronic respiratory conditions (Chronic obstructive lung disease COPD) among the Deaf participants was lower than the general population. This was possibly linked to the low rates of reported smoking. The self-reported rate of asthma, by comparison, was higher than what would be expected from the QOF, but our data were self-report of the condition, and are closer to the figures for *lifetime* prevalence of asthma as found in the Health Survey of England 2010.

The structured interview with the Deaf adviser collected data on use of GP services, and found widespread difficulties with communication between Deaf people and professions in primary and secondary care. Forty-five percent of participants (more of the older group) said they made appointments with a GP by having to go in person –compared to 30% of the general population who also used the telephone (90%). At all ages Deaf people were more likely to express a *preference* to see a specific doctor than hearing people, with clear tendency for older people to *want to see* a specific doctor. However, the Deaf respondents were *actually less likely* to see their preferred doctor than the respondents to the GP survey; with exception of older Deaf people (over 65 years) who mostly saw the doctor they preferred (80%).

The Deaf respondents reported much higher rates of dissatisfaction than those in the GP Patient Survey with the doctors' explanation of their condition or tests required. Only 11% of Deaf participants thought their doctor was very good at involving them in decisions and 25% said the doctor was poor or very poor in this respect (compared to only 3% in the GP survey). The preference of the vast

majority was for the use of signing with the doctor. However, it was encouraging that in just under half of the most recent visits to the doctor, signing had been used and in nearly 60% of the visits an interpreter was present. As a positive indicator, this latter figures has to be treated with some caution as in our follow–up interviews, reported separately) there was widespread dissatisfaction with the quality of the interpreting service and the lack of awareness of professionals concerning how effective the interpreted session was.

As this survey was based on a quota sampling method and even though all travel expenses were covered, it did not result in a sample which we can be sure was completely representative of Deaf people in the UK (there is no comprehensive demographic profile for Deaf people available in the UK). However, the quota for age, gender, ethnic group and geography was achieved. There were also some methodological limitations, as some of the data on chronic health conditions were derived from self-report (although it should be remembered that this is also the case for the Health Survey of England), and we had to utilise comparative data on the hearing population based on routinely collected data from England only.

In conclusion, a survey of the health of deaf adults in the UK showed higher rates than the general population of obesity, hypertension and asthma. Deaf respondents' self-reported rates of smoking and alcohol consumption were much lower than the general population. Deaf patients reported difficulties in accessing primary care, seeing the doctor they wanted, and in communicating with doctors. Deaf people have lower levels of trust in the doctors they see. In spite of some improvements in the availability of BSL interpreters, many barriers remain for the Deaf community in engagement with health care.

However, we need to recognise that this issue of access is bilateral or even trilateral (if there is an interpreter present). Solving the problem will need adjustment by all parties involved and solutions solely on the Deaf side will not produce improved health. Further and more significant, is the relationship between personal wellbeing of the Deaf person and the "external" disenfranchisement with the (hearing) health care system. This relationship is explored more thoroughly in part 2 of this research study when we are able to examine in more detail, Deaf people's views on their own health.

 In the meantime we can see that the Deaf community suffer from poorer health than the general population and that causes are complex and longstanding.

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1. The Background

Hearing loss is one of the most common conditions among the general population, with most of those who are affected by it, acquiring a degree of hearing loss in later life. Relatively few people are born with a permanent hearing loss. There are many ways of counting this population but it seems likely that the core community of sign language users is quite small, even when we start with large figures for hearing loss in the UK.

Hard of hearing people are the largest group (up to 9 million₃) who have a measurable hearing loss. The vast majority with a permanent hearing loss, are of retirement age and their hearing loss may increase in severity over time. Hard of hearingness is typically associated with elderly people and around 60% of people over 70 years are estimated to have a significant hearing loss (Davis, 1989). People in this group or others who lose their hearing from their twenties onwards are very unlikely to use sign language and are likely to remain culturally hearing. (Kyle, Sutherland and Stockley, 2012, p 15)

Not all those born with a significant hearing loss are British Sign Language users. Here we use Deaf (with capital D) to refer to those who are culturally Deaf, use sign language and expect to be part of the Deaf community. In this sense, Deaf is equivalent to French, or Spanish or English. Membership of the Deaf community is not determined by extent of hearing loss – it is rather a choice based on identity and cultural experience and by language preference itself. There are no official figures of how many Deaf people[1] there are who use British Sign Language (BSL) as their first language; various sources have estimated it is between 25,000 and 70,000 (Ladd, 2003). We consider the true figure to be lower than even the lower of these figures, especially if we consider only those who are functionally monolingual. The recent UK Census 2011, places this BSL-monolingual figure closer to 15,000.

There is now a range of descriptions of the Deaf community and its coherence and shared experiences. There are also accounts of its marginalisation (Ladd, 2003, Lane, 1992). What is clear is that for those who do not speak or hear, access to health care (and of course, many other services) is curtailed. There are frequently complaints by Deaf people about access to health care (Ringham, 2012) but the true consequences of this perceived lack of access are not clear. In this review, we try to establish what we know about Deaf people's health and in the research study, we attempt to measure the health of a typical sample of Deaf people in England, Wales and Scotland.

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[1] The use of the capital letter in "Deaf" acknowledges the cultural and linguistic affiliations associated with this model. However, the lower case "deaf" is used with children whose affiliations are yet to be established and in a generic sense with adults who may or may not be members of the Deaf Community (see also Appendix 4).

1.1. Health Inequalities and Change

The Charter of Fundamental Rights of the European Union clearly states in article 35, that everyone has the right to good health care, regardless of disability and race.

"Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices" (Official Journal of the European Communities, 2000, c364 16-17).

Although people with disabilities may have the same general care needs as those without disabilities, it is important that they also have the same access to mainstream health care services. Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) reinforces the point that each of us has the right to receive the highest standard of health care, without discrimination. This requires health care providers to take into account the needs of Deaf people.

What is challenging in the current climate is that the NHS (National Health Service) in UK is yet again undertaking a restructuring of their services. The White Paper, *Equity and Excellence, Liberating the NHS* (DH, 2010), considered how the service could:

- Put the patients at the heart of everything the NHS does;

- Focus on continuously improving the things that really matter to patients – the outcomes of their healthcare;

- Empower and liberate clinicians to innovate, with the freedom to focus on improving healthcare services
  (Department of Health, 2010)

The Government asked for views on how greater choice and control could be given to patients and how this could be achieved in practice. This included giving patients choices and allowing them to take part in a shared decision-making process about their healthcare.

The central proposal is "shared decision-making" and this was defined by Coulter and Collins (2011):

…a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. – cited Department of Health (2012b, p8

This would enable patients to have the necessary information in order to make informed choices, which includes making the information accessible in a way that can be understood by patients regardless of their specific needs. The follow-up proposals on this (Department of Health, 2012a) has a somewhat narrow view of impact,

A review of the available literature finds no evidence to suggest that giving patients more say in decisions about their care and treatment has created any specific inequalities. A paper by Cookson and Laudicella (2011) looking at the impact of the choice of provider policy suggests that inequalities have stayed the same or reduced slightly since the introduction of this entitlement to make choices at referral (DH 2012b, 3.2, p11).

When considering the 'protected characteristics', there is no mention of those who may not be able to exercise their choice through speech – ie Deaf people. Under the heading of disability, only mobility is mentioned as a factor inhibiting choice. Deaf people are often excluded from taking part not only in this exercise of choice but in the Government process of review as that process is not linguistically nor culturally accessible. Negative experiences *after* the implementation are unlikely to create significant positive change.

Economic status is often considered to be of major importance when we examine the delivery of health care (Adler and Ostrove, 1999). Those who are better educated and financially stable have been able to make better use of medical specialists, including dental services. Those who fall within the lowest earning bracket are recognised to be more likely to use the emergency services. Regardless of whichever income bracket people may fall in to, generally most have made good use of their local GP services. There is however, some disparity. People within the lower income bracket are more likely to consult their GP more frequently (Van Doorslaer et al, 2006). Deaf people are statistically more likely to visit their GP more often (Dye and Kyle, 2001). Despite visiting their GP more, Deaf people have also reported being least satisfied with the service received from their GP leading to them having to return to the GP for further clarification and explanation (Dye and Kyle 2001).

Access to health care is likely to remain a problem for some time to come. However, in this review we are more concerned with measures of health and process of care than in re-iterating the frustrations of poor access.

1.2. Health of Deaf Children and Adolescents

No one dies of hearing loss. No specific disease arises from Deafness. There are syndromes and illnesses which may result in hearing loss eg rubella (Bhandary et al, 2012), meningitis (Richardson et al, 1997). It does not appear that hearing loss makes the person more susceptible physically to other illness. Deaf people develop, as far as can be monitored in large scale data studies, in exactly the same way physically and intellectually, as do hearing children. Deaf people do not look different in a crowd. Yet the consequences of hearing loss are considerable in a hearing society where achievement is based on speech and hearing. Those consequences are almost certainly to be seen when the Deaf person attempt to s engage with pubic services and in particular, where there is necessity for

engagement, such as in the area of personal health.   Surprisingly little has been written about the health *outcomes* for Deaf people.

The vast majority of published work in the area of hearing loss in childhood and adolescence, deals with the factors surrounding the hearing loss and its extent. The whole of audiological science concerns itself with the workings of the auditory system and how and why it may appear to be non-functional in some children (or adults) (see for example Fuchs, 2010). Where it deals with outcomes, these tend to be in the area of spoken language. Since the determination of such outcomes is usually in the hands of other non-medical professionals, much of the emphasis is then on the prevention of the hearing loss in the first place and the direct replacement of auditory function or remediation of the auditory sense.   Research has considered the need for early discovery of hearing loss and the causes of that hearing loss.

1.3.   Newborn Hearing Screening Programme (NHSP)

In the UK, around 840 babies are *said* to be born each year with permanent hearing loss in both ears. This figure has been widely reported/repeated. It forms a sort of Chinese whisper as one site reports it as 840 babies a day! However, the figure comes from studies carried out on a cohort of children born between 1985 and 1990 in the Trent region of the UK by the Institute of Hearing Loss. The figure 840 has been simply projected on to the national figures from the Trent area. It is part of an argument presented for the implementation of newborn screening.

Watkins (2011) surprisingly adopts the same figure without question but offers a figure of 0.5 per 1,000 births having a severe or profound deafness which mapped to the UK live births figure (Office of National Statistics, General Registrar for Scotland, Northern Ireland Statistics and Research Agency) suggests 404 cases in 2010. However, even this is not quite as the original. Davis et al (1997) claim that 24 per 100,000 have a hearing loss greater than 95dB from birth, which translated nationally to 2010 birth statistics would imply194 cases per annum. Even with the additional of congenitally severely hearing impaired we would reach only 364 cases.

These figures can also be used to supply a basic estimate for the size of the Deaf community. We would expect this to be drawn from those with the greatest hearing loss plus a proportion of those with lesser hearing losses and some who had acquired a hearing loss. When applied to the UK population these incidence figures would imply a community between 14,400 and 27,000. We believe this to be a much more realistic range than the optimistic 50,000 to 70,000 figures which are often reported.

Watkins (2011) suggests the cost of the NHSP is £20,000 per discovered case but goes on to argue that this is value for money given the better outcomes of earlier discovery of hearing loss.

Deafness, when diagnosed, may come as a shock for some families, presenting challenges in learning how to communicate with a Deaf child. As many as 90% of deaf babies are born into hearing families where there may have been no known history of deafness. Hearing parents may not be able to communicate effectively with their deaf children and most parents are likely to have very little or no experience of dealing with deafness prior to their child's diagnosis (Rawlings and Jensema, 1977).

1.4.   Impact of Delayed Diagnosis

A delay in identifying a hearing loss is claimed to have implications for families concerned:

- Support services may not be mobilised

- In mild/moderate hearing loss, the parents may not believe the child has a hearing loss and treat the child as slow in learning

As for the deaf child the implications could include:

- delays in acquiring language, in either a spoken (Gregory and Mogford 1981) or in signed form (Kyle & Woll, 2004)

- long term impact on their educational achievement, confidence and social skills

'Each day in the life of a young child with an undetected hearing loss is a day without full access to language. When hearing loss goes undetected, the resulting language deficits can become overwhelming obstacles to literacy, educational achievement, socialization, and school readiness' (Eiserman et all, 2008), Moller, 2000).

Expression of concern like this has led to the prioritisation of Newborn Hearing Screening programme as a first response to hearing loss.

It is expected that babies with hearing loss can be confirmed as young as five weeks old, and be fitted with hearing aids within sixteen weeks and/or targeted for a cochlear implant programme. Additionally, their families can start to receive support almost immediately. While it seems obvious that support services should arrive as early as possible, research by Young (2010) seems to indicate that this is not necessarily effective in the views of the parents. There is some uncertainty as to how to intervene with very young Deaf children in order to create the basis for future growth.

1.5. Risk of hearing loss in babies

Before the NHSP was implemented (2006), only babies who are included in the four categories below were likely to be referred for a hearing test at birth or soon after.

- Babies who were born prematurely, those born before 37 weeks gestation are at particularly high risk.

- Babies who had to spend some time (more than 48 hours) in neonatal intensive care, or special care baby unit.

- Where there has been previous history of deafness in the family.

- Those born with cranio-facial abnormalities

This practice tended to identify mostly those children with additional complications. Most Deaf people in the community today were discovered later and most do not have cochlear implants. A large proportion do not wear hearing aids (Kyle et al 2005). Although a significant proportion will gain little benefit from the supplied hearing aids, for some with a capacity to hear this may affect their access to health care and ultimately lack of access may affect their own health.

Among the children from Asian communities a greater number were diagnosed later than average for UK born children. A higher rate of hearing loss, 4.69 per thousand births as opposed to 1.38 per thousand among non-Asian children, is probably explained by poverty and poor access to healthcare in the home countries of these communities. The prevalence of infections such as rubella in many Asian countries is also higher due to a lack of vaccination. (Positive Practice Standards in Social Services – Executive Summary, 2002). This context is to be found in the UK in areas where there is a large immigrant population, such as in Bradford. Ethnic minority Deaf people may experience greater degrees of exclusion from information on health.

1.6. Causes in Early Childhood with health outcomes

We will not review the data on cause and extent of hearing loss. There are many other reviews and books written on this. However, we are interested in health issues which surround onset of hearing loss.

The number of children with hearing loss is said to increase from 1 to 2 per thousand by the age of 9 years (Fortnum, Summerfield, Marshall et al, 2001), that is, children born with a hearing loss are joined by the same number who acquire a hearing loss in their early years. Most of these are illness-related onsets of hearing loss or are progressive types of deafness.

In this section we are not so concerned about the cause per se, but more in the impact this might have on subsequent health.

One of the most common illnesses that can result in childhood deafness is meningitis. Baraff, Lee and Schriger (2000) in a meta-analysis of outcomes, place hearing loss as the major impact but also indicate learning disabilities as a direct effect as well as the presence of seizures. Otitis Media (infection in the middle ear) is relatively common among children but is typically temporary. Nearly 32% of deaf children have a progressive hearing loss.

Tinnitus is an accompanying condition of hearing loss but may be likely to create additional problems, especially in the area of mental health,. Holger (2003) offers an analysis of the impact of childhood tinnitus.

1.7.   Other health outcomes of childhood hearing loss

Homer and Guest (2004) (http://www.batod.org.uk/index.php?id=/resources/publications/on-linemagazine/deafblind/visioncare.htm) claim that between 30% and 60% of Deaf children have sight problems. This statistic does not usually trigger major concerns and is not seen as an outcome of the hearing loss.

1.8.   Deaf Children with Additional Complex Needs (ACN)

As many as 40% of deaf children may have additional complex needs (Holden-Pitt and Diaz, 1988; Stredler-Brown and Yoshinaga-Itano, 1994; Fortnum et al, 1996). Such deaf children may enter the system as having severe learning difficulties and may be educated for their learning problems (which are deemed to be more severe) rather than their hearing loss. A large but generally un-researched, majority will not be members of the Deaf community.

We can see from the above that if we examine the Deaf children, and then presumably Deaf adults, are likely to have additional problems of a physical nature.

1.9.   Mental Health

The mental health of Deaf people has recently been reviewed in a Lancet article (Fellinger , Holzinger, & Pollard (2012). They concluded that a quarter of deaf individuals have additional disabilities and a high probability of complex mental health needs. The literature suggests that deaf people do not have a specific psychopathology and that mental health problems in deaf populations are mostly common mental disorders, such as anxiety and depression. There is some evidence that Deaf people are more likely to report psychotic symptoms. A Dutch study (Thewissen et al, 2005) showed that adults with hearing loss were three times more likely than those with full hearing to report having had psychotic symptoms.

The prevalence of autism in people who are deaf is significantly higher than in hearing individuals, and ranges from about 2% to 4%(Jure et al, 1991).

The authors argue that to improve access to mental health care it will be necessary to provide specialist services with professionals trained to directly communicate with deaf people and with sign language interpreters.

1.10. Access to Health Care

Articles on Deaf access to health care are common in the literature because this topic forms, more or less, a universal complaint.

Barnett et al (2011) provide a succinct analysis of the access issues for Deaf people in regard to health care in the USA and consider that these problems affect health outcomes. Many other studies examine the problem eg National Primary Care Research and Development Centre (2003) in the Manchester area (http://www.population-health.manchester.ac.uk/primarycare/npcrdc-archive/Publications/GP%20D.access.pdf).
They concluded:

This study shows that many Deaf people are severely disadvantaged when they use primary care. Issues of communication are central to the problems Deaf people experience. Good two-way communication is vital for both a successful GP consultation and for patient safety. In this study poor communication resulted in many patients leaving the consultation without knowing much more about their illness, what they were supposed to do next, and in some cases even how to take the medicine prescribed for them. The cumulative effect of poor communication across all aspects of care is perhaps best reflected in the finding that 40% of the Deaf people had complained, or felt like complaining, about some aspect of the service received from their GP practice in the last twelve months. One person had taken their GP to court. Page 5

Similarly a small scale study by Pullen (reported in Kyle et al, 1997, p125) said four out of eight elderly people interviewed could sometimes understand their doctor and the other could not understand their doctor at all.

An Action on Hearing Loss Survey (Ringham, 2012) and a Deaf interview study, (Reynolds 2007) confirm the extent of these difficulties in interaction with health professionals. Reynolds (2007) considers this is related to the medicalisation of 'deafness'- ie the fact that Deaf people associate the health care with the audiological interventions they have experienced in the past.

Encouraging improvement in access to health services is complicated by the fact that there is no *specific* legal requirement on any Health Agency, to *provide sign language interpreting;* only to take steps to ensure equality of access. The way in which this can be achieved is not clearly spelled out, monitored or implemented. Indeed in Deaf Health in Scotland (Kyle et al, 1997) Health Trusts were clear in regard to their approach to Deaf people. Wherever they detected a problem they would carry out a needs analysis and then take appropriate action to meet that need. The trouble was that no Trust considered that there was a pressing need in regard to Deaf access. In many cases, the Trusts had not detected any common, expressed need by the Deaf community. As a result, there was (and is still) no general accepted principle and no specific provision in regard to any health care for Deaf people.

Data from the DPIC study (Dye and Kyle, 2000) indicated that compared to hearing people, Deaf people were much more likely to visit the GP (even though they disliked the experience); they were more likely to be given prescriptions than hearing people, which might be seen as an easier way to manage the health problem when communication itself is a difficulty.

Although 34% said they used text relay services to make an appointment, 23% asked a friend and 21% went themselves to the health centre, just to make the appointment. Ninety-one percent said that there was no one who could sign at the Health Centre.

Deaf people prepared in advance with 46% making notes before their visit to the GP. Interestingly, 39% tried to speak first and then gesture eg point to the pain.

Around 44% asked for pen and paper and 43% spoke first and then wrote down. Some 21% used a sign language interpreter but 29% used family or friend to mediate and 44% tried to lip-read the doctor. When asked why Deaf people went to the doctor more than hearing people, 61% said it was because they did not understand the first time and had to go back to check.

1.10.1. Direct contact with Emergency Services and Hospitals

Of the topic areas covered in the interviews in Kyle et al (2005), emergency service access and access in A&E are probably the most predictably problematic and the most disturbing. In certain situations, Deaf people have no option but to try to communicate directly. At the point of greatest need in emergency situations, Deaf people's well being is greatly at risk and often for the sake of most trivial of alterations which minimal Deaf awareness training would provide. Deaf people frequently languish in waiting areas not knowing that their names have been called.

> It happened to me at the A&E. I waited for a long time, unaware that my name was called out 3 times. After a while I saw the staff change their shift. I went up and asked what happened and they said they called my name three times. I had told them I was Deaf. They need more Deaf awareness training, to change their attitude and staff should be able to sign.

> I went to hospital, told them my name and that I was Deaf. I showed them where I was sitting, so there was no need to shout but they should come up to me or "wake" me when it was time to see the doctor. But after waiting, I saw someone call my name with exaggerated mouth pattern. I was embarrassed ... I told them ... but they simply ignored what I had said.

Deaf people consider this failure as a matter of 'attitude'. Hearing people are seen not to care, to be resistant to change in their routine and sometimes, just ignorant of the needs of Deaf people even when these have been pointed out. It is a matter of considerable frustration. This frustration can turn into very bad experiences.

> It happened with my (hearing) wife who was diagnosed with breast cancer. It was confusing as the doctor explained to her about it in front of me. I was lost for information. My wife was upset and she was crying while trying to explain to me.

> The doctor was not aware of Deaf needs. On the next visit, I called for an interpreter so that my wife did not have to try to explain to me what the doctor said.
>
> One time after a chest operation, I was transferred from one hospital. I was left in the waiting room overnight as the bed wasn't ready. I was in so much pain and they gave me no medication. I was cold and really suffering. The next day, the nurse found me and said "you are up early". I explained that I hadn't been given a bed. The medical team were shocked and I demanded to be sent home to recover.

This is an area of great concern where communication barriers and lack of simple procedures were reported to be seriously affecting Deaf people's well being. In terms of waiting, Deaf people see the problem as lack of a visual display system and simple lack of Deaf awareness – one would think these would be simple matters to rectify. In the case of the communication issues, they see the problem in terms of lack of emergency interpreters.

1.10.2. Dealing with Doctors

In all surveys of Deaf people, contact with the local GP and with medical services is one of the most problematic areas (Ringham, 2012). Deaf people feel their personal well-being is at risk and view the communication transaction with some apprehension. However, there were some Deaf people who reported success with the doctor.

> My GP is fine and understandable as he is my family doctor for more than 30 years. He is Deaf aware and uses gesture. No problem.
>
> My doctor can use fingerspelling. It helps better to communicate. She has really good Deaf Awareness. I am not very good at English. She wrote only simple words. Most doctors do not do that!

These responses were very much in the minority; usually there were complaints of lack of communication and problems of attitude. Deaf people as usual partially solved the problem by taking a relative or friend but in this situation, there are major questions about privacy and independence (Kyle et al, 2005).

In a hearing society, particularly in the UK, personal privacy is closely guarded. It is true that people have close friends with whom personal problems can be discussed but people expect these confidences to be respected. In any case, they have the choice to make the information available to the other person. In contrast, Deaf people receive second hand information from other people. The doctor speaks and a friend or relative passes on the information which is deemed relevant to the extent of their communication abilities – which is often not at the level of fluency in BSL. The hearing person makes the choice about which information to share with the Deaf person – about that Deaf person's well-being. When the intermediary is a family member, there is a serious dilemma about which other people might be informed. The Deaf person has no control over this – "He knows a lot of information about me" – and there is a suspicion that the person "tells the family". Doctors themselves may also be concerned about this aspect and also about the

difficulty with which family members are able to manage details of a serious nature in regard to illness and even death. This creates great insecurity (as discovered in Kyle et al, 2005).

> Always brought a friend with me. He knows a lot of information about me.
>
> My aunt always goes with me to the GP. I am not happy as it affects my privacy and also can affect her if anything is seriously wrong and she tells the family.

Where Deaf people reject the intermediary, they go to the doctor on their own. In this case, they have to rely on the doctor's preparedness to make adjustments in communication. In island locations, where there are simply no alternatives, Deaf people reported being unhappy about their poor communicative contact with doctors.

> Writing notes does not help. I am never happy with doctors. Last year I went to hospital, my daughter helped my as interpreter. It was impossible to find a interpreter. It was a very bad experience. My doctor told me I may have cancer but it really frightened my daughter because we are in the same family it was not right. I do not have any privacy.
>
> I am used to going on my own – all my life. .... Doctor would write down just one word like 'operation' or 'hospital'. I would show or point to my body where the problem is. If there is a problem with the children, my husband goes. I wouldn't want an interpreter as it is my privacy. The doctor should sign to communicate with me.

This lack of appropriate interpreters is worse in these remote areas of the UK where there are no services at all.

> I have a work colleague, who is head cook, who I taught to sign, She helps me phone the doctor and sometimes she comes with me. Sometimes I go on my own. It is difficult to communicate with the doctor - I have to lip-read or write down. I only get a brief response. I had a smear test and waited for the result by letter – there was none. That was three years ago. Also I had a urine test and I am still waiting for the result. I told them I was Deaf and unable to use the phone, so I gave them the number to fax me with the result - no response. It is so hard being Deaf with little support.
>
> It is so hard – there is no one to help with communication. It is so difficult to explain to the doctor what I want to say. It is difficult to do it by writing..... Social worker never helps in this island. There is a Deaf club but the social worker never comes to meet us Deaf people to see if we need anything or any help – nothing at all.

In health settings, Deaf people 'lose control' of their own bodies and their own well- being. The problems that can be caused by these circumstances are enormous. However, as before, it is the Deaf person who ends up feeling bad about the lack of information or explanation.

It is quite clear that Deaf people are outsiders in health settings. It is very difficult to establish ownership of their own health information. Adjustment is seldom by the health professional and the net result is to reduce the Deaf person's self esteem.

Such problems also have further serious repercussions ie in depression and withdrawal.

In contact with health services Deaf people continuously use the terms frustration and loss of privacy (Kyle et al, 2005). Deaf people often blame themselves for the problems with the doctor – yet the root of this must be the service provision as every Deaf person can recount a bad experience with health staff in hospitals or in a doctor's surgery.

Naish and Clarke (1996) interestingly consulted GPs as well as Deaf people. The responses from Deaf people were in line with most other expressions of dissatisfaction in other studies. However, the insights from GPs were interesting. They believed that provision of interpreting was a patient responsibility; most were not aware of Deaf people's poor comprehension of written English and more than half thought that speaking loud and slowly, was the appropriate means of communication. Doctors were under the impression that 85% of speech could be lip-read by Deaf people. However, the doctors did consider family members who "interpreted" for the Deaf patient, to be an unsatisfactory 'provision' as they tried to help and would over-simplify the information. Less than 10% of the GPs responding at that time had had awareness training to help them in interacting with Deaf patients. It does not seem very likely that this situation has changed a great deal since this work was carried out.

There is a range of other data, including the GP surveys, which are even more recent but contain much less qualitatively interpretable data. They support the general view that for Deaf people, engagement with health care staff is problematic (Ringham, 2012).

The issue for this study is to what extent Deaf people's health is compromised by this difficulty in access.

2. The Deaf Health Study

The World Health Organisation has spent a great deal of time pointing out the extent of health inequalities in society and looking for remedies. Many researchers have investigated the connection between health status and what are termed avoidable health inequalities (Costa-i-Font & Gil, 2008,). They see health inequalities being determined by

"health prevention related inputs, inequalities in access/ utilisation of health-care services, inequalities in financing …. and in gender" (page 7).

The Charter of Fundamental Rights of the European Union: article 35 states that

"Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices" (Official Journal of the European Communities, 2000).

Euphix (2009, http://www.euphix.org/object_document/o5679n29797.html[2]) carries the statement:

"The overall picture emerging from research is that richer, better educated people find their way to medical specialists and dentist more easily and more frequent, while people in the lower income brackets tend to use more emergency services. The access to GP services seems fairly equally distributed across income. However, once people go to see their GP the poor are more likely to consult them more often. In contrast, the level of pro-rich inequality as regards access to medical specialist increases with the total number of specialist visits." (Van Doorslaer et al., 2004).

We suspect that Deaf people fall into the category of poverty in access. Kyle et al (2005) in an interview study of Deaf people in 7 locations in Scotland, confirmed that Deaf people felt they had no direct access to health care. They reported almost unanimously, problems in communicating with health care professionals. In an earlier study (Dye and Kyle, 2001) Deaf people reported more frequent yet less satisfactory visits to the GP.

We suspect on the basis of anecdotal evidence in the UK that culturally Deaf people (sign language users) have poorer physical health than hearing people, but there is no definitive detailed research study which has investigated this.

In this study we collected the data that would allow us to investigate the relationship between access to healthcare and health status in the community of Deaf sign language users.

The study is presented in succeeding chapters

- Methodology and description of the sample of the Deaf population

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[2] Euphix website has now been taken offline.

- Deaf people's self report of health issues
- Obesity
- Hypertension
- Lipid Profile and Cardiovascular Risk
- Depression
- Diabetes
- Smoking and Drinking
- Access to Health Services
- Discussion and Implications
- Recommendations

3. Methods

3.1. Aim

The purpose of the Deaf Health study was to assess the current health condition of the Deaf community in the UK, and to determine the link between their health status and the issues they face in communication and thereby their access to health care.

3.2. Study Design

The Deaf Health study reported here represents the second and third phases of a three phase investigation into the health of deaf adults in the UK, part funded by the Big Lottery.

The first phase was an online survey of 533 Deaf people, run by Ipsos MORI in conjunction with Sign Health during 2010-11. The results will shortly be published by Sign Health.

The second phase was a structured assessment of the health status of a purposive sample of 300 Deaf adults, undertaken in conjunction with Bupa Healthcare in 2012-13. Participants for this 'health check' were recruited from two sources: (a) approaching those respondents to the phase 1 online survey who gave consent to be contacted and (b) through direct contact with the Deaf community. The structured health assessment consisted of the standard health check provided by Bupa and an interview with a Deaf advocate to collect data on use of GP services, which would allow direct comparison with health survey data for the general population, using routinely collected GP data in England (the GP Patient Survey).

The third phase was a qualitative study of 47 BSL users, collecting data on behaviour and experiences which may affect health. Interviewees were recruited from those who had participated in the phase 2 health assessment. Individuals were chosen to be representative of the specific health conditions discovered from the online survey and from the medical assessments. Detailed interviews were carried out in BSL with this sub-sample by Deaf researchers, in order to elicit directly the issues surrounding communication and contact with health care professionals. The report on this phase of the work is presented separately.

3.3. The participants

3.3.1. Sample

A representative sample of 300 Deaf sign language users in the UK was invited to attend a Bupa centre to undergo a structured health assessment and interview (see

Appendix 1 for the schedule and interview questions). The sample was constructed according to a quota which matches the UK population in regard to age and gender

Table 3.1: sampling plan

	18-24 yrs	*25-44 yrs*	*45-64 yrs*	*65 yrs +*
Male	18	51	46	31
Female	18	54	50	32

The purposive sample included a small yet proportionate involvement of ethnic minority groups. Socio-economic status is an issue as the Deaf community tend to be downwardly mobile as their financial circumstance and social participation tend be less than their parents. The Deaf community is thereby more likely to be found in lower socio-economic groups, but possibly for different reasons to those in the mainstream society. Socio-economic and educational status could not be controlled variables in this study without an extensive set of pre-interviews; they had to be allowed to vary across the sample.

3.3.2.   Recruitment

The first round of recruitment from those who completed the online survey in phase 1 produced only 80 participants for the health assessments. The following approach was then adopted to provide 220 people to meet the target of 300:

Five centres (planned numbers in brackets) were targeted: London (60), Bristol (40), Manchester (40), Glasgow (50) and Nottingham (30). These locations were chosen as likely to be representative of the diverse range of health issues (for the community as a whole). There were also appropriate test centres available.

We adjusted the individual quotas (by age, gender) as we progressed, and we predicted a pattern of take up in the centres as we moved through them consecutively.

In each area, a local Deaf "finder" was employed to create a quota sample of potential participants, to be *invited* to take part. That is, individuals active in the local Deaf community and already known to us from our considerable amount of previous research, made direct contact with Deaf people who matched the quota sample. These were Deaf people known locally who might be regular or irregular attendees at Deaf clubs and gatherings. Use of letters or other text materials were counter productive at this stage as they would not be accessible to the potential participants (that is, their level of literacy would not guarantee that they could read and understand the text). In any case we had no means to send or email such material as at this point, as we did not have their names or addresses. The quota samples for each location were constructed to achieve the overall sample.

The Bupa health assessments were arranged approximately 2 weeks after the contact/introduction by the finder, to allow further contact and explanations and to allow the participants to reconsider their participation if they wished to do so. Participants attended the local Bupa centre and were supported by a Deaf support worker and by a sign language interpreter.

At the health assessment, it was also explained that some people (about one in six) were to be asked to have a personal interview with a deaf researcher from the University. Selection of these invitees was made by the medical team at the University and were chosen on the basis of the presence of specific health conditions and as likely to have experiences with health care professionals. Unfortunately, there was no means to predict response rate (from those invited) and it was not always possible to include all first-choice interviewees.

3.3.3.   Setting

Bupa was chosen as a partner in this research, because they offer a standardised health assessment by trained health advisers in centres throughout the UK. The target Bupa centres were those that could provide a complete set of test results at the time of attendance – these were –London (Kings Cross), Bristol, Nottingham, Manchester, Glasgow, Solihull, Brighton and Cardiff.   All Bupa health advisers had been trained to a similar appropriate level, and a standardised health check was offered in all centres. Detailed discussions were held with Bupa at a senior level and pilot assessments were carried out in Bristol before the main study commenced.

Bupa services were booked and participants invited to attend at a specific time. At these sessions, sign language interpreters were available in order to mediate between the health advisor and the Deaf participant.

Since contact had been often by text message (ie not be letter), on arrival, each participant received a simplified summary of the project – Appendix 3). A BSL version of this summary was recorded and made available on the website (see http://deafhealth.org.uk/?page_id=180).

3.4.   Procedure

In this phase 2 of the project, researchers texted and emailed/mailed the participants from the online study who had indicated that they were prepared to be contacted for further involvement. Those who then responded were sent information about the medical assessments at Bupa. As far as possible locational detail was used to construct the sample for the medical assessment (addresses were not always accurate or available for those who had completed the online survey).

The letter sent to participants included;

- A simplified information sheet (Appendix 3)

- A reply slip, to candidates to confirm acceptance of the date and time,

- An SAE or return email address or text number directed to the Centre for Deaf Studies, University of Bristol

In the letter, it was explained that participants could view the information provided in the letter in BSL on-line. The website has information in BSL that explains: the project as a whole, the medical assessment and the interview.

A second letter/email was sent to confirm the agreed time and date. In the second letter, they were asked to bring any current medication with them and they were requested not to eat anything for six hours before arriving for their health assessment. We carried out a pilot study at the Bristol Bupa centre and then further trial sessions for the whole procedure (to train interpreters and Deaf health support workers) so that all modifications were made prior to the main set of tests being carried out.

3.4.1. *The medical examination and health check*

The health assessment schedule and interview detail are set out in Appendix 1. The interviews and tests were administered by trained Bupa health advisers, with a sign language interpreter who had been briefed and provided with a relevant BSL lexicon for the terms used in the health assessment. The Deaf participants were also supported throughout by Deaf health support workers fluent in BSL.

When Deaf participants arrived, Deaf health support workers were on hand to explain the plan of what would be happening during the assessment. Once they were happy with the information they received in BSL, they signed the Consent form. The information that they were given was:

- an explanation of the different tests that they would need to go through

- support for the completion of the medical assessment form

- explanation that the results were to be given to them at the end of the assessment by the Bupa health adviser and that there would be an interpreter present. It was also explained that they could request further support from the Deaf health support worker to go through the results with them in order to make sure that they had understood all the text, and if necessary to stress the importance of following up the recommendations with their GP if necessary.

The health assessments took approximately one hour. The assessment started with a (fasting) blood test, after which the participant was given a light snack and a drink. Participants were weighed with light clothing and no shoes, and their height measured using a stadiometer. BMI (wt/ht^2) was then calculated .

Blood pressure was measured in the resting state, sitting.   The standard protocol was for Health Advisers to take at least 2 blood pressure measurements with the lowest reading recorded. The standard equipment used by Health Advisers was an automatic BP machine, with Omron the main supplier although the exact model varied from centre to centre. Occasionally a check was done using an aneroid sphygmomanometer by the doctor if needed.

Body fat percentage was measured via bio-electrical impedance. The equipment used is standard at all Bupa sites – Bodystat 1500 http://www.bodystat.com/products/bodystat-1500/

3.5.   Ethical issues in the conduct of the study

This research was given ethical approval by the NHS Local Research Committee (NRES Committee South West – Frenchay). Throughout the study, good practice in research governance and ethical procedures was followed.   Because of the number of organisations involved there was a distributed responsibility for data protection and the management of participants' expectations. At any point in the process, participants could have access to and control over data held concerning their health or involvement in the study. They were entitled to withdraw at any point for disclosed or undisclosed reasons and their data was removed from the study.

Participants in the prior online survey carried out by Ipsos MORI who had indicated that they were prepared to be contacted by SignHealth, were approached in the first instance. When the response rate and the characteristics of the sample coming forward, did not match our requirements, we returned to the ethics committee in order to offer a more direct approach to the contact with members of the community. This ensured that individuals were not under pressure to take part and could choose to engage or withdraw at any point.

At each stage, explanation in BSL as well as in text was offered. On arrival at the Bupa centre, explanation was given about the assessment verbally and in text form and this was also explained in BSL. Participants were required to sign a consent form regarding the data collected and to agree for their contact details to be available to the University of Bristol in order that they could be reached in regard to follow up interviews. Following the medical assessment, the results were explained to the participant by the Bupa Health Adviser, through an interpreter. The participant was also given guidance on who to consult about the results, and about the interview stage of the project for the further sample to be chosen from those who had take the health assessment.

3.6. Comparative Data Sets used

The data collected here were compared to the Quality and Outcomes Framework (QOF, 2011 and 2012), the GP Patient Survey (2012) and the Health Survey of England (2010, 2011). Some reference has been made to similar studies carried out in Scotland and in Wales.

The Quality and Outcomes Framework (QOF) is a voluntary annual reward and incentive programme for all GP surgeries in England; it sets targets for the treatment of patients and for the management of health. In doing so it generates statistics on the extent of ill health and chronic conditions. (see http://qof.hscic.gov.uk/ or http://www.nice.org.uk/aboutnice/qof/qof.jsp for more information).

The GP Patient Survey assesses patients' experiences of the access and quality of care they receive from their local GPs, dentists and out-of-hours doctor services. Data are collected from questionnaires sent out to random samples of patients. The response rate for 2011-12 was 38%, indicating the usual problems in creating a representative sample. (see http://www.gp-patient.co.uk or http://www.england.nhs.uk/statistics/2013/06/13/2012-13-gp-patient-survey-aggregated-wave-1-and-2-results/).

There is a separate survey for Scotland but the questions are set a little differently. Despite some of the participants residing in Scotland it was felt more appropriate to use the questions from the English version and thereby the Scottish participants were included in the comparative analysis for the English results.

The Health Survey for England (HSE) is an annual survey designed to measure health and health related behaviours in adults and children living in private households in England. Measured height and weight data are recorded as part of a core data set (which also includes general health, smoking, drinking, blood pressure measurements) and topic specific health indicators (from http://www.noo.org.uk/data_sources/adult/health_survey_for_england). Although this is a large scale study, it has all the usual problems in response rates and participation. The sample for 2011 is over-represented in women 56% and varies in response (better in the North of England than in London. Overall response rate was 59% of all those adults eligible to take part and those who proceeded to the nurse interview was 39%. Only 29% gave a blood sample.

Inevitably, these data sources do not produce identical figures. The HSE 2011 offers their explanation of why there are differences:

> There are several possible reasons for the lower QOF figures. Firstly, it is known that GP registers overstate the true number of patients, for example because of the time lag in updating lists when patients move to a different practice or die (known as
>
> GP list inflation). This increases the denominator which will decrease the apparent prevalence. Secondly, there may be some people living in England who are not registered with any GP and if these people had a CVD diagnosis they would be missing from the numerator. Thirdly, there may be under-recording by GP practices of diagnosis in their patients due to time constraints or IT failure. One or more of

these factors has improved since 2006, as GP registers now more closely match these survey results (ie in 2011). (HSE, 2011, volume 1 page 35)

We will therefore treat the data with care when comparison is made in our analysis.

3.7. Analysis

Wherever there is a hypothesis to test it may be relevant to use some statistical test. However, most of the data is nominal (in categories) and so does not support high powered statistics. Survey data in the medical field – ie such as HSE, does not usually provide statistical tests for all findings nor to support the tables it presents. Descriptive statistics are used to illustrate the main points and to highlight changes over time and according to selected variables.

Wherever it is possible to source original "normative" data, we have applied simple statistical tests which indicate similarities and difference in distribution. This usually means the use of Chi squared tests to determine patterns within the Deaf group and to examine differences between the data from the Deaf and hearing populations. In many cases, we did not have ready access to the raw data of the large scale surveys and have had to work back from percentage tables to create raw numbers which can be used in the analysis. There are many rounding "errors" which occur in this process and therefore, quoted figures may not always correspond exactly to the data if generated from the original data sets. It will be possible at a future time, to work with the UK Data Service, to extract more precise comparative data and to consider more effective statistical analysis. However, this will be usually when a very specific question needs to be asked rather than to provide a global picture of health as was required in this study.

4. Results

4.1. Details of the Deaf participants

In total 301 Deaf sign language users responded to the request to attend for health assessments at Bupa centres in Bristol, London, Brighton, Solihull, Cardiff, Manchester and Glasgow. Three people did not complete the health assessments due to a range of factors, such as lateness of arrival. Primary data analysis focused on 298 participants. There were minor variations in the completeness of the records and the analysis has been carried out on all appropriate cases – base numbers are shown where relevant.

The demographic data show that the sampled population is close to what was planned (Table 4.1). There were very few respondents to the Sign Health online survey in the youngest age group and this is also seen in the Bupa test participants.

People in middle age from 45 to 64 years were over-represented in the sample (41% of the sample as compared to 35% of the general population).

Table 4.1 Basic sampling variables (n=298)

		Study sample number	Target number by UK census	% in study	% in SignHealth online survey	(national stats) %
Age	18-24 yrs	8	36	3	5	9
	25-44yrs	113	105	38	46	40
	45-64 yrs	122	96	41	40	35
	65-82 yrs	55	63	18	9	16
Gender	Male	139	150	47	43	49
	Female	159	150	53	57	51
Ethnicity	White	261	264	89	87	88
	Black and Minority Ethnic Groups	35	36	12	13	12

The ethnic mix in the sample matches the other surveys of the UK population.

Compared to the Census 2011 (for England and Wales) there is a slight imbalance of too many females among the participants (53% versus 51%) and this is most marked proportionately in the middle-aged group (too many) and in the elderly group (too few) (Table 4.2). Note however, that large scale health studies such as the GP Patient Survey (GPPS) often have more female respondents than males (GPPS, 2013 has 57% female respondents).

Table 4.2: Age group and Gender (% in each age grouping)

	18-24	25-44	45-64	65+
Males	3	39	33	25
Females	3	37	48	13
Census 2011 – England & Wales MALES	9	37	35	18
Census 2011 – England & Wales FEMALES	9	36	34	20

Despite these variations, we believe the sample is typical of what might be expected of the sign language using Deaf community, when approached in the way we have done. Younger Deaf people are less accessible and less involved in the community activities; males are less likely to engage with health issues.

4.2. Geographical distribution

The reporting of postcodes of the participants was not complete but Figure 4.1 provides an indication of the distribution from the 230 postcodes provided.

Health assessments were carried out in eight sites: Glasgow, Manchester, Solihull, Nottingham, Brighton, Bristol, Cardiff and London. Potential participants were invited to the centre closest to their homes.

Figure 4.1: Location of the participants.
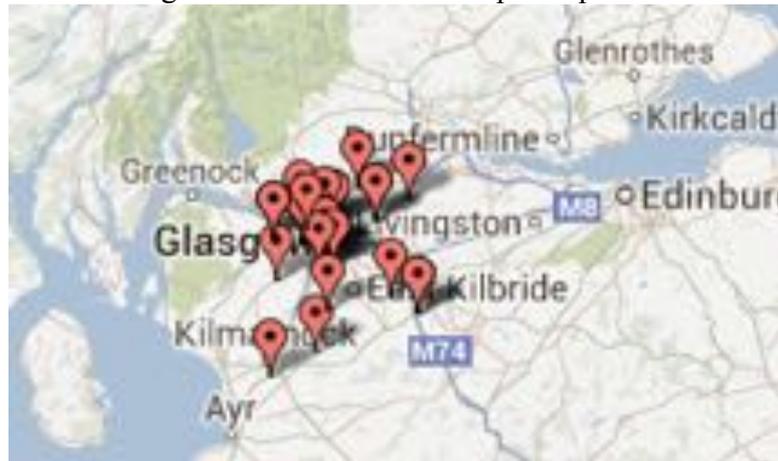
3. Self report of health issues

Participants were asked about a list of health problems in their medical history. Table 4.3 shows a list of medical conditions, and the percentages of participants who reported the condition as part of their medical history. The results from the NHS Quality Outcomes Framework (QOF) for England are provided as a comparator with the general population.

Table 4.3: % of Deaf participants who self-report health problems, by gender

	% who self-report this problem [b]	M	F	Sign Health online survey (2013)	QOF 2012
"Do you have any of the following problems?"					
Raised blood pressure (hypertension)	23	22	23	3	14
Angina	2	1	3	*	
Heart Failure	1	1	2	*	1
Atrial fibrillation (AF)	3	2	4	*	2
Diabetes	6	7	6	4	6
Asthma	16	15	16	3	6
Chronic Obstructive Pulmonary Disease (COPD)	0	1	0	2	2
Underactive thyroid (hypothyroidism)	5	4	6	3	3
Chronic Kidney Disease (CKD)	1	0	1	*	4
Rheumatoid arthritis[a]	9	8	9	1	*
Problems with eyesight (other than needing glasses)	14	14	14	*	*
Physical disability	7	6	8	*	*
Epilepsy	4	5	3	1	1
Depression	23	14	31	*	12
Schizophrenia	<1	1	0	*	*
Bipolar disorder	1	1	1	*	*
Other psychoses	<1	1	0	*	*
Dementia	<1	1	0	*	1
"In the past, have you had any of these medical problems?"					
Stroke	1	1	2	*	1
Heart Attack	3	2	3	*	*
Cancer	6	4	7	3	2

[a] it was suspected that participants took this to mean all forms of arthritis

[b] this self report is taken to mean the reporting of a doctor-diagnosed problem – not a self-diagnosis

* data not available

Compared to the QOF, the Deaf participants reported increased percentages of high blood pressure, asthma, epilepsy and depression. The raised percentage of reported cancer should be interpreted with caution as it is based on relatively small numbers. The only major gender difference is in the reported history of depression. These data are self-reported but the expectation is that they are not self—diagnoses but rather reflect what the doctor has said. They are comparable to the data produced by the Health Survey of England where reports of this nature are termed "doctor-diagnosed".

Problems with eyesight reported at 14% is very high. There are only 0.6% of the population registered as blind or partially sighted and even the high estimate of the RNIB (https://www.rnib.org.uk/aboutus/research/statistics/Pages/statistics.aspx) of 2 million with sight problems, represents only approximately 3% of the population. There are particularly conditions where both sight and hearing would be affected but without this data on the sample in this study, we are not able to analyse this further.

Table 4.4 (%) of sample self-reporting health problems, by age

	18–44 yrs	45-64 yrs	65 yrs +
"Do you have any of the following problems?"			
Raised blood pressure (hypertension)	7	26	53
Angina	0	3	5
Heart Failure	<1	2	2
Atrial fibrillation (AF) *	<1	6	2
Diabetes	3	13	5
Asthma	18	13	15
Chronic Obstructive Pulmonary Disease (COPD)	0	0	2
Underactive thyroid (hypothyroidism)	6	3	5
Chronic Kidney Disease (CKD)	1	1	0
Rheumatoid arthritis *	4	10	18
Problems with eyesight (other than glasses)	11	17	16
Physical disability	3	12	2
Epilepsy	6	3	0
Depression	20	25	25
Schizophrenia	<1	0	0
Bipolar disorder	<1	<1	0
Other psychoses	1	0	0
Dementia	0	0	2
"In the past, have you had any of these medical problems?"			
Stroke	1	2	0
Heart Attack	2	2	5
Cancer	2	8	13

* we consider these data points to be les reliable as the concept AF may have been misunderstood and the "Rheumatoid arthritis " taken to mean all arthritis.

As expected, the Deaf sample reported gradual increases in chronic health problems with age. Interestingly, depression is widely reported in all age groups.

There was a high percentage of Deaf participants reporting a family history of premature heart problems (at less than 60 years of age): there appears to be a high

prevalence of this history in the Deaf sample: 26% (25-44 yrs); 33% (45-64 yrs), only 16% (65 yrs +). It is hard to tell how this relates to figures for the prevalence of family members with heart problems in the hearing population (since the data which is reported in the health statistics is the measurements of risk taken from those who have already developed heart problems themselves). Also given the nature of family relations, Deaf people in a hearing family will often not have access to information such as causes of illness and symptoms, in other members of the family.

Of the 17 people who had had cancer, 15 had been treated by surgery; 5 had had radiotherapy; 4 had chemotherapy.

Of 113 (38%) people who said they had had an operation in the last ten years, 70 (62%) said the experience was a good one. This may say more about expectations and health outcomes than the treatment itself.

3.4.   Prevention and Screening

We asked participants if the had certain preventative treatment or screening. The first of these was for the prevention of flu (Table 4.5).

Table 4.5: Have you had a flu jab in the last 12 months? (n=295)

	No	Yes	Not sure	n=
20-44 yrs	73.3	23.3	2.5	120
45-64 yrs	62.5	37.5		120
65-82 yrs	12.7	87.3		55
All ages	57.6	41.0	0.3	

The key figure here is the percentage of people over the age of 65 years. These Deaf participants are more likely to have the flu jab than the general population (87% compared to 74.0% - for the winter 2011-12, http://webarchive.nationalarchives.gov.uk/20130107105354/https://www.wp.dh.gov.uk/immunisation/files/2012/06/Flu-vaccine-uptake-A-Z_SHA-PCT_2012_acc.pdf). For those under the age of 65 years, the general population data concerns those deemed to be at risk (where the uptake is 51.6%). It would seem likely that some Deaf participants are considered at risk (but clearly this does not apply to all). Of those in the 45 – 64 years group, 37.5% had had a flu jab.

We asked about bowel cancer screening. This is now another national priority with postal kits sent directly to those over the age of 60 years.   Of those over the age of 65 years, 61.1% report having had a bowel cancer screening while 21% of those aged 45-64 years report this. So far, the extent of take-up of bowel cancer screening appears not to be published in the general population data.

In the case of female participants we asked about cervical smear; 67% reported they had had a smear in the last three years. The other participants gave dates of last smear as far back as 1983 (this includes those now over 65 years who would no longer attend for a screen). Figure 4.2 shows the data for those Deaf women under 65 years of age where 76% reported a smear in the last three years. National figures have a target of cervical screening of 80% in the last five years. The data reported suggests 78.6% has been achieved (http://www.cancerscreening.nhs.uk/cervical/about-cervical-screening.html). The figure for the Deaf women over last five years is 87.7%, indicating a good level of take-up.

Figure 4.2: When did you last have a cervical smear? (Deaf Women 25-64 yrs, n = 114)
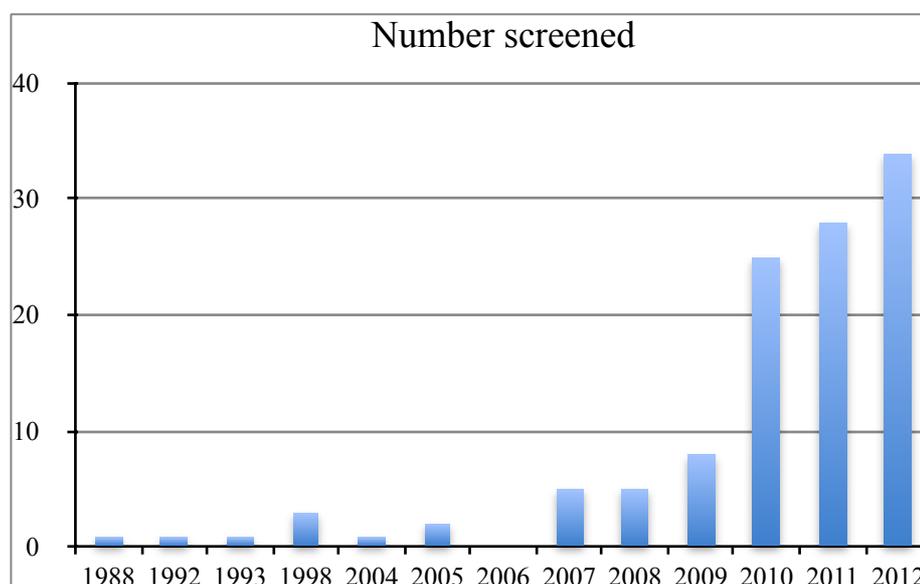
We asked also about last mammogram. The target in England is for all women to be invited for mammogram between the ages of 50 and 70 years. Reported success rate is 76.9% in 2010 (http://www.nhs.uk/Conditions/Cancer-of-the-breast-female/Documents/Breast%20screening%20data%2053-70%202010.pdf)

Since the programme is a rolling one, some women are not invited until the age of 53 years. If we exclude those who have not attended in the age range of 50 to 52 years, we find a success rate for Deaf women of 76.3%, which is very close to the national average.

It seems that Deaf people are being included in these national campaigns. This may be due to the Deaf Women's Health Campaign, which was a grass roots development engaging Deaf women and organised by Deaf women. It is somewhat in decline at this time, but there is almost certainly an impact on the level of awareness of this major screening and prevention opportunities.

3.5. Prescribed drugs

We asked participants to bring details of the medication they were taking at this time (or even to bring the bottles or packets for the health adviser to inspect). Table 4.5 shows the medication reported to be used regularly by participants (many said they "did not know" when asked by the Bupa health adviser).

Table 4.6: Drugs reported in use (% reporting this drug)

Treatment	% reporting this medication	n=	Typical purpose
statin	14.7	299	Reduce cholesterol
aspirin	12.9	239	Primary or secondary prevention of cardiovascular disease
beta blocker	5.6	230	Anti-hypertensive Reduce blood pressure
ace inhibitor	6.5	230	Anti-hypertensive and/or secondary prevention of stroke and/or treatment of chronic kidney disease
thyroxine	6.7	299	Treatment of hypothyroidism
diuretic	6.0	301	Heart failure, Antihypertensive,
paracetamol	5.7	299	Analgesic
ssri	4.0	299	Anti-depressant
NSAID	4.7	299	Analgesic
metformin	3.3	299	Oral hypoglycaemic for treatment of diabetes
calcium channel blockers	3.3	301	Anti-hypertensive
Angiotensin II Receptor Blockers	3.4	299	Anti-hypertensive and/or treatment of chronic kidney

These medication statistics overlap because participants may have more than one treatment. Medication prescribed in regard to certain reported conditions eg depression, seem to be less common than might be expected if the conditions had been doctor-diagnosed. This may mean that medication is not reported by the Deaf participant; or that the self report is not supported by clinical opinion (ie it was not doctor–diagnosed – this seems less likely); or the opposite, (eg in the case of depression) that the clinician does not recognise these symptoms as sufficiently distinct from their expectations of well-being for those with hearing loss. It may be that the doctor works on the assumption that the norm for a Deaf person is to be unwell – in this case, depressed.

None of the participants reported taking medication in regard to obesity.

3.6. Medical assessment

Two hundred and ninety eight participants completed the Bupa health assessments, which took approximately one hour each. The assessment included the fasting blood test; the participant was interviewed by the Bupa health adviser and then physical measurements (height, weight, body fat, blood pressure) were made. The results are grouped together by condition, and examined in greater detail in the following chapters.

5. Obesity

At the Bupa centres, as well as the health interviews, schedule of simple health indicator tests was carried out. A BSL interpreter was present throughout.

5.1. Height of the participants

All participants had height and weight measured. Table 5.1 shows the height of participants of different ages and gender).

Table 5.1 Height of the participants (metres) by age and gender (mean, standard deviation)(n=298)

	18-24 yrs	25-44 yrs	45-64 yrs	65-82 yrs	Mean
Males	1.75(0.08)	1.75 (0.07)	1.75 (0.07)	1.71 (0.06)	1.74 (0.07)
Females	1.70(0.04)	1.63(0.07)	1.62 (0.07)	1.59(0.06)	1.62 (0.07)
Overall	1.72 (0.06)	1.69 (0.09)	1.67 (0.09)	1.67 (0.08)	1.68 (0.09)

There is a marginal decline in height with age which is comparable to the general population. Men's height was less than the general population (1.74 compared to 1.75) although the Deaf women were taller (1.63 compared to 1.62). These differences look small and may be accounted for by the different age profiles of the groups. There is no support for the notion that Deaf people might be of different stature to that of the general population.

5.2. BMI data

BMI (wt/ht^2) was calculated.

Body Mass Index is a simple measure used to indicate whether someone is of a healthy weight for their height. International guidelines for adults define overweight as BMI >25-30 and obese as BMI > 30.

Table 5.2 shows the baseline body-mass index groupings for the participants.

Table 5.2: Body Mass Index by Gender (% of cases) (n=295)

	Underweight <20	Desirable 20-25	Overweight 26-30	Moderate obesity 31-40	Severe obesity 41+	n=
Male	1	28	45	26	1	139
Female	1	28	37	29	5	159
Overall	1	28	40	28	3	298

The figures suggest 71% of the Deaf participants are overweight and over 30% are clinically obese. In comparison, in the general population, 65% of men and 58% of women are overweight while 24% of men and 26% of women are obese (National Obesity Observatory – reporting Health Survey of England Data). The overall difference between Deaf people and the Health Survey of England is highly significant (chisquare=23.5, df=2, p<.001).

Figure 5.1 shows the data taken from the Health Survey of England 2011 (http://www.hscic.gov.uk/catalogue/PUB09300) and this confirms a different gender distribution in the general population with men more likely to be overweight than women.

Figure 5.1: Obesity in England (2011)
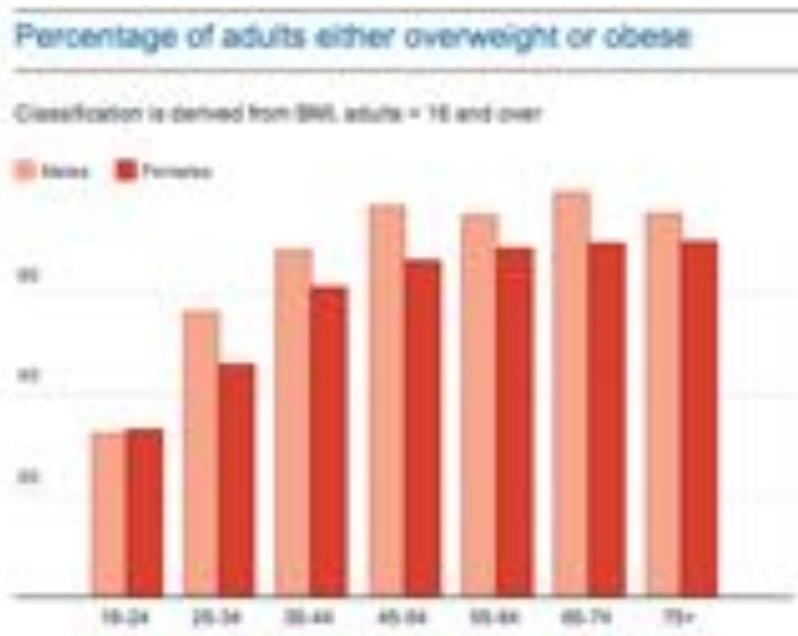
In the HSE dataset, 65% of men and 58% of women were overweight or obese while the corresponding figures for Deaf participants were 72% and 71%. Mean BMI for men in HSE was 27.2; for women 27.1. In the Deaf group, men's mean BMI was 28.1 and women 29.3.

Deaf women seem to have a greater problem of obesity relative to Deaf men than hearing women do relative to hearing men. However, the difference between Deaf men and Deaf women is not significant on this sample size.

As in the general population, BMI tended to increase with age, particularly in those over 65 years old (Table 5.3).

Table 5.3: Body Mass Index by age (% of cases) (n= 288)

	Underweight <20	Desirable 20-25	Overweight 26-30	Moderate obesity 31-40	Severe obesity 41+	n=
25-44 yrs	1	33	45	21	1	113
45-64 yrs	0	31	31	34	4	121
65 yrs +	0	10	56	31	4	53

Although there is a general increase in weight by age in the general population, this group of Deaf participants are heavier than the general population.

There are differences in terms of where the person lives. This may correlate with the HSE findings that greater deprivation is linked to greater incidence of obesity. Table 5.4 shows the distribution of BMI by region. The highest levels of overweight and obesity were seen in those Deaf participants from the Midlands and the North of England.

Table 5.4: BMI levels (% in each category) by region

	Underweight/ Desirable 20-25	*Overweight 26-30*	*Moderate obesity 31-40*	*Severe obesity 41+*	*n=*
London &South	33.0	45.0	18.0	2.0	100
West & Wales	29.0	37.1	30.7	3.2	62
Midlands	14.6	34.6	47.3	3.6	55
North	17.1	48.8	29.3	4.9	41
Glasgow	46.0	24.3	24.3	5.4	37

This can be made simpler to show the statistically significant differences. There appears to be a greater problem of obesity in Deaf people living in the north. There is no obvious reason for the lower BMI figures for the Glasgow group – there appears to be a larger group in the BMI-desirable category.

Table 5.5: North South divide in BMI (%)
(Chisquare=7.1, df=1, p<.005)

	Desirable weight to overweight	Obesity & severe obesity	n=
London-South	74.7	25.3	162
Midlands, North & Scotland	60.2	39.9	133

The obesity trends are also reflected in the results of the body fat analysis. Table 5.6 shows the categorisation of the sample by percentage body fat.

Table 5.6:   Distribution of percentage of sample in Body Fat categories (n=295)

Below Average	Desirable	Above average	High
6.2	7.6	36.7	49.5

This is probably consistent with the findings in regard to body mass index and seems to suggest a general problem among Deaf people. Tables 5.7 and 5.8 show the percentage of the Deaf participants in each body fat category, by gender and age.

Table 5.7:   Distribution (% of sample) in Body Fat categories by gender (n=289)

	Below Average	Desirable	Above average	High	n=
Male	13.2	14.7	57.4	14.7	136
Female	0	1.3	18.3	80.4	153

There seems to be a significant problem for Deaf women on this measure (chisquare=122.6, df=3,p<.001).

Table 5.8: Distribution (% of sample) in Body Fat categories by age (n=295)

	Below Average	Desirable	Above average	High
18-24 yrs	14.3	28.6	57.1	0
25-44 yrs	10.3	11.2	41.1	37.4
45- 64 yrs	4.2	6.8	24.6	64.4
65 yrs +	0	0	53.9	46.2

There does seem to be a specific and different problem for Deaf participants in regard to weight. Although the general population is often described as having an 'epidemic' of obesity it seems that this Deaf group are experiencing this to a greater extent.

5.3. Alternatives/Additions to BMI

There are various alternatives to the measurement of BMI and these are currently discussed in the literature. The HSE 2011 considers waist circumference as a significant additional measurement (p 330).

The 2006 NICE evidence-based guidelines include details on prevention, identification, assessment and management of overweight and obesity, with one aim being to increase health professionals' awareness of how to manage overweight and obesity in primary care.[2] The guidelines highlight the impact of overweight and obesity on risk factors for developing other long-term health problems such as coronary heart disease, Type 2 diabetes, osteoarthritis and some cancers. It states that risk of these co-morbidities should be identified using both BMI and waist circumference as assessment tools in those with a BMI less than $35kg/m^2$. …… The NICE categories are defined as follows:

Table 10B			
BMI classification	Waist circumference		
	Low	High	Very high
Normal weight (18.5 to less than 25kg/m²)	No increased risk	No increased risk	Increased risk
Overweight (25 to less than 30kg/m²)	No increased risk	Increased risk	High risk
Obesity I (30 to less than 35kg/m²)	Increased risk	High risk	Very high risk
Obesity II (35 to less than 40kg/m²)	Very high risk	Very high risk	Very high risk
Obesity III (40kg/m² or more)	Very high risk	Very high risk	Very high risk

National Institute for Health and Clinical Excellence. *Obesity: guidance on the prevention, identification, assessment and management of overweight and obesity in adults and children*. NICE, London, 2006. [On-line] www.nice.org.uk/guidance/CG43 page 4 (Accessed 20/08/2012).

For men, low waist circumference in this classification is defined as less than 94cm, high as 94–102cm, and very high as greater than 102cm. For women, low waist circumference is less than 80cm, high is 80–88cm and very high is greater than 88cm.

We examined waist circumference (Table 5.9).

Table 5.9: Distribution (% of sample) in waist circumference categories by gender (n=288)

	Low	High	Very High	n=
Male	41.9	22.1	36.0	136
Female	24.3	20.4	55.3	152
Overall Deaf	32.6	21.2	46.2	

Mean waist circumference for Deaf males was 97.9 cm (SE 1.1) and for Deaf females was 92.6 cm (SE 1.1). This compares to 97.1 (SE 0.38) and 88.5cm (SE 0.38) for the general population (HSE 2011). The raised waist circumference for Deaf males and females was 57.1% and 75.7% respectively as compared to 34% and 47% for the HSE. These differences are highly significant (for males: chisquare=9.7, df=1, P<.01; for females: chisquare=47.6, df=1, p<.001)) That is,

Deaf people have significantly higher risk of illness (coronary heart disease, Type 2 diabetes, osteoarthritis and some cancers - according to NICE, 2006) - as can be seen in Table 5.10 which reflects the NICE categories above.

Table 5.10: Risk estimates from BMI and Waist Circumference (risk adapted from the NICE, 2006 predictions) - % of the Deaf sample in each risk category (n=288)

BMI	Low Waist Circumference	High Waist circumference	Very High Waist Circumference
Underweight/ Desirable 20-25	**23** No increased risk	**6** No increased risk	**1** increased risk
Overweight 26-30	**9** No increased risk	**13** increased risk	**18** high risk
Moderate obesity 31-40	**1** increased to very high risk	**2** high to very high risk	**26** very high risk
Severe obesity 41+			**2** very high risk

The BMI categories in this study do not match the NICE categories exactly but the pattern is clear. At least 48% of Deaf people would be placed in the "high to very high risk" category as a result of their BMI and waist circumference measurements. Twenty-eight percent alone are in the "very high risk" category.

The statistics tend to point in the same direction. Although we can see that there is an enormous social problem in regard to obesity, Deaf people have this problem to a greater extent. It is also to be noted that Deaf women experience the problem more than Deaf men – which is the opposite of the population as a whole. According to NICE, these results should be triggering concern and should produce action among health practitioners, to deal with the problem.

6. Hypertension

1. Blood Pressure Data

Measurements were made of the resting blood pressure of the participants. We classified these using the BHS guidelines 2004 as: low-normal (systolic<120: diastolic<80); high normal (120-139; 80-89), mild hypertension (140-159; 90-99) and moderate-severe hypertension (160+; 100+). In fourteen cases, data were not available.

Compared to data from the Health Survey of England (2011) where they term the groups as "hypertensive uncontrolled and untreated"), Deaf participants are much more likely to have hypertension (ie in the mild-moderate-severe classification (Table 6.1) than the general population (chisquare=6.9, df=1, p<0.01).

Table 6.1: Comparison (%) of Measured Blood Pressure, by gender (Deaf n=287; HSE 4,753)

	mild-moderate-severe hypertension	
	Deaf	HSE (2011)
Males	41.7	20
Females	32.2	17
Overall	36.6	18

Table 6.2 shows the percentage of participants in each classification, by gender, and Table 6.3 by age.

Table 6.2: Distribution (%) of Measured Blood Pressure, by gender (n=287)

	low-normal	high normal	mild hypertension	moderate to severe hypertension	n=
Males	10.6	47.7	25.8	15.9	132
Females	29.7	38.1	24.5	7.7	155
Overall	20.9	42.5	25.1	11.5	

Table 6.3: Distribution (%) of Measured Blood Pressure, by age (n=287)

	low-normal	high normal	mild hypertension	moderate to severe hypertension	n=
20-44 yrs	28.8	51.7	15.3	4.2	118
45-64 yrs	19.3	38.7	30.3	11.7	119
65 -82 yrs	6.0	30.0	36.0	28.0	50
All ages	20.9	42.5	25.1	11.5	

As in the general population (Table 6.4), blood pressure rises with age in the Deaf community. However, there is clearly a much greater problem for Deaf people in each age group.

Table 6.4: Comparison with Health Survey of England for measured mild & moderate-severe hypertension by age (% with this measured level) (Deaf n=284: HSE 2011 n=4,362)

	Deaf	HSE 2011
20-44 yrs	19.5	11.5
45-64 yrs	42.0	23.7
65 -82 yrs	64.0	36.7
All ages	36.6	21.1

Moderate-severe hypertension is significantly more common in Deaf men (15.9%) than in Deaf women (7.7%) (chisquare = 18.1, df=3, p<.001).

As reported in the HSE2011, there are also differences in measured blood pressure between the geographical regions where participants live (Table 6.5). Such differences may relate to socioeconomic factors and health care provision.

Table 6.5: Distribution (%) of Blood Pressure, by location of testing (n=287)

	low-normal	high normal	mild hypertension	moderate-severe	n=
London-South	25.8	47.3	16.1	10.8	93
West & Wales	30.2	39.7	20.6	9.5	63
Midlands	11.3	37.7	39.6	11.3	53
North	14.6	34.2	31.7	19.5	41
Glasgow	13.5	51.4	27.0	8.1	37

The pattern is statistically significant and if we simplify this table, we can see clearly that Deaf participants in the South have consistently lower blood pressure readings than those in the North.

Table 6.6: North South Divide and measured blood pressure %
(Chi square=10.3, df=1, p<.001)

	Low-normal/high-normal	mild hypertension/ moderate-severe hypertension	n=
South	71.8	28.2	156
Midlands, North & Scotland	53.4	46.6	131

One of the most important issues for hypertension is whether it is diagnosed and treated. In tables 6.7 and 6.8 we consider whether participants are aware of/have had diagnosed, their hypertension. Clearly some people having been diagnosed, will now have their hypertension controlled. Large numbers of others remain unaware of the issue.

Table 6.7: Comparison of measured BP categories with Knowledge of BP categories (showing the row%)(n=283)

Measured Hypertension	No	Yes	Don't know	
		Self report of raised blood pressure		
Low normal	86.7	10.0	3.3	100% n=60
high normal	74.8	15.1	10.1	100% n=119
mild hypertension	65.3	31.9	2.8	100% n=72
moderate-severe	34.4	50.0	15.6	100% n=32

Table 6.8: Comparison of measured BP categories with Knowledge of BP categories (showing the column %)

Measured Hypertension	Self report of raised blood pressure		
	No problem	Yes – raised BP	Don't know
Low normal	26.1	9.5	9.5
high normal	44.7	28.6	57.1
mild hypertension	23.6	36.5	9.5
moderate-severe	5.5	25.4	23.8
	100% n=199	100% n=63	100% n=21

Twenty-three percent of participants (based on n=294) self reported that they had hypertension (Table 4.3). Thirty-eight percent of these (based on n=283) now were measured with normal levels (ie were controlled). The remainder (62% of those who were aware that they had diagnosed hypertension) still appeared to have (mild-moderate-severe) hypertension (Table 6.8).

Of those with moderate-severe hypertension, only 50% said that (were aware that) they had high blood pressure (Table 6.7). That is, 50% of those with moderate-severe hypertension are un-diagnosed cases. Of those with mild hypertension only 36.5% knew that they had hypertension. This means that 63.5% of those with mild hypertension are un-diagnosed.

Data from the USA, suggests that it is common for people with hypertension to be unaware of their condition (although many fewer Deaf people are aware of their hypertension):

"In the United States, about 77.9 million (1 out of every 3) adults have high blood pressure.
Data from NHANES 2007–10 showed that of those with high blood pressure, - 81.5 percent are aware they have it

- 74.9 percent are under current treatment
- 52.5 percent have it controlled
- 47.5 percent do not have it controlled " American Heart Association 2013
(http://www.heart.org/idc/groups/heart-public/@wcm/@sop/@smd/documents/
downloadable/ucm_319587.pdf)

However it seems that a much higher percentage of Deaf people (than hearing people) are unaware of their raised blood pressure. Of those who believe they do not have a problem of high blood pressure, 29.1% *do* have mild to severe hypertension (Table 6.8).

These statistics indicate clearly that Deaf people are less aware of their problems of hypertension than other national surveys indicate for the general population.

HSE 2011 additionally offers three measures:

- "detection rate" (those with survey defined hypertension (also includes controlled) who also self-report it);

- "treatment rate (those who self report hypertension and also report having treatment) and

- the "control rate" (those who have treatment and their blood pressure measurement is reduced to less than 140/90).

The *detection* rates are reported as 61% (male) and 66% (female). We take this to mean the ratio of controlled HT plus the uncontrolled HT divided by all identified HT. The corresponding figures for Deaf people are 44% (male) and 54% (female) ie much lower. The comparison is not perfect as HSE excluded younger women (<34 years) from their calculations. Where we re-calculate the percentages from re-created raw scores (HSE 2011, Table 3.12), the figures are reduced to 58% and 59% respectively. The differences between Deaf males and men in the population is significant with chisquare (5.16, df=1, p<.05). The difference between Deaf females and hearing females on the second calculation is not significant.

We asked about the medication which people were taking for hypertension. The data are somewhat affected by the fact that there are incomplete records (21%) when asked about type of medication. However we also asked the participants to bring a list of the drugs and/or for the person to bring their drugs with them; we have recorded these separately. The analysis is further complicated as a result of people forgetting which medication they took and not bringing details with them.

Of those (104 people in total) who appeared to have high or very high blood pressure –only 9 out of 79 (11% of those reporting both data points) were taking ACE inhibitors; of those who *were* taking ACE inhibitors (only 15 people), only one has the desirable measured blood pressure. In a further analysis, of 15 people prescribed ACE inhibitors, 11 reported that they thought they had a problem of hypertension. However, 14 out of the 15, still measured as having high blood pressure.

Of those with high or very high blood pressure (79), 6 are taking beta blockers. Of those who are taking beta blockers (in total, 13), only 2 have the desirable measured blood pressure. Of 13 people who were prescribed beta blockers, only 6 reported that they had hypertension (implying that over half were not aware of the reason for taking this drug). Of those 13, taking beta blockers, 5 still had high blood pressure when measured.

We have worked on this further and using personal accounts and lists of medication which people brought with them have identified all those where at least one medication for hypertension was discovered. We included beta blocker, ace inhibitor, calcium channel blockers, Angiotensin II Receptor Blockers and diuretic. We considered whether Deaf participants were aware of the treatment/medication they were receiving. Six percent of those who said they had no hypertension were receiving medication, which could have been associated with reducing hypertension. Of those who said they did not know a similar 5% were receiving some medication. However, of those who said they did have hypertension, only 51% were receiving medication to reduce their hypertension.

If we use the recorded presence of medication, as the indicator of treatment then the treatment rate changes to 36% overall (32% male and 40% female) compared to the HSE2011 which has males at 54% and females at 59%. The difference is significant for males (chisquare=10.9, df 1, p<.001) and for females (chisquare=8.4, df=1, p<.001)

The detection and treatment rates are lower for Deaf people.

We have examined these figures in comparison to those reported in the HSE (2011).

Hypertension is defined as the presence of persistently raised blood pressure, measuring 140/90mmHg or above…¨ hypertension is common in England. In 2009, 23% of HSE participants reported doctor-diagnosed hypertension and 29% had survey-defined hypertension – page 64

The comparative figures in this study for Deaf people are 22% self-reported (doctor-diagnosed) and 37% for measured hypertension (but this latter figure does not include those whose hypertension is controlled which would add probably nearly 10% to this measured figure).

The rate of routine detection and treatment is much lower among Deaf people than among the general population.

The QOF measure of hypertension is the percentage of patients with hypertension in whom the last blood pressure (measured in the preceding 9 months) is 150/90 or less (i.e. QOF BP5, which was 79.7% for 2011-12). This is a different classification to that of HSE and most publications. Among those Deaf people apparently receiving treatment for hypertension (based on the above medication) ,

only 42% had reduced levels at 140/90 or less – the control rate. This is contrasted with the HSE2011 which suggests 62% control rate for hypertension in the general population.

The overall pattern for Deaf people points to much higher rates of hypertension than in the general population. There is more undetected hypertension and more diagnosed but uncontrolled hypertension.

7. Lipid Profile and Cardiovascular Risk

We considered the presence of cardiovascular disease (CVD) as the self–report of any one or more of the following: angina, heart failure, heart attack, stroke and atrial fibrillation. This is consistent with the definition used in the HSE 2011 for doctor-diagnosed CVD. In the HSE 2011, the participants were asked to self-report the presence of the problem and whether the doctor had confirmed this. However, they also point out the difficulty in this form of self-reporting.

> It is important to note that no attempt was made to verify these self-reported diagnoses objectively. There is, therefore, the possibility that some misclassification may have occurred because some participants may not have remembered (or not remembered correctly) the diagnosis made by their doctor. HSE2011, p 24

In our study, we asked Deaf people the same question although we did not specifically confirm with them that the information on this had come from the doctor. Since the rationale for the study has been that Deaf people's access to health care is compromised by communication, it would not seem to be a very useful measure to try to confirm with the interviewee, that "the doctor had said this" – since many people do not know what the doctor says. It seems unlikely that a Deaf person would simply make up the diagnosis; however, clearly there is a possibility that the Deaf people will under-report the doctor diagnosis. On first inspection it does seem like this might be the case. Report of CVD is significantly less among Deaf than for the general population (chisquare=7.8, df=1, p<.01). However, as we will see, the measured cholesterol levels are consistent with this lower prevalence.

Table 7.1: Self-reported cardiovascular disease (CVD) for those aged 25 – 84 years (%) (n=288; HSE2011 n=8,380[3])

	Deaf Self report CVD	HSE self-report ('doctor diagnosed') CVD
Male	3.7	12.7
Female	10.7	13.1
All	7.4	13.0

There appears to be considerably less report of CVD among Deaf participants than self-reported CVD among the population as a whole. There is also variation by age and by geography.

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[3] Data adjusted from HSE2011, to exclude 85 years +.

Table 7.2: Age and CVD (%) (Deaf n=288, HSE2011 n=8,380)

	Deaf Self report CVD	HSE self-report ('doctor diagnosed') CVD
25-44 yrs	1.7	5.3
45-64 yrs	11.5	14.1
65-82 yrs	11.1	26.2

Table 7.3: Geographical location and CVD (%) (Deaf n=288, HSE n=7,526-estimates)

	Deaf Self report CVD	Estimate of HSE self-report ('doctor diagnosed') CVD)
London-South	7.0	~ 14
West & Wales	11.1	~ 18
Midlands	1.8	~ 16
North	9.8	~ 20
Glasgow	8.1	n/a

In this sample of Deaf participants there is a consistently lower report of cardiovascular problems although we must be careful as the actual numbers reporting are small.

As in the case of hypertension treatment, there is a difference between the numbers of people reporting that they have CVD and the numbers who are on a treatment regime which would be consistent with CVD. Numbers are small.

However, 22 people said they had CVD while 36 people were taking aspirin or clopidogrel. However, of those who said they had no CVD, 11% were taking aspirin or clopidogrel; of those who said they did have CVD, only 45% were taking aspirin or clopidogrel.

The HSE2011 is hard to integrate here as they exclude younger people and the data for females is treated as unreliable. For men, aged 55-84 years, the treatment rate for ischaemic heart disease and stroke was between 61% and 70%; for Deaf men aged 45-84 years, the treatment rate for all CVD was 45%.

The baseline figure for CVD then changes (if we assume that these treatments are directed at doctor diagnosed CVD) – 14% of Deaf people were taking clopidogrel or aspirin – ie treatment consistent with the presence of CVD.

7.1. Cholesterol data

Cholesterol is a fatty substance (a lipid) which is vital for the normal functioning of the body. The liver produces this substance but is also to be found in foods that people eat. If there is an excessively high level of lipids in a person's blood there

may be an effect on health. There is no obvious symptom of high cholesterol but there is an increased risk of vascular disease, in particular coronary artery narrowing leading to heart attacks.

It is often suggested that fasting is necessary before taking blood samples but some recent work in America (Sidhu and Naugler, 2012) suggests the impact of not fasting may not be great on community studies such as this (although there may be some individual effects depending on other drugs being taken, for example). For the Deaf participants, it has been difficult to establish the extent to which they had fasted. Even with reminders on what to take prior to the tests, individuals forgot or ignored instructions. Asking whether they had fasted produced potentially unreliable responses as people listed different foods but without establishing the time when the foods were taken – nor the time when the blood sample was taken. We have analysed the participants' results as is, without being absolutely certain of the extent of fasting prior to testing.

The mean level of cholesterol in both male and female Deaf participants (4.6 mmol/L and 4.5 mmol/L respectively) was lower than in the HSE (5.1mmol/L and 5.2 mmol/L respectively). The distribution of cholesterol levels is shown in Table 7.4 with levels above 5 mmol/L being considered to be elevated.

Table 7.4: Distribution (%) of total cholesterol levels, by gender (n=274)

	desirable cholesterol (≤5mmol/L)	elevated cholesterol	HSE 2011 elevated cholesterol
Men	77.5	22.4	56
Women	58.6	41.3	57
Overall	67.5	32.4	57

Women seem to have a greater problem with high cholesterol although overall levels are considerably less than in the HSE 2011.

As we have seen already there appear to be differences in most health measures according to where the person lives.

Table 7.5: Distribution (%) of total cholesterol levels, by geographical region

	desirable cholesterol (≤5mmol/L)	elevated cholesterol	n=
London & South	60.6	39.4	99
West & Wales	62.9	37.1	62
Midlands	82.1	18.0	39
North	86.5	13.5	37
Glasgow	59.5	40.5	37

Cholesterol levels appear to be higher in the South and in Scotland.
The HSE 2011 considered the effect of taking lipid-lowering drugs (LLD), such as statins on the measured level of cholesterol. There was a clear reduction for men and especially for those who had reported CVD. This was also seen among the Deaf participants (although numbers are relatively small).

Table 7.6: Cholesterol average (mmol/L) for CVD participants and those taking statins (n in brackets)

	No CVD reported	With CVD	total
No statins	4.7 (237)	5.0 (11)	4.69
Statins prescribed	3.7 (31)	4.0 (11)	3.80
Overall	4.6	4.5	4.58

With prescribed statins the cholesterol level drops to an average below the new health target level of 4 mmol/L. If we consider the taking of statins as the presence of treatment, then the control rate for Deaf people is 95% which seems successful in keeping cholesterol levels below 5 mmol/L. However, the treatment rate looks weaker at 31% that is, less than a third of those who would have elevated cholesterol, have been provided with treatment. Treatment rate for the general population seems higher (HSE2011) at 79% for men and 71% for women. However, there are caveats in this data (small numbers for certain groups) which caution against relying on these absolutely.

7.2. Lipid Profile

We then proceeded to investigate the lipid profile of participants. Firstly we examined the distribution of low density lipoprotein (Table 7.7), but in 50 cases this was not measured/reported. We defined the 'ideal' level as ≤3.00mmol/L.

Table 7.7: Distribution (%) of LDL levels, by gender

	Ideal (<=3.0)	elevated (>3.00)	n=
Male	72.8	27.2	112
Female	66.9	33.1	124
Overall	69.7	30.3	

In this case the gap between males and females narrows with only a third of female participants having high LDL cholesterol levels.

Secondly, we considered the ratio of total cholesterol (TC) to high density lipoprotein (HDL). Table 7.8 shows the results by gender (30 missing cases). The desirable ratio is ≤4.5.

Table 7.8: Distribution (%) of total cholesterol/HDL ratio, by gender (n=268)

	Desirable (≤4.5)	elevated
Male	85.3	14.7
Female	88.8	11.2
Overall	87.1	12.9

This brings the figure for Deaf females down to below that of Deaf males. We see very little difference according to age.

Table 7.9: Distribution (%) of total cholesterol/HDL ratio, by age

	Desirable (≤4.5)	high
20-44 yrs	89.29	10.71
45-64 yrs	85.59	14.41
65 -82 yrs	85.71	14.29
All ages	87.13	12.87

The cholesterol and lipid results showed that a minority of the Deaf participants had lipid profiles outside the desirable range. We did not specifically ask whether the participants were aware of their cholesterol level, but as only 15% reported taking a statin, we speculate that at least half of Deaf participants with high cholesterol were not aware of the meaning of this medication or of the impact on their own health. As can be seen in the follow-up interviews, Deaf participants were unlikely to understand "cholesterol" and the concept of "risk" was not well understood.

We made a comparison of cholesterol levels and blood pressure (Tables 7.10 and 7.11). Although we predict a correlation of higher blood pressure with higher cholesterol, the relation for Deaf participants is at best a weak one (Cramer's V at 0.10).

Table 7.10: Comparison of total cholesterol/HDL ratio and blood pressure (n=263) (row %)

Measured Blood Pressure	Desirable (≤4.5)	elevated	n=
Low normal	94.4	5.6	54
high normal	87.6	12.4	113
mild hypertension	88.1	11.9	67
moderate-severe	69.0	31.0	29

Table 7.11: Comparison of total cholesterol/HDL ratio and blood pressure (n=263, column %)

Measured Blood Pressure	Desirable (≤4.5)	elevated
Low normal	22.3	8.8
high normal	43.2	41.2
mild hypertension	25.8	23.5
moderate-severe	8.7	26.5
n=	229	34

Only among those with the highest level of blood pressure does there appear to be a raised cholesterol level. This group will be at the highest risk of developing cardiovascular disease in the future. Of those with raised cholesterol levels, the majority have normal blood pressure (Table 7.11).

Cholesterol levels are lower among this group of Deaf people (compared to the general population). This is unexpected given their raised hypertension and greater obesity

7.3. Cardiovascular Risk

As a result of the health assessment carried out at Bupa centres it was also possible to collate individual data and present as a risk score. Bupa uses a formula combining a series of variables: age, total cholesterol, HDL cholesterol, blood pressure, diabetes and cigarette smoking. Points awarded are converted to a CHD risk figure and then compared to an average 10 year CHD risk. It is not specified as to which exact normative figures these refer. However, the figures cannot be used if the person is under 30 years or if the person is not Caucasian. The following results apply:

- Cases which were not tested or omitted because they already had medication or where the person was under 30 years of age and no normative data was available = 22%

Of those who were tested and reported:

- 71% had a lower risk of CVD than the general population
18% had the same level of risk as the general population
10% had a higher risk than average for the general population.

We can draw simple conclusions from these variables that

(a) Deaf people have a lower risk of future CVD than do the general population

or

(b) This standard formula may be flawed as it produces a hugely skewed impression of the Deaf community.

It is notable that the use of cholesterol and smoking are key indicators and these are factors which are lower in the Deaf community as a whole.

8. Depression

One major area of concern seen in the preliminary analysis was the self-report of depression. There are various statistics on this but the NICE treatment guidelines (2010) suggest:

> The estimated point prevalence for a depressive episode (F32/33, ICD–10; WHO, 1992) among 16- to 74-year-olds in the UK in 2000 was 2.6% (males 2.3%, females 2.8%), but, if the broader and less specific category of 'mixed depression and anxiety' (F41.2, ICD–10, WHO, 1992) was included, these figures rose dramatically to 11.4% (males 9.1%, females 13.6%) (Singleton et al., 2001).
>
> Prevalence rates have consistently been found to be between 1.5 and 2.5 times higher in women than men
> *page 22, National Clinical Practice Guideline 90, National Collaborating Centre for Mental Health*

The QOF figures for clinical depression in the GP returns are reported as 11.7% for 2011-12 which corresponds to the category of mixed depression and anxiety. This figure is showing an increase of 0.5% from the previous year.

The self-reported depression figures for Deaf participants (n=287) are higher than for the general population: 23.7% overall with 31.8% women and 14.3% of men. We see slight increases with age: 25-44 yrs (21.7%), 45-64 yrs (25.2%) and 65- 82 yrs (25.9%).

There is some variation by location (Table 8.1) though there is not an obvious pattern.

Table 8.1: Variation in Depression by geography

	% reporting depression	*n*
London & South	23.4	94
West & Wales	29.0	62
Midlands	22.2	54
North	14.6	41
Glasgow	27.8	36

Despite the relatively high rate of self–report of depression only 4% of the participants reported that they were taking SSRIs (anti-depressant medication). Only 15% of those who reported that they *had* depression were using anti-depressant drugs.

There was no clear association between depression and self-report of alcohol use although those who were taking SSRIs, reported much lower use of alcohol than the rest of the group.

Depression is an area of health which needs further more detailed consideration for the Deaf community and the quantitative findings in this study are not sufficient to explain the high self-report of depression. In order to explore this we would have needed to have collected measures of mental well-being.

The topic re-appears in the qualitative analysis in the interview study (Deaf Health Part 2)and we offer a more evidence-based analysis at that point.

9. Asthma and COPD

According to the QOF returns (2011-12), asthma has one of the highest prevalence rates for illness over all ages at 5.9%. The Health Survey of England (2010) reports that 16% of adult men and 17 % of adult women had been diagnosed with asthma at some time in their life. Nine percent of men and 10 percent of women reported asthma as a *current* problem. The current report of asthma (ie doctor-diagnosed in the last 9 months) can be seen to be approximately 10% less than the "ever diagnosed" asthma figures.

Asthma was reported at a similar level among the Deaf participants if compared to the lifetime prevalence ie 15.4% and 16.5% for men and women respectively. The question in the interview did not distinguish clearly between asthma now and in the past. Although many of the other variables assessed in the health assessment tend to indicate that Deaf people have more problems, in the case of asthma, we cannot be sure how different from the general population, Deaf people are.

There is a trend for asthma to reduce over the age range (Table 9.1) for the general population but this is less marked among Deaf people.

Table 9.1: HSE (2010) and Deaf participants (n=286) asthma diagnosed at some time (%)

	25-44 yrs	45-64 yrs	65-85 yrs
HSE male	17.7	12.5	11.3
HSE female	18.4	16.0	15.0
Deaf male	18.9	10.9	15.2
Deaf female	16.9	14.5	15.8

There are also some regional differences (Table 9.2); while the HSE (2010) figures tend to be stable across regions, the figures for the Deaf participants varies considerably. Size of the group in each region is relatively small but in the largest group (London) self-reported asthma is less than the HSE (2010) figures. The geographical regions used do not match exactly here and the HSE 2010 figures are presented as an estimate only.

Table 9.2: Regional differences in reports of asthma (%) (n=294)

	% reported	*HSE 2010 % estimate*	*Deaf n*
London & South	12.0	15	94
West & Wales	22.2	16	62
Midlands	20.0	17	54
North	10.0	16	41
Glasgow	16.2	n/a	36

In the HSE (2010) 4% of men and 5% of women had at some time been diagnosed with chronic obstructive pulmonary disease (COPD). The response from Deaf participants was less than one percent – ie only one person mentioned COPD. It seems that these serious respiratory problems are less recognised among Deaf participants than in the general population.

While asthma is reported more extensively by Deaf people, it is not absolutely clear that this is significantly greater than the lifetime prevalence for the general population. The likelihood is that there are more Deaf people currently with asthma than in the general population but because of the difference in phrasing of the question we cannot be sure how much more common this is for Deaf people.

10. Diabetes

One of the major concerns in public health in the UK is an increase in the prevalence of diabetes. The Health Survey of England (2011) tends to provide a single figure for both Type 1 and Type 2 diabetes.

> The HSE interview makes no distinction between Type 1 and Type 2 diabetes because of changing patterns of the disease. In previous years it was assumed that participants who reported having a diagnosis of diabetes before the age of 35 and who were on insulin therapy at the time of the survey had Type 1 diabetes, and all other participants with doctor- diagnosed diabetes were classified as having Type 2 diabetes. However, small but increasing numbers of people are now being diagnosed with Type 2 diabetes below the age of 35, and some adults with Type 2 diabetes are now prescribed insulin therapy,[22,23] so these distinctions are no longer reliable. HSE 2011, p 100.

The HSE 2011 observes:

> "In 2011, 7.0% of men and 4.9% of women aged 16 and over had doctor-diagnosed diabetes; the prevalence among men being significantly greater than among women. …..
>
> Diagnosed diabetes increased with age, from fewer than 2.6% of men aged under 45 to 25.7% aged 85 and over, and from fewer than 2.3% of women aged under 45 to 14.8% of those aged 75-84, and 11.5% aged 85 and over.
>
> Diagnosed diabetes was highest among those with the lowest household income. 11.0% of men and 5.9% of women in the lowest quintile of equivalised household income had diabetes, compared with 4.7% of men and 3.7% of women in the highest quintile."
> page 97, HSE (2012)

The prevalence for the QOF shows increases from 3.9% in 2007-8 to 5.5% in 2010-11. Diabetes UK suggests that 90% of cases are Type 2 diabetes. They provide an overall UK figure of 4.6% in 2012 with England higher at 5.8%. (http://www.diabetes.org.uk/Documents/Reports/Diabetes-in-the-UK-2012.pdf) Comparatively, however, UK is reported to have lower levels of diabetes than other developed countries, according to HSE (2011).

The comparable figures for the self report of Deaf participants was 7.4% for males and 5.7% for females with an overall figure of 6.5% which is higher than the prevalence above but confirms that men are more likely to have diabetes. Re-calculating the HSE 2011 figures and removing the oldest age group who do not match the Deaf sample, we find 8.7% of males and 5.1% females have doctor-diagnosed diabetes. The overall figure is then 6.7%, very close to that of Deaf people.

We considered the relationship of self-report of diabetes and the measurement of glucose levels. We used the accepted classification of less than 6.1 mmol/l as normal, 6.1 to 7.0 mmol/L as pre-diabetic and 7.1 or more as diabetic (Tables 10.1 and 10.2). Examining only the measured diabetes scores, there are 8.1% who are pre-diabetic and 2.6% who are diabetic. In total, there was 10.7% measured pre-diabetes and diabetes.

Table 10.1: Self-reported diabetes and measured diabetes (row %) (n=267)

Self-Report	normal	pre-diabetic	diabetic	n=
no diabetes	92.4	6.8	0.8	249
diabetes	44.4	27.8	27.8	18
Overall	89.1	8.2	2.6	

We found that of those who believed they did not have diabetes, 7.6 % had blood sugar levels which suggested that there could be a problem. Of those who reported diabetes, 44% had normal levels of blood sugar – presumably meaning that the problem was under control. However, this still left nearly 56% of those who recognised they had diabetes which was not under control – although we note that the actual numbers are small in this sample.

Table 10.2: Self-reported diabetes and measured diabetes (column %) (n=267)

Self-Report	normal	pre-diabetic	diabetic
No diabetes	96.6	77.3	28.6
diabetes	3.4	22.7	71.4
n=	238	22	7

Of those with raised levels of blood sugar at pre-diabetic levels, more than three quarters (77.3%) were unaware of it (Table 10.2). Of those with diabetic levels, more than a quarter (28.6%) were unaware of it (but in this case the numbers are very small).

Of those people who claimed to be diabetic (18 participants), nine were prescribed Metformin. Of those 9, only 3 had normal blood sugar levels when tested. The treatment regime was not bringing their diabetes under control in two thirds of the cases.

The HSE (2011) uses measured levels of glycated haemoglobin as indicators of undiagnosed diabetes and claim that 2.3% males and 2.1% females were undiagnosed in 2011. The Bupa screen did not include glycated Hb, so the only indicator of undiagnosed diabetes is the percentage of those with pre-diabetic sugar levels. In the case of Deaf participants, those undiagnosed figures were 7.1% and 5.3% for males and females respectively. The percentage of undiagnosed with

diabetic sugar levels is very low – less than 2% (ie 2 cases for males and zero for females.

In terms of measured diabetes and gender, we see greater prevalence (pre-diabetic plus diabetic) than HSE 2011, with males at 12.2% and females at 9.9% (Table 10.3).

Table 10.3: Measured blood sugars, age and gender (row %) (n=265)

Males (n=123)	normal	pre-diabetic	diabetic	n=
25-44 yrs	87.8	8.2	4.1	49
45-64 yrs	83.3	9.5	4.8	42
65-82 yrs	93.8	3.1	3.1	32
Overall ages	91.1	8.1	4.1	
Females (n=142)				
25-44 yrs	92.5	7.5	0	53
45-64 yrs	87.5	9.7	2.8	72
65-82 yrs	94.1	5.9	0	17
Overall ages	91.5	8.5	1.4	

As reported in the HSE 2011, there is a variation with age with 14.3% of males and 12.5% females measured as pre-diabetic or diabetic in the 45- 64 years age group. However there seems to be no simple linear relation with age (although the numbers in the oldest groups are probably too small to be certain).

The HSE (2011) indicates that diabetes co-occurs with obesity:

Prevalence of (doctor diagnosed) diabetes was greatest among those who were obese (14.7% of men and 9.9% of women). This was much greater than the prevalence among those who were overweight but not obese (5.0% and 4.3% respectively), or those who were not overweight (2.7% and 1.5% respectively).

……. hyperglycaemia (determined by raised glycated haemoglobin) was more prevalent among those who were obese compared with adults who were overweight but not obese, or not overweight. For example, 20% of men who were obese had hyperglycaemia, compared with 4% of those who were overweight and 2% who were not overweight; equivalent figures for women were 14%, 6% and 2%. Page 105

Among the Deaf participants the impact of obesity was similar with nearly 21% of men and 16% of women who were classed as moderate or severely obese, having pre-diabetic or diabetic blood sugar levels.

***Table 10.4: Percentage of Deaf males and females with measured pre-diabetic and
diabetic blood sugars in relation to measured BMI (n=270)***

	Normal-overweight	*Moderate-severe obesity*
Male	8.6	20.6
Female	6.5	16.0

Perhaps not surprisingly the relationship of obesity and diabetes applies also to
Deaf participants.

There is a similar association with hypertension and this is widely reported in the
general population (Table 10.5).

***Table 10.5: Percentage of those with measured pre-diabetic and diabetic blood sugars in
relation to measured hypertension (n=262)***

	Low-high normal blood pressure	*mild-moderate-severe hypertension*
male	8.6	13.7
female	8.4	13.0

The patterns for diabetes for the Deaf participants appear to be similar to those of
the general population although there is a tendency for the results to be more
extreme.

Taken overall, Deaf participants are marginally more likely to be diabetic than the
general population and are likely to be less aware of the problem. It would seem
also that their treatment regimes are not successful in controlling the problem.

The Bupa assessment also calculated a diabetes risk score. This is based on a
weighting for age, BMI, waist circumference, whether they had 30 minutes of
physical exercise, how often they ate vegetables or fruit, whether they had taken
anti-hypertensive medication, whether they had been found to have high blood
glucose, and whether any member of their immediate family had been diagnosed
with diabetes.   The source of the normative data on this is not explained in the test
sheets. It should also be noted that the calculation is different from the online risk
assessment tool at Bupa and at Diabetes UK. However, the following applies to
the Deaf participants:

- Not recorded = 9% - these were not recorded because they were already
  said to have diabetes or because there was no time in the assessment to
  calculate this risk.

Of those whose risk was calculated:

- 36% have a one in a hundred risk of developing diabetes

- 43.4% have a one in twenty-five risk

- 14.3% have a one in six risk

- 6.3% have a one in three risk

As with much of the analysis here, the patterns of health are not the same for Deaf people and the correspondences between the different variables do not always seem consistent. This may be partly because clinical history is harder to establish for each BSL using participant.

11. Smoking and Drinking

There are major areas of concern in regard to the use of tobacco and alcohol, within most Western societies. Despite their ready availability, medical opinion considers the use of tobacco and alcohol to pose major risks to health. They are implicated in many calculations of public ill-health and are the subject of much debate and a great deal of effort in health education. Simple questions concerning smoking and drinking were included in the health interviews.

11.1. Self-reported Smoking

The same percentage (8%) of men and women reported smoking. This compares to the reported UK rate (2010) of 21% for men and 20% for women (source: http://www.cancerresearchuk.org/cancer-info/cancerstats/types/lung/smoking/#percent). More women have never smoked (72%) compared to men (61%). It appears that Deaf people smoke much less than do hearing people.

With regards to smoking, our figures (in Table 11.1) were lower (8.1%) than those from the Sign Health (2013) on-line survey, in which 17% of Deaf respondents currently smoked (compared with 20% in the Health Survey for England, 2009). Figures from Robinson & Bugler(2010) referring to trends up to 2008 indicate smoking rates for both men and women to be around 21%. These differences may reflect the selection differences in those Deaf people who responded online and those who took part in the health assessments.

Table 11.1: Smoking and Gender among Deaf participants (%) (n=296)

	Never smoked	Ex smoker	Smokes cigarettes, /roll-ups/ pipe
Males (n=137)	62.0	29.2	8.8
Females (n=159)	71.7	20.8	7.5
Overall	67.2	24.7	8.1

Slightly more Deaf men smoked than did Deaf women.

There are also small differences between age groups in smoking (Table 11.3).

Table 11.2: Age and Smoking by Deaf participants (%) (n=298)

	Never smoked	*Ex smoker*	*Smokes cigarettes, /roll-ups/pipe*	*n=*
20-44 yrs	66.4	26.1	7.6	121
45-64 yrs	71.4	20.2	8.4	122
65-82 yrs	64.8	33.3	1.9	55

It would appear that smoking is not such a significant aspect of Deaf life as it is of hearing people's lives. We might argue that the promotion of cigarette smoking in the media is less accessible to Deaf people or that the visual health promotion campaigns regarding smoking are more visible to Deaf people. However, it does seem clear that many fewer Deaf people smoke than do hearing people.

11.2. Self-reported alcohol consumption

Deaf people reported less alcohol consumption than the general population.

Participants were asked to define their average weekly consumption of alcohol in units (but without definition of what a unit of alcohol represented in standard drinks). Average alcohol consumption was self-reported as 5.4 units for men and 3.4 units for women. Self-reported alcohol consumption by gender and age is shown in Table 11.3.

Table 11.3: Age and Gender and self -report of alcohol consumption (Mean Average number of units per week)

	Male	*Female*	*n=*
18-24 yrs	2.0	8.0	8
25-44 yrs	5.3	3.5	113
45-64 yrs	7.3	3.0	122
65 yrs +	3.2	3.5	55
All ages	5.3	3.4	298

These figures are very low in comparison to the self-reported alcohol consumption for the general UK population of 15.9 units for men and 7.6 units for women (GLS, 2010). The raised level of young Deaf females is consistent with stereotypes of UK young female drinking habits, but the actual numbers involved here are too small to take this any further.

We should also remember that there is an increasing evidence base to support the view that there is huge under-reporting of alcohol consumption.

We cannot tell if Deaf people under-report to a greater extent than do hearing people. However, we do consider it likely that Deaf people *are* under-reporting their consumption of alcohol.

Our findings were consistent with what was reported by Sign Health (2013) from their online survey, in which 34% of men and 66% of women claimed they did not drink at all (compared with 28% and 44% for males and females in the general population from the Health Survey for England, 2009). Our study shows 33.1% of Deaf males, and 40.3% of Deaf females do not drink at all. If we remove these from the calculation, the extent of drinking among those who do drink is 8.0 units (males) and 5.7 units (females) which is well below the figures reported for the general population. As has already been pointed out, we do not feel confident about the self-reporting in this case.

The indications are that Deaf people overall do not have a significant problem with alcohol but further detailed analysis will require a separate study which can more accurately measure consumption.

In both smoking and alcohol consumption it seems that Deaf people are less likely to indulge than hearing people. However, there are insufficient questions in the interview to pursue these aspects much further in this study. Although anecdotal evidence suggests that Deaf people may not be able to obtain advice and support in dealing with these problems (hence making them more serious, when they arise) the overall extent of the problem is not as great as in the general population.

12. Access to Health Services

In this section we consider the responses to questions asked by the Deaf adviser at the health check. These are questions mostly relating to access to health services. Comparative data for the general population are derived from the GP Patient Survey (GPPS) for England (2012-2013) (see section 3.6). Even though the questions taken from the GPPS are rather complex when translated from English to sign language there is merit in being able to make the comparison with the GPPS results. With almost all of the questions participants could choose from a set of multiple choice answers.

12.1. Contact with primary care health services

To estimate use of service, a key indicator which has been used was 'how recently had respondents gone to the see their general practitioner?' However, the wording of the question in the GPPS had changed slightly in 2012 (from an earlier version on which our project questions were based) and referred to whether the person had seen or spoken to the GP. This would probably increase the amount of contact compared to Deaf people (since the latter could not call). The GPPS figures vary a little from one survey date to the next (as do the questions). We have tried to use data available online from the period corresponding to our health assessments with Deaf people (2012-13).
 The data in the GPPS are based on over 1 million respondents, with 44,000 online returns, 2,100 returns in non-English forms and 72 sign language forms submitted online.

In the following tables we compare responses from Deaf people in interview with the self-completed forms returned to the GPPS.

Table 12.1: Frequency (%) of responses to the question : When did you last see a doctor at your GP surgery or health centre? (n=278)

	past 3 months	3-6 months ago	more than 6 months	n=
20-44 yrs	64.1	17.1	18.8	117
45-64 yrs	60.5	16.7	22.8	114
65- 82 yrs	59.6	25.5	14.9	47
Overall	61.9	18.3	19.8	278
GPPS	58	17	24	964,999

There appears to be no strong age-relationship (Table 12.1) - which we might have expected, if we assumed older people were more likely to use health services.

Over 60% of Deaf participants had been to the doctor in the last 3 months. However, this may be an over-estimate on the whole population of Deaf adults, as those coming forward in this study may have had specific recent experiences, which they wished to explain. Nevertheless, this is a higher percentage than the GPPS (surprising, given that previous research indicates that Deaf people dislike going to the doctor).

If we examine the same data by gender (Table 12.2), we see a gender difference but also a Deaf vs general population difference.

Males in the general population go to the doctor less frequently (ie over 6 months since last visit) 32.4% than Deaf males (21.9%). Deaf males have been to the doctor as frequently as (hearing) females in the general population – ie over 60% in the last three months.

Table 12.2: Frequency (%) of responses to the question : When did you last see a doctor at your GP surgery or health centre? (n=278)

	past 3 months	3-6 months ago	more than 6 months	n=
GPPS				
male	49.8	17.8	32.4	457,828
female	60.9	17.7	21.3	483,673
Deaf				
Male	60.9	17.2	21.9	128
Female	62.7	19.3	18.0	150

Despite their reported dislike of the visits to the GP, Deaf people seem to go more frequently, although this is not significant statistically.

It is often thought that Deaf people would build a relation with a particular GP and that this may make communication easier. When asked, the majority of Deaf people preferred to see a particular GP (Table 12.3).

Table 12.3 Responses (%) to the question: Is there a particular GP you prefer to see? (n=286)

	Yes	*No*
20-44 yrs	67.8	32.2
45-64 yrs	69.8	30.2
65- 82 yrs	84.6	15.4
All ages	71.7	28.3
GP Patient Survey	59	37

This prediction tends to be supported and at all ages: Deaf people are more likely to express a preference to see a specific doctor than do hearing people (chisquare=11.1, df=1, p<.001). It seems there is a strong preference for older Deaf people to want to see a specific doctor (85%).

The participants were then asked if this preference was also reflected in the doctor who is *actually seen* (Table 12.4).

Table 12.4 Responses (%) to the question: How often do you see the preferred doctor? (n=221)

	always	*a lot of the time*	*some of the time*	*never/almost never*
20-44 yrs	8.2	35.3	44.7	11.8
45-64 yrs	20.7	29.4	38.0	12.0
65- 82 yrs	19.8	60.9	15.2	4.4
All ages	15.7	38.1	35.8	10.3
GPPS	46	23	26	5

Older people *a lot of the time* or *always* saw the doctor they prefer (80%). However, it is the respondents to the GP survey who are *much* more likely to *always* see their preferred doctor (chisquare=89.3, df=3, p<.001). Interestingly, this figure seem to be declining from previous GPPS surveys, perhaps reflecting some of the access issues that hearing people face also).

We then asked the Deaf participants two questions which were not in the GP Patient survey, about reasons for preferring a particular doctor and how contact was made with the health centre. Table 12.5 shows that the reasons for preferring one doctor over another were predictable, being mainly communication. However, for older people, the relationship built up over time was more important.

Table 12.5: Responses (%) to the question: Is there a special reason to prefer that GP?
(n=207)

	good communication	many years contact	other
20-44 yrs	58.2	20.3	21.5
45-64 yrs	54.0	31.0	16.1
65- 82 yrs	39.5	51.2	16.3

The responses as to how they usually made contact with health centre are in Table 12.6.

Table 12.6: Usual means to contact GP (percent mentioning this method) (n=295)
(Note there were multiple responses and the rows to do not sum to 100%)

	text msg	typetalk	going in	other call	fax	online
20-44yrs	3.3	40.5	42.2	20.7	0.8	5.0
45-64 yrs	2.5	45.1	43.4	12.3	4.9	5.7
64-82 yrs	5.4	29.1	56.4	16.4	16.4	1.8
All ages	3.4	40.3	45.3	16.4	5.4	4.7

Forty-five percent of participants (more of the older group) said they made appointments with GP by having to go in person – 32 % of GPPS said this but 89% of GPPS said they used the telephone.   Very few (3%) make contact online – less than Deaf people although 24% of GPPS would prefer to make contact through online means.

Participants were asked about the ease of this method of contact (Table 12.7)

Table 12.7: Responses (%) to the question ease of the designated method of contact
(n=294)

	very easy	easy	difficult	very difficult
20-44 yrs	10.32	38.10	38.10	7.14
45-65 yrs	10.00	40.83	33.33	15.83
66-82 yrs	17.31	51.92	25.00	5.77
All ages	11.41	41.61	33.89	10.40

Forty-four percent of Deaf people find that making contact with the GP or health centre is *difficult* or *very difficult*. There is no identical question for the recent GPPS, but there is a question concerning ease of access by telephone (which 89% have used). Only 17% found it *not very easy* or *not at all easy* to make contact by telephone (compared to 44% of Deaf participants having difficulty).   This seems to be confirmation of the difficulties Deaf people face in initiating contact, even

before they are able to try to communicate their health issues with qualified personnel.

Often Deaf people seem to complain about the first person to person contact. We asked about the receptionist, and the results are shown in Table 12.8.

Table 12.8: Responses (% to the question: How helpful was the receptionist? (n=291)

	very helpful	*fairly helpful*	*not very helpful*	*not at all helpful*
20-44 yrs	9.4	49.6	31.6	9.4
45-64 yrs	11.8	44.5	37.0	6.7
65- 82 yrs	12.7	58.2	29.1	0.0
All ages	11.0	49.1	33.3	6.5
GPPS	54	37	6	2

Nearly 40% of Deaf people found the receptionist not very helpful or not at all helpful – only 8% of the GPPS found the receptionist unhelpful. Fifty-four percent of the GPPS found the receptionist very helpful – only 11% of Deaf people found the receptionist very helpful. The difference is highly significant (chisquare=504.9, df=3, p<.001). Clearly there are issues in making contact and then in dealing with the customer-facing staff.

Another question tried to determine if appointments could be made quickly (Table 12.9). The GPPS survey question was a little different: "Last time you wanted to see or speak to a GP or nurse from the GP surgery, were you able to get an appointment to see or speak to someone?" and then "how long after initially contacting the surgery did you actually see or speak to them?".

Table 12.9: Responses (%) to the question: in last 6 months, have you tried to see a GP fairly quickly (same day or next 2 days)? (n=289)

	yes	*no*
20-44 yrs	50.0	50.0
45-64 yrs	54.2	45.8
64-82 yrs	47.2	52.8
All ages	51.2	48.8

Of those who tried, 65% were able to see their GP within two days. The question in the GPPS was phrased slightly differently but 84% of GPPS respondents were able to have an appointment "*a few days later'* (wording taken from GPPS) and 35% *on the same day*.

We asked why the person was <u>not</u> able to be seen 'fairly quickly'. Of those who had not been seen quickly (n=76), 53% said that there were no appointments (the GPPS in a similar question had 67% who found there were no appointments at a suitable day/time). The other main reason for not having an appointment quickly (32%) was the lack of interpreters.

12.2. Experience of consultations

The next major section of the interview concerned the skills and attitudes of the doctor and of the nurse. The issue was whether the doctor gave enough time (Table 12.10), and in listening (Table 12.11).

The question asked was how good the practitioner was in various interactions.

Table 12.10 Responses (%) to: giving you enough time (n=298)

	Very good	*good*	*Neither good nor poor*	*poor*	*Very poor*	*n/a*
Deaf	18.7	47.3	17.5	9.4	3.0	2.4
GPPS	53	35	8	2	1	1

Ratings in the GPPS were higher (88% *good* or *very good* at doctor giving enough time) compared to the Deaf participants (66%). On the negative side 12% of Deaf people said the doctor was *poor* or *very poor* at giving enough time (compared to only 3% of GPPS). Combining the categories of poor and very poor, the difference in response is highly significant (chisquare=212.4, df=3, p<.001).

Table 12.11 Responses (%) to: Listening to you (n=298)

	Very good	*good*	*Neither good nor poor*	*poor*	*Very poor*	*n/a*
Deaf	14.8	46.3	19.8	11.1	3.4	
GPPS	55	34	7	2	1	1

Those in the GPPS were much more likely to say the doctor was good at listening (89%) than Deaf people (61%). Fourteen per cent of Deaf people thought the doctor was *poor* or *very poor* as compared to only 3% of the GPPS. Combining the categories of poor and very poor, the difference in response is highly significant (chisquare=212.4, df=3, p<.001).

Participants were asked if the doctor was good at explaining tests and treatments which were on offer (Table 12.12).

Table 12.12 Responses (%) to: explaining tests and treatments (n=299)

	Very good	*good*	*Neither good nor poor*	*poor*	*Very poor*	*n/a*
Deaf	12.6	36.2	23.9	15.34	7.2	4.8
GPPS	50	34	9	2	1	4

As might be predicted from the above, Deaf participants rated the explanations by the GP, poorer than those respondents in the GPPS. Combining the categories of poor and very poor, the difference in response is highly significant (chisquare=622.9, df=3, p<.001). Forty-nine percent considered explanations to be *good* or *very good* as compared to 84% in GPPS. Twenty-three percent of Deaf participants thought explanations were *poor* or *very poor*, compared to only 3% of GPPS respondents. It seems likely that the doctor was unable to communicate freely with the Deaf patient.

Lack of explanation might make people feel uninvolved in their own care and heighten the sense of marginalisation. Responses from the Deaf participants tend to support this exclusion (Table 12.13)

Table 12.13 Responses (%) to: ….. involving you in decisions about your care (%) (n=297)

	Very good	*good*	*Neither good nor poor*	*poor*	*Very poor*	*n/a*
Deaf	11.5	34.3	23.9	14.8	9.8	3.7
GPPS	43	34	11	2	1	7

Those in the GPPS were likely to rate their involvement as good 34% or very good 43%. In contrast, only 12% of Deaf participants thought their doctor was *very good* at involving them in decisions about their care and 25% said the doctor was *poor* or *very poor* (as compared to only 3% of GPPS). Combining the categories of poor and very poor, the difference in response is highly significant (chisquare=665.6, df=3, p<.001).

We can expect any doctor to treat the patient with care and concern and this was rated also (Table 12.14).

Table 12.14: Responses (%) to: Treating you with care and concern (%) (n=287)

	Very good	good	Neither good nor poor	poor	Very poor	n/a
Deaf	12.9	48.1	24.7	7.7	5.9	
GPPS	51	34	9	2	1	2

Although there was some improvement in perceptions of care, there was still a considerable gap between those GPPS respondents who rate the care and concern as *very good* (47%) and Deaf respondents (13%). There were also more Deaf respondents who suggested the level was *poor* or *very poor* (14%) as compared to only 4% in GPPS. Combining the categories of poor and very poor, the difference in response is highly significant (chisquare=259.8, df=3, p<.001).

Table 12.15:Responses (%) to: Taking your problems seriously (%) (n=298)

	Very good	good	Neither good nor poor	poor	Very poor	n/a
Deaf	14.3	44.7	19.5	12.6	6.5	2.4

Nineteen percent of Deaf people felt that in regard to taking their problems seriously the service was *poor* or *very poor*. This question was not used in the version of the GPPS.

12.3. Methods of communication

Of course, one of the major issues in consultation is communication (patients expect to be able to communicate directly and intelligibly in a shared language) but this topic is of much greater significance to sign language-using Deaf people. We asked about which methods Deaf participants had used and which methods they preferred to use. The results are complicated by the fact that participants gave multiple answers (even to the question of which method they had used last time). As a result we present this data in two ways, firstly by looking at all choices and combinations (Table 12.16 and Figure 12.1) and then by selecting only those who made a single choice (Table 12.17 and Figure 12.2).

Table 12.16: Responses (%) to ..Methods used to communicate with doctor and preferred methods (%) (n= 293)

	BSL with interpreter	SSE	BSL without	SSE without	Spoken English	Spoken English and lip-reading	Speaking & signing	Writing down	Take a friend	other
used	28.8	0.7	2.4	19.6	7.9	45.7	1.7	15.1	1.4	0
preferred	53.7	6.1	30.1	3.7	0	4.4	3.1	5.1	0	2.7

Figure 12.1: Used vs Preferred method of communication, by most used (%)
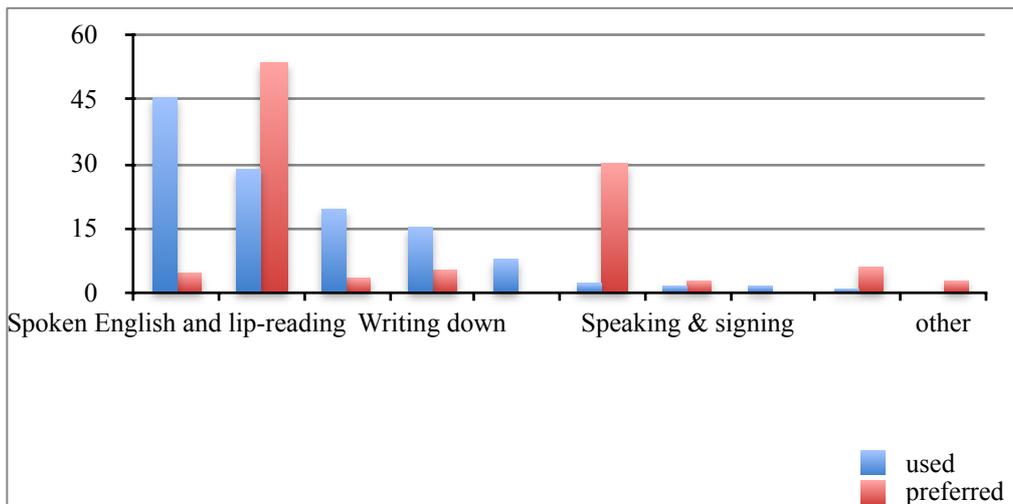
Interestingly, after 'spoken English & lip-reading', the second most common method used was 'BSL with an interpreter'. It seems as if there has been some progress in regard to providing a support service to the interaction with the doctor. However, some caution should be exercised here as a somewhat contrary result was given in the qualitative analysis of the interviews in the study (see part 2 of this report).

Considering only those participants who made a single response:

Table 12.17: Methods used to communicate with doctor and preferred methods (%)

	BSL with interpreter	SSE	BSL without	SSE without	Spoken English	Spoken English and lip-reading	Speaking & signing	Writing down	Take a friend	other
Used (n=229)	27.1	0.4	1.8	17.0	3.5	36.7	0.4	12.7	0.4	0.0
Preferred (n=279)	52.0	5.0	29.8	3.2	0.0	2.5	2.2	2.5	0.0	2.9

Surprisingly, perhaps Deaf people do not want to use writing down as a method, much preferring sign language in some form.

Figure 12.2: Used vs Preferred method of communication, arranged by most used (single choices only)
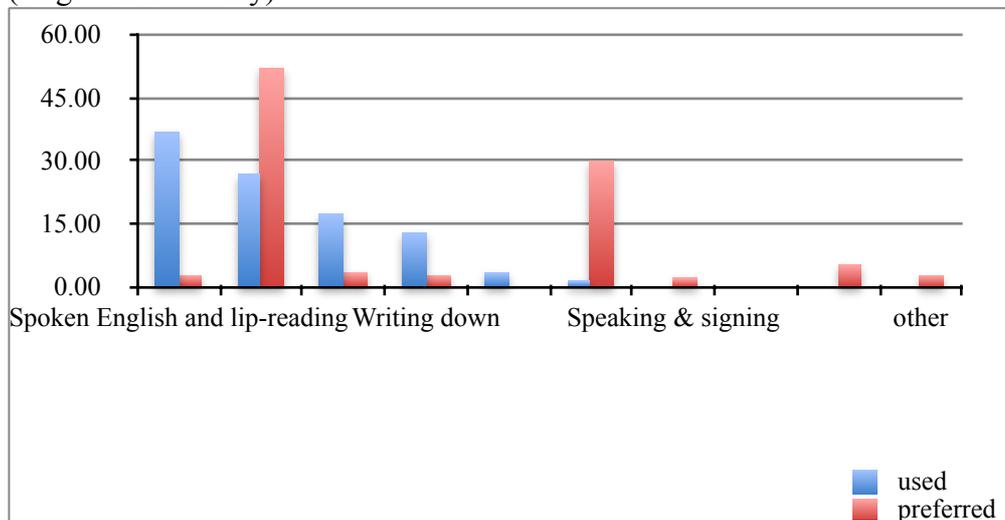
We can simplify this considerably by focusing only on those who used/preferred only signing variants and speech/English variants (Table 12.18)

Table 12.18: Use of and preference for signing vs speaking (%)

	BSL	English
used (n=227)	46.7	53.3
preferred (n=265)	94.7	5.3

Not surprisingly the preference of the vast majority was for the use of signing with the doctor and this coincides with a rejection of the use of English (speech, lip-reading and writing down). However, it was the case that in just under half of the most recent visits to the doctor, signing had been used and in nearly 60% of the visits, an interpreter was present. When we probed further in the follow-up interviews, it was not always the case that the presence of an interpreter (or other "signer") allowed the Deaf participant to understand the transaction with the doctor.

As a summary question we asked how well the participant felt that he or she communicated with the doctor (Table 12.19).

Table 12.19: Responses (%) to: how well do you communicate with your GP? (%)
(n=282)

	Very well	*Well*	*OK*
20-44 yrs	10.7	18.8	70.5
45-64 yrs	14.7	43.1	42.2
65- 82 yrs	27.8	37.0	35.2
All ages	15.6	32.3	52.1

{NOTE: There is a problem with this question in that it is made with the assumption that doctor and patient share the same English language. It also has an odd coding arrangement which does not allow a negative comment on the communication. This does not allow strong conclusions to be drawn.}

The result tended to confirm that Deaf people are not able to communicate well with the doctor.

We asked about overall confidence and trust in the doctor (Table 12.20).

Table 12.20: Responses (%) to: do you have confidence and trust in the doctor? (%)

	Yes definitely	*Yes to some extent*	*No not at all*	*Don't know/ can't say*
20-44 yrs	14.3	58.0	23.5	4.2
45- 64 yrs	29.9	50.4	16.2	3.4
65-82 yrs	36.7	53.1	10.2	0.
All ages	24.6	54.0	18.3	3.2
GPPS	67	26	4	2

There is clearly a major difference between Deaf participants and the GPPS respondents in the extent to which they have confidence and trust in the doctor. The difference in response is highly significant (chisquare=310.2, df=2, p<.001). While GPPS respondents express definite confidence and trust (67%), many fewer Deaf participants express this trust (25%). It is also to be noted that 18% of Deaf participants (and nearly a quarter of those aged up to 44 years) say "no not at all" in reference to their trust in the doctor.

In the GPPS, there are also questions concerning experiences of interaction with the practice nurse. However only 53% (156) of the Deaf participants said that they had seen a practice nurse in the previous 6 months (the basis for comparison with GPPS) and it was considered that the numbers involved in the subsequent analysis when broken down would be rather too small to produce an effective analysis and this data has not been processed at this time. It seems highly unlikely that communication issues will be solved in interacting with the nurse or that there would be a major difference in response to these questions when applied to interaction with the nurse.

13. Discussions and Implications

13.1. Summary of findings

This survey of the health of BSL using Deaf adults in the UK has produced evidence of levels of hypertension, obesity, asthma and depression, higher than those in the general population. In contrast, self-reported smoking rates and alcohol consumption were lower than in the general population. Access to general practice was a continual problem for the Deaf respondents, with difficulties in communication itself, in making appointments and in accessing interpreters. Compared to the GP Patient Survey for England, Deaf patients were less able to see the doctor of their choice. The preference of the vast majority was for use of signing with the doctor. In just under half of the most recent visits to the doctor, signing had been used and in nearly 60% of the visits an interpreter or person who could sign, was present. Deaf participants had significantly less confidence and trust in their doctor than the respondents in the general population (from the GPPS).

13.2. Strength and limitations of study

Strengths

This survey makes an important contribution by describing the overall health status of BSL-using deaf adults in the UK in 2012-13. An estimate is given of the prevalence of common chronic diseases in the Deaf population, and comment can be made on the apparent awareness of the deaf individuals of their health problems and their use of health services.

By using an independent provider (Bupa Healthcare) we were able to obtain a standardised health assessment for all participants, resident in England Scotland or Wales. Recognising that many deaf patients have difficulties in accessing GP care, we decided not to use the participants' general practices as the site for the medical assessment. The disadvantage of not having access to the participants' own medical records was offset by the advantage of having a structured health report on each participant. Despite some issues in Deaf awareness among Bupa general staff, the presence of BSL interpreters and Deaf support workers, provided a unique experience for many Deaf participants (some of whom had never had an interpreter present in a health consultation). We were very grateful to Bupa Healthcare for their contribution to this research, and the feedback from almost all participants was that they were very satisfied with the health check provided by Bupa.

The questions in the survey of Deaf patients' usage of health services were derived from routine surveys used for the general population, and provided interesting comparisons, illustrating the difficulties experienced by deaf people in accessing

healthcare. These quantitative results have been further enriched by the qualitative interviews with a selected group of deaf adults with health problems.

Together with the findings of the Ipsos MORI online survey (SignHealth, 2013), we believe these results provide a clear, but very worrying, picture of the current state of Deaf Health in the UK.

Limitations

In addition to the points made about the sampling, there are several limitations in the methodology which should considered when interpreting the results.   Many of these limitations also apply to the large scale studies such as the Health Survey of England and the GP Patient Survey. Participation was voluntary and the samples do not match exactly to the characteristics of the population as a whole.

Firstly, we were reliant on self-report for the medical history and often for the medication usage (although many participants brought a printout of their medication). We did not have access to individual's health records or prescription records. Self-report of medical problems can be associated with bias in both directions - an exaggeration of medical diagnoses (eg any wheeze is categorised as asthma), or an under-reporting of chronic conditions (eg hypertension, high cholesterol) through lack of awareness or denial. However, in mitigation, this is a standard approach in large scale health studies such as the Health Survey of England and the expectation is that self-reported does not mean self-diagnosed but refers to the patients' recall and re-statement of what they have been told by the doctor.

Secondly, the medical assessment offered by Bupa, whilst broadly the same as their routine 'well person' check, was a single check on one day and did not include any information from the individual's existing medical record. For example, no serial BP or ambulatory BP measurements were available on participants, and no measurements were made of lung function. The blood test was supposed to be taken on a fasting sample, but although clear written instructions were given to participants before attending the health assessment, some did not fast adequately and this could have interfered with their lipid profile and blood sugar results. Again, in mitigation, there has been some doubt cast on the requirement for fasting when the study is carried out on a large number of people in population studies. It seems likely that the effects of non-fasting in the study of Deaf participants is not as great as might have been feared.

Thirdly, the datasets used to provide comparisons with the hearing population have their own limitations. The Quality Outcome Framework (QOF) data are derived only from English general practices. The data are aggregated by practice rather than at patient level and cannot be treated as prevalence data. When using the QOF in making any comparison between deaf and hearing populations, we are treating our sample of deaf adults as if they all belonged to the same general practice, and

comparing them as a group to other general practices in England. Where other population-based datasets exist (eg GPPS or National Obesity Observatory or Health Survey of England) we have used those as the comparator, recognising that there will be some deaf individuals included in the population sample.

The General Practice Patient Survey for England (GPSS) uses a standard series of questions, to be able to compare one general practice with another. Not all of these questions were appropriate for Deaf people, and we had to add extra questions to obtain specific information about Deaf people's issues in communication.

Fourthly, meaning may have changed in translation from English to BSL and the researchers had no direct control over the way in which the questions were signed – whether through an interpreter or directly from a Deaf support worker. The questions inherited from the GP patient surveys were often ambiguous or complex to sign– some may not be exactly equivalent when translated to BSL (even though they seem the same in English). For example,

"if you couldn't be seen within the next two days the GP surgery or health centre was open, why was that?"

The use of the negative is a problem for the referent 'THAT (in BSL) as it cannot refer to a non-existent event.

13.3. Findings in context

Many of the data resulting from this research are unique, as there have been so few studies of the general health of BSL using deaf adults. The need for more research on the health of deaf people was highlighted in a recent review in the Lancet by Alexander, Ladd and Powell (2013).

The most striking finding is the high prevalence of obesity in the Deaf sample, particularly in women. We had no reliable data on activity levels in our sample, nor details of diet, but it is probable that the overweight and obesity seen in deaf people is due to the same factors as the general population- ie a mixture of intake of calories in excess of metabolic requirements and a lack of physical activity. In addition to living in the same obesogenic environment as hearing people, Deaf adults also face barriers due to communication difficulties and stigma in participating in sporting activities and joining gyms and clubs. Health promotion messages on healthy eating and regular exercise designed for the hearing population may not be reaching the Deaf community, especially the older members of the community (in whom the obesity problem is greatest). The problem of access of the Deaf community to health promotion messages is illustrated by the finding that understanding and knowledge of AIDS and risk behaviours were lower in people from the Deaf community than in hearing participants (Woodroffe et al 1998).

The results on blood pressure (BP) are also concerning - not just the levels of hypertension but also the apparent lack of awareness of the problem. This lack of awareness of raised blood pressure is also a common (but less prominent) issue in the general population.

Because of difficulties in accessing routine health checks in primary care, it can be predicted that Deaf people are less likely to have their blood pressure measured routinely than hearing people. Our data also suggest that even if prescribed anti-hypertensives, the Deaf patient may not be taking enough tablets, or may not be taking the medication regularly, to control the BP. A survey by RNID (2004) claimed that 33% of BSL users reported that they left consultations with their family doctor unsure about medication instructions or subsequently took the wrong doses.

Studies from the USA have shown that Deaf people are at a double disadvantage in accessing health information about cardiovascular disease (Margellos-Anast et al 2006). Pollard and Barnett (2009) showed that even highly educated deaf adults scored only at the level of schoolchildren aged 14–15 years for health literacy.

The combination of the levels of untreated hypertension and the raised cholesterol and abnormal lipid profiles seen in our sample cumulatively result in increased risk of cardiovascular events (stroke and heart attacks). This is potentially related to the reduced life expectancy which we tentatively associate with Deaf compared to hearing populations (based on studies of disability and disability-free life expectancy eg Sagardui-Villamor et al. (2005) and drawn from observation and anecdote from Deaf people). However we did show the expected associations between pre-diabetic glucose levels and BMI in the Deaf sample.

Given the prevalence of obesity, one might expect the rates of diabetes to be higher than it was but the self-reported rates of diabetes in the Deaf sample showed a similar relationship to obesity as did the data in the general population. However, of those Deaf people measured with raised levels of blood sugar at pre-diabetic levels, more than three quarters were unaware of it. Of those with diabetic levels of measured blood sugar, more than a quarter were unaware of their risks.

13.4. Comparison with literature on depression in deaf people

Depression is recognised to be common in Deaf people (Fellinger et al 2012), and it appeared to be a particular problem for women in our sample. These findings have been replicated in other surveys around the world. Studies in Norway (Kvam et al, 2007) and New Zealand (Bridgman et al 2000) have confirmed depression and anxiety were more common than in the hearing population. In Austria, anxiety and somatisation scores were found to be higher in Deaf women than Deaf men, but the sexes had similar amounts of paranoid ideation, depression, and interpersonal sensitivity (Fellinger et al, 2005). There are many reasons why Deaf adults have higher rates of depression than hearing people, including social

isolation, low self-esteem as a result of language deprivation, child maltreatment or adult unemployment, and difficulties in accessing diagnosis and treatment. To address this, the UK government have published guidelines for best practice: ' Mental health and deafness—towards equity and access' (Department of Health, 2005) and new structures are in place to support Deaf children and Deaf adults in regard to mental health.

13.5. Geographical and regional variation

Although the numbers in the sample were too small to make individual comparisons between centres, the pooled data certainly showed some trends in health status in the North compared to the South of the UK. Most apparent was the North–South divide in prevalence of obesity and hypertension which mirrored the social gradient and inequality seen in the hearing population. These differences reflect a complex range of factors (Barnett et al 2011), including a combination of poor-quality education, higher unemployment than in hearing individuals (Health Survey of England 2011) and subsequent poorer housing and access to facilities.

The responses to the questions on the access to and experience of health services have many important points for the health service in the UK. There were too few people with cancer to make any comments about specialist treatment services.

Access problems to general practice were commonly reported, including difficulties in making appointments and problems with the way health centre receptionists interacted with deaf people. Even more so than hearing patients, deaf patients want to see a doctor they know and trust, and with whom they have previously had a good experience communication experience. The pressures on general practice consultation times make it difficult to ensure access to a particular doctor at short notice (because there is no system of prioritization or personalization of care). The impact of this lack of connection is magnified for Deaf patients, when a new doctor with no Deaf awareness training and possessing no strategies to deal with a BSL user, has to deal with the Deaf patient.

It was disappointing for the Health Service that so many Deaf respondents were not confident in their doctor or rated them as poor in their communication or listening skills, but on the other hand it was encouraging that in just under half of the most recent visits to the doctor, signing was available and in nearly 60% of those occasions an interpreter was present.

Signing is the preferred means of communication for Deaf BSL users, and studies report that Deaf patients appreciate provision of medically skilled interpreter services, and especially practitioners who know sign language (Middleton et al, 2010). Despite this positive response here, we found when we interviewed nearly one in 6 of the respondents, there remained significant problems in access to health care through the interpreters provided. That is, Deaf people reported that

unqualified interpreters were used, that they did not understand the interpreter and that they felt the interpreter was another hearing person "on the doctor's side".

Differences between hearing and deaf patients' experience of consultations, with Deaf people being more critical of GPs, may reflect a cultural difference in willingness to criticise but in reality is more likely to reflect the challenges that Deaf people face when consulting with doctors.

Even if the doctor cannot use BSL, other strategies are now available to general practice, including booking appointments online, using text to communicate between receptionists, nurses, doctors and patients, and use of video relay services in consultations.

The study of Deaf Health has been instructive and worrying and suggests the need for considerable change in all aspects of the health awareness among Deaf people and in the professionals responsible for the delivery chain. It is too simple to treat the health consultation as a given structure, to which the Deaf person has limited access. By doing this, the support will always be seen as an aid to the Deaf person. In fact, the consultation breaks down for all parties involved if there is no shared language. Preparation of more visually appropriate interactions, more recourse to suitably qualified interpreters (in the medical field and in the Deaf cultural field) are essential. For this, to make a difference, responsibility for change must be accepted by all parties: doctor, interpreter and Deaf person.

At the same time in order to drive this change, a better understanding of Deaf wellness is needed and this aspect is discussed more extensively in part 2 of this study.

14. Recommendations

There can be further processing and statistical analysis of this rich data in order to set out further recommendations or to answer specific questions. It is also the case the that data from person to person interviews, which followed the data collection here, also contribute to the understanding of Deaf people's health which is necessary if it is to be possible to improve it.

The following are some preliminary thoughts on the actions which might be taken.

1. Improving identification of chronic diseases

This would focus on better use of 'well-person' checks by Deaf people; ideally sessions set up specifically with groups of Deaf people and interpreters on call

The setting up of this facility could be a target for GPs and might be incorporated in the QOF.

2. Information provision

It seems obvious that there ought to be a community-based and community-led initiative to increase awareness amongst deaf adults about importance of screening and health checks.

3. Facilitation of communication between GP surgeries and deaf patients:

This might include more visually accessible websites for making appointments, use of text for communicating with patients and relay for interpreting services during consultations

It will be a distinct advantage if it was made easier for deaf patients to see the doctor they want- eg a prioritisation system.

4. Deaf awareness training

It is recommended that attention be given to improving customer service for deaf patients. This would include deaf awareness training for receptionists, visual displays for calling patients to consultation and supporting video explanations.

5. Quality Indicators

It would be helpful to develop a recommended list of quality indicators for deaf friendly general practice for commissioners to include in contracts with primary care.

6. Professional training (as initial or CPD)

Include communicating with Deaf patients in the curriculum for GP and practice nurse training. This could be extended to all health care professionals.

7. Training

Deaf awareness can be included in the curriculum for medical and nursing students

Training for BSL deaf advocates and supporters in specific health issues would be useful.

There are many other aspects which need to be addressed. At the heart of the problem, is the difficulty for the Health Service structures to be flexible enough to deal with those who do not speak and for whom visual interaction is paramount. It should be clear that considerable change is needed if Deaf people are to reach equality of access in health.

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16. Appendix 1 The Assessment Plan and Data Collection at BUPA centre

The first section and the medical tests will be carried out by the BUPA health adviser; the questions on access will be dealt with by the Deaf advocate.

DeafHealth Project
Health Assessment data collection form

To be administered by BUPA health advisor to DeafHealth participant with aid of British Sign Language interpreter, following project explanation and signing of consent form.

Assessment Number: (to be supplied by DeafHealth)
Site of Assessment:
Assessor/Health Adviser:
Date of Assessment:
Time of Assessment:

Deaf Advocate: <name>
BSL interpreter: <name>

Explanation of the assessment completed: <confirm>
Consent Form signed: <confirm>

- **Background**

1.1	Date of Birth	
1.2	Gender	0 Male 1 Female
1.3	Ethnicity	0 White 1 Mixed 2 Black or Black British 3 Chinese 4 Asian or Asian British 5 Other ethnic group

- **Current medications**

Do you take any of the following regularly, either over-the-counter or prescribed?

		Yes	No	Don't know/ unsure
2.1	Aspirin	1	0	2
2.2	Clopidogrel	1	0	2
2.3	Dipyridamole	1	0	2
2.4	Beta blocker	1	0	2
2.5	ACE inhibitor	1	0	2
2.6	ARB	1	0	2
2.7	Warfarin	1	0	2
2.8	Other medicine?			

2.9 Thinking about the medicine you have had, would you say

I always have the correct medicine from the doctor   ☐

I sometimes have the wrong medicine   ☐

Not sure ☐

2.10 If you had the wrong medicine would you say this was

because of communication problems ☐

there was a mix-up at the chemist ☐

some other reason ☐

 what was the reason …………………………………………………….

- **Medical history**

Do you have any of the following problems?

		Yes	No	Don't know/ unsure
3.1	Angina	1	0	2
3.2	Heart failure	1	0	2
3.3	Raised blood pressure (hypertension)	1	0	2
3.4	Diabetes	1	0	2
3.5	Chronic kidney disease (CKD)	1	0	2

		Yes	No	Don't know/unsure
3.6	Chronic Obstructive Pulmonary Disease (COPD)	1	0	2
3.7	Asthma	1	0	2
3.8	Epilepsy	1	0	2
3.9	Underactive thyroid (hypothyroidism)	1	0	2
3.10	Depression	1	0	2
3.11	Schizophrenia	1	0	2
3.12	Bipolar disorder	1	0	2
3.13	Other psychoses	1	0	2
3.14	Dementia	1	0	2
3.15	Atrial fibrillation (AF) *	1	0	2
3.16	Rheumatoid arthritis *	1	0	2
3.17	Learning disability?	1	0	2
3.18	a physical disability?	1	0	2
3.19	Problems with eyesight (other than needing glasses)	1	0	2

In the past, have you had any of these medical problems?

		Yes	No	Don't know/ unsure
3.20	Stroke (Cerebrovascular accident or event) or mini-stroke (Transient Ischaemic Attack) *	1	0	2
3.21	Heart attack (myocardial infarction) *	1	0	2
3.22	Cancer	1	0	2
3.23	Where was the cancer? ………………			
3.24	were you treated by surgery			
3.25	were you treated by radiotherapy			
3.26	were you treated by chemotherapy			
3.27	Did you have some other treatment for cancer			

- **Family history**

4.1	Have you any relatives (biological brother, sister, mother, father) who suffered from angina or had heart attack - less than 60 years of age?	0 No 1 Yes 2 Not sure

4.2	How many children have you?	<number>

- **Prevention and screening**

Have you had?

		Yes	No	Don't know/ unsure
5.1	A flu jab (influenza vaccination) in the last 12 months?	1	0	2
5.2	A bowel cancer screening (faecal occult blood) test?	1	0	2

If participant is female:

			Was this part of national screening? Or follow-up to treatment?	Never had	Can't remember
5.3	When did you last have a cervical smear?	_____ year			
5.4	When did you last have a mammogram?	_____ year			

- **Lifestyle**

6.1	Average alcohol intake per week	_____ units	
6.2	Smoker?	0 Never smoked	
		1 Ex-smoker	
		2 Currently smokes - cigarettes	_____ cigarettes/day (average)
		3 Currently smokes – pipe/ rolls own	_____ oz/day (average)

The following questions are asked by the Deaf Advocate

- **Access to healthcare**

7.0	How do you make contact with your Health Centre or GP	1. text message 2. typetalk 3. by going in person 4. ask a member of family or friend to call 5. fax 6. online booking system
7.1	Do you find this method of contact	1. very easy 2. easy 3. OK 4. difficult 5. very difficult
7.3	How helpful do you find the receptionists at your GP surgery or health centre?	$_0$ Very helpful $_1$ Fairly helpful $_2$ Not very helpful $_3$ Not at all helpful
7.4	In the past 6 months, have you tried to see a doctor fairly quickly? By 'fairly quickly' we mean on the same day or in the next 2 days the GP surgery or health centre was open. **If yes, ask 7.5 or else got to 7.6**	$_1$ Yes $_0$ No $_3$ Can't remember
7.5	Thinking about the last time you tried to see a doctor fairly quickly. Were you able to see a doctor on the same day or in the next 2 days the GP surgery or health centre was open? **If no, ask 7.2c, or else got to 7.7**	$_1$ Yes $_0$ No $_3$ Can't remember
7.6	If you couldn't be seen within the next 2 days the GP surgery or health centre was open, why was that?	$_0$ There weren't any appointments $_1$ The times offered didn't suit me $_2$ The appointment was with a doctor I didn't want to see $_3$ I could have seen a nurse but I wanted to see a doctor $_4$ Another reason $_5$ Can't remember
7.7	In the past 6 months, have you tried to book ahead for an appointment with a doctor? By 'booking ahead' we mean booking an appointment more than 2 full days in advance. **If yes, ask 7.8, or else got to 7.9**	$_1$ Yes $_0$ No $_3$ Can't remember
7.8	Last time you tried to, were you able to get an appointment with a doctor more than 2 full days in advance?	$_1$ Yes $_0$ No $_3$ Can't remember

7.9	When did you last see a doctor at your GP surgery or health centre? **If "More than 6 months ago", ask 7.10 else go to 7.11**	0 In the past 3 months 1 Between 3 and 6 months ago 2 More than 6 months ago 3 I have never been seen at my present GP surgery or health centre
7.10	Why haven't you seen a doctor in the past 6 months?	0 I haven't needed to see a doctor 1 I couldn't be seen at a convenient time 2 I couldn't get to the GP surgery or health centre easily 3 I didn't like or trust the doctors 4 Another reason, please specify _____
7.11	Is there a particular doctor you prefer to see at your GP surgery or health centre? **If yes ask 7.12 else go to 7.14**	1 Yes 0 No 3 There is usually only one doctor at my GP surgery or health centre
7.12	How often do you see the doctor you prefer to see?	0 Always or almost always 1 A lot of the time 2 Some of the time 3 Never or almost never 4 Not tried at this GP surgery or health centre
7.13	Is there a special reason for you to prefer that GP	good communication many years of contact etc

Last time you saw a doctor at your GP surgery or health centre, how good was the doctor at each of the following?

		Very good	Good	Neither good nor poor	Poor	Very poor	Doesn't apply
7.14	Giving you enough time	0	1	2	3	4	5
7.15	Asking about your symptoms,	0	1	2	3	4	5
7.16	Listening to you	0	1	2	3	4	5
7.17	Explaining tests and treatments	0	1	2	3	4	5
7.18	Involving you in decisions about your care	0	1	2	3	4	5

7.19	Treating you with care and concern	0	1	2	3	4	5
7.20	Taking your problems seriously	0	1	2	3	4	5

7.21	Did you have confidence and trust in the doctor you saw?	0 Yes definitely 1 Yes to some extent 2 No, not at all 3 Don't know/can't say
7.22	Have you seen a practice nurse at your GP surgery or health centre in the past 6 months?	1 Yes 0 No 3 Can't remember
7.23	How easy is it for you to get an appointment with a practice nurse at your GP surgery or health centre?	0 Haven't tried 1 Very easy 2 Fairly easy 3 Not very easy 4 Not at all easy 5 Don't know.

Last time you saw a practice nurse at your GP surgery or health centre, how good was the practice nurse at each of the following?

		Very good	Good	Neither good nor poor	Poor	Very poor	Doesn't apply
7.24	Giving you enough time	0	1	2	3	4	5
7.25	Asking about your symptoms	0	1	2	3	4	5
7.26	Listening to you	0	1	2	3	4	5
7.27	Explaining tests and treatments	0	1	2	3	4	5
7.28	Involving you in decisions about your care	0	1	2	3	4	5
7.29	Treating you with care and concern	0	1	2	3	4	5
7.30	Taking your problems seriously	0	1	2	3	4	5

7.31	In general, how satisfied are you with the care you get at your GP surgery or health centre?	0 Very satisfied 1 Fairly satisfied 2 Neither satisfied nor dissatisfied 3 Fairly dissatisfied 4 Very dissatisfied
7.32	When you go to see a doctor how do you *usually* communicate with him/her?	1. BSL (British Sign Language) using an interpreter * 1 2. SSE (Sign Supported English) using an interpreter *2 3. BSL without an interpreter 4. SSE without an interpreter 5. Spoken English 6. Spoken English and Lip Reading 7. Mixture of speaking and signing 8. Write things down
7.33	What would be your *preferred* communication method in a consultation with a doctor or nurse?	1. BSL (British Sign Language) using an interpreter * 2. SSE (Sign Supported English) using an interpreter * 3. BSL without an interpreter 4. SSE without an interpreter 5. Spoken English 6. Spoken English and Lip Reading 7. Mixture of speaking and signing 8. Write things down 9. I have a friend or family member with me to interpret 10. Other (please specify)
7.34	Do you communicate with your GP?	Very well well OK 0 1 2
7.35	If you could do one thing to improve access, what would it be?	

The Medical Assessment is carried out by the BUPA Health Adviser and the results are given immediately afterwards. The explanation is translated to BSL by an interpreter.

- **Medical examination**

Essential

8.1	Pulse	_____ bpm	0 Regular	1 Irregularly irregular	3 Not sure
8.2	Height	_____ m			
8.3	Weight	_____ kg			

8.4	BMI *	_____ kg/m²			
8.5	BP (best of three)	Systolic *	_____ mmHg		
		Diastolic	_____ mmHg		

Note: The BUPA assessment includes:
Blood pressure and pulse measurement
Body mass index (BMI) measurement
height-to-waist ratio
Body fat percentage
full cholesterol test profile (including ldl and hdl cholesterol)
HbA1c – diabetes measure
coronary heart disease risk assessment
diabetes risk assessment
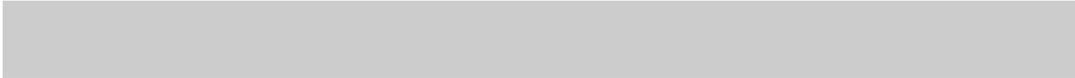
17. Appendix 2 Interview schedule for personal data

Deaf Health Project
PERSONAL DATA RECORD
(store page 1 separately from the other details)

Location of interview:
Interviewer:
Date of Interview:
Purpose of interview explained?   Yes ❑
Consent form signed?   Yes ❑

_____

Participant Record Number: _____

PERSONAL INFORMATION

1.   **Full Name:**

_____

2.   **Address Details:**

Address 1:   _____

_____

_____

3.   Post Code: _____

4.   **Contact Details:**

Minicom or Text Number: _____

Fax Number: _____

E-mail Address:

_____

5.   **Date of Birth:**   _____ *Day*   _____ *Month*   _____ *Year*
6.   **Gender:**   *Male:* ❑   *Female:* ❑
7.   **Your marital status is:**
   Married: ❑   *Single:* ❑   *Divorced:* ❑   *Separated:* ❑   *Widowed:* ❑
8.   **What is your ethnic group?**

   A. White:
   English ❑ Welsh ❑ Scottish ❑ Northern Irish ❑ British ❑

Irish ❑
Gypsy or Irish Traveller ❑
Any other White background, write in _____

B. Mixed/multiple ethnic groups
White and Black Caribbean ❑ White and Black African ❑   White and Asian ❑
Any other Mixed / multiple ethnic background, write in

_____

C. Asian / Asian British
Indian ❑ Pakistani ❑ Bangladeshi ❑
Chinese ❑ Any other Asian background, write in _____

D. Black / African / Caribbean / Black British
African ❑ Caribbean ❑
Any other Black / African / Caribbean background, write in

_____

E. Other ethnic group
Arab ❑   Any other ethnic group, write in _____

Participant Record Number: _____

COMMUNICATION AND HEARING

9. **Do you call yourself:**

    Deaf: ❑   *Hearing Impaired:* ❑   *Hard of Hearing:* ❑ *Partially Hearing:* ❑

10. **What is your preferred method of communication?** *(Please tick __one__ only!)*

    Sign Language: ❑   *Spoken Language:* ❑   *Signing and Speaking*: ❑
    Gestures: ❑   *Writing:* ❑   *Other:* ❑ _____

11. **When did you become Deaf?**

    At birth: ❑   *0 – 3 years:* ❑   *3 – 6 years:* ❑   *6 years or older:* ❑

12. **Do you wear a hearing aid**

    Always sometimes never

13. **Do you use a cochlear implant**

    Always sometimes never

14. **Without wearing a hearing aid or cochlear implant, can you hear at all, a person talking in a normal voice two feet away from you?**
    Yes ❑   *No* ❑

15. **Without wearing a hearing aid, can you hear at all a person shouting on the other side of the room?**
    Yes ❑   *No* ❑

YOUR FAMILY

16. **Tell us about your family:**

Members	*How many?*	Deaf or Hearing?
Mother		Deaf ❑ Hearing ❑
Father		Deaf ❑ Hearing ❑
Brother (s)		Deaf _____ Hearing_____
Sister (s)		Deaf _____ Hearing _____
Husband/ wife/ partner		Deaf ❑ Hearing ❑
Your children		Deaf _____ Hearing_____

YOUR JOB AND QUALIFICATIONS

17. **Are you:**

Employed: ❏   *Unemployed:* ❏   *Retired:* ❏
Student: ❏   *At home*: ❏   *Other:* ❏

18. **What is your main job title?**

_____

19. **What does your job involve?**

_____

_____

___

20. **How many hours per week do you usually work?** _____

21. How old were you when you left school? _____ years

22. **When you were at school, what qualifications did you get?** (List the three best)

Subject	A-Level	GCSE	O-Level	CSE	Other	Year Achieved

23. **After you left school, did you achieve any qualifications?** (list the three best)

Subject	A-Level/ GCSE/ O-level/ Certificate/ Diploma/ Degree

SIGN LANGUAGE

24. **At what age do you think you <u>learned</u> signing?**

Younger than 5 years ❏   *Between 5 and 10 years* ❏
Over 10 years but before you left school ❏   *After you left school* ❏

25. **Where did you learn sign language?**

At school ❏   *From your parents/ family* ❏   *On a course* ❏
From other deaf people outside of school ❏
From other deaf people inside school ❏   *Other:* ❏ _____

26. Do you always understand other deaf people who are signing to you?
yes sometimes no

27. Do you understand other deaf people when they are signing to each other?
yes sometimes no

28. Do you always understand the interpreter?
yes sometimes no

WHERE YOU LIVE

29.   Is your house in the:

City Centre ❏   *Suburbs* ❏   *Village* ❏   *Countryside* ❏

30.   How many people live with you? (apart from yourself)

[If family members – indicate what relationship you have e.g. mother, father, partner, etc. If not family member, is it flatmate, boarder, landlord, etc?]

Type of relation	Are they …?		They communicate with you in:				
	Deaf	*Hearing*	*Sign*	*Gesture*	*Sign & Speech*	*Writing*	*Speech*

OBTAINING INFORMATION

31.   For information do you read:

	Every day	*At least once a week*	*Once a month*	*Rarely*	*Never*
Newspapers					

Deaf News					
Magazines					
Books					

32. Do you use a computer to obtain information?

Yes with confidence ❏ yes but I am not confident ❏ rarely or never ❏

33. Do you use the Internet to find out about staying healthy?

Every day ❏   At least once a week ❏   At least once a month ❏
Rarely or never ❏

34. If you find a difficult medical or health word, do you

look it up on the Internet ❏
ask a friend or family member ❏
look it up in a book ❏
don't bother ❏

<mark>GOING TO THE DOCTOR</mark>

35. Thinking about the last 12 months, how often did you go to:

	16 or more times	10-15 times	5-9 times	Less than 5 times	Never
a) GP Surgery or Health Centre					
b) NHS hospital					
c) Private hospital					

36. Thinking about the last year, did you make repeat visits to the doctor for the same problem?

yes ❏ no ❏

37. When you made a repeat visit why was this?

the doctor asked you to come back ❏
you did not get enough information the first time ❏
the information the first time was not clear ❏
the medicine was not correct ❏
the problem got worse ❏
you needed more medicine ❏
other reason ❏ _____

38. **Have you booked/used sign language interpreters for the following people/places?**
    a) Visiting doctor
    b) Hospital appointment
    c) Health workshops or health information days
    d) Health appointments for your child or relation

<mark>YOUR PHYSICAL HEALTH</mark>

39. Compared to one year ago, how would you rate your health in general <u>now</u>?

Much better now than one year ago ❏   Better now than one year ago ❏
About the same ❏   Worse now than one year ago ❏
Much worse than one year ago ❏

40. **What exercise do you take?**

_____

41. **How often do you do exercise?**

_____

42. **Do you think you are well, physically:**

Very well ❏   *Quite well* ❏   *Well enough* ❏   *Not very well* ❏

YOUR MENTAL HEALTH

43. Do you feel you are well "inside":

Very well ❏   *Quite well* ❏   *Well enough* ❏   *Not very well* ❏

44. Do you think that deaf people have more mental health problems than hearing people?

Yes ❏   *No* ❏   *Do not know* ❏

45. If you had a question about health, would you use a help-line (e.g. NHS Direct)?

Yes ❏

Yes but only with *video relay service* ❏

yes with text relay service (TypeTalk) ❏

No ❏

Do not know ❏

46. If you were feeling depressed who would be the <u>first</u> person you would tell about the problem? (tick one only)

Family ❏   *Close friend* ❏   *Doctor* ❏   *Social worker* ❏
Professional in Mental Health ❏   *Help-line* ❏   *Interpreter* ❏ *No one* ❏

47. Who would you prefer to have help from? (tick one only)

Deaf person ❏   *Hearing person* ❏   *Both* ❏ *Do not know* ❏

48. Why would you want them to help?

_____

IN GENERAL

49. Do you feel that the health service for Deaf people is

Very good ❏ good ❏ OK ❏ not good ❏ poor

50. In the last 12 months, do you feel personally, that you had a

a good service/support from the health service? ❏

a poor service/support from the health service ❏

Not sure ❏

Thank you

there is now a second part where we can talk about your experiences in more detail

Deaf Health Project

PART 2: Open Questions

This section to be used by the Interviewer only

Encourage the person to talk openly and freely about the experiences.

Use only one question in each section – use the probing questions only if the interviewee does not give much information from the first.

Explain the purpose of the questions informally – for example,

" we want to find out about your experiences of using health services and receiving information. We want to know what happened and how you managed to get around the problems if there were any. We especially need to know about how you communicated and if you understood. Also tell us about your experiences in using BSL either with hearing friends or family or interpreters."

Explain that the session will be video recorded but will be used only to allow analysis of what has been said. It will be viewed only by the immediate research team at the University of Bristol and will not be shown elsewhere. Any quotes from what people tell us, will be disguised so that the person cannot be identified.

After the warm up, you can vary the order of the questions according to what the people say and you can add new examples if it makes it easier for them to describe their experiences. However, you should mark the order you used for the questions, in the margin.

Warm Up questions

(a) Can you remember any situations where you went somewhere and were surprised to find the person at doctor or hospital could communicate with you on signing or fingerspelling? Tell us what happened.

(b) Are there any other situations where you went and you found that the people at the desk or in the service, could not understand you and you had to give up in frustration? What did you feel at the time and then afterwards, did you do anything to complain? Did you ever go back to that place?

Contacting Health Services about your physical health

Thinking about the last year, how do you usually contact your doctor or health centre if you or your family have health issues?

Has this process been smooth or have there been some problems?

Do they book an interpreter for you?

Do you find them helpful?

On arrival and at reception

When you arrive at the reception desk in your health centre, are you able to understand and be understood by the receptionist?

Do you feel this is a smooth process or are there some stresses?

How do you usually communicate with the receptionist?

Do you think this situation could be improved – how?

If you are waiting for service

Can you tell us about good experiences or bad experiences you have had when in the waiting room?

How do you know when it is your turn to go to see the doctor or nurse?

Have there been embarrassing experiences in waiting your turn?

Going to hospital

Can you tell us about the last time you went to the hospital for yourself or with a family member or friend?

Did you feel you had a good service?

What were the problems? Which aspects were good?

Waiting at Hospital

At the Emergency & Accident Department in the hospital or at a clinic in hospital, you usually have to wait your turn…
Can you tell us about your experiences in the waiting room in the hospital.
How recently was this?
How would you improve facilities for the deaf people in the waiting rooms?

Going to the Dentist

Can you tell us about your experiences of going to the dentist
Is it possible to improve this service for Deaf people?

CURRENT MEDICAL ISSUES
(this section will be the most extensive in discussing current health)

Discovering the problem

You have mentioned in your medical assessment replies that you have had xxx health problem, can you tell me about how this was discovered and how you are being treated?

How were you told about this?

How did you feel at the time?

What were they able to do for you?

Preventing the Problem

Was it possible for you to know about the problem earlier?

Could the tests be carried out earlier?

How would it help if you had known earlier?

What would be good for Deaf people so that they know more about this problem?

<allow the person to talk in detail about the current health problem and how they feel about it>

Your Medical Assessment

As part of the project, you recently attended a BUPA centre and went through a number of medical tests.

What information did you receive about yourself?

How was the information given to you?

Did you receive adequate feedback on the results of the tests?

After Your Medical Assessment

When you attended, you were given the results of your tests and this was explained. Did you discover some new information about your health?

What did you feel about this?

Did you learn new information about your health?

Do you feel this medical assessment helped you?

Do you now have more clear information (is it still confusing?).

Going to the GP afterwards

Did you go to see your doctor as a result of this?

What did your GP say to you about the tests and results?

Mobile Text messaging

Most deaf people have mobile phones and can text each other

If doctors were to start using the text system for contact, do you think this would be beneficial to deaf people.

Would it be helpful to use texts with hospital or clinics?

What other things would you like to see in future with texting/SMS?

Internet

Nearly every house has access to the Internet…

What kind of information do you look for on the Internet?

What sort of medical advice have you looked for on the Internet?

Using newsletters, leaflets, video

Now Deaf organisations made information videos with signing…

Have you seen any signed videos? Were they any good? What have you learned from these videos?

Have you looked at leaflets about health? Were these helpful?

Have you seen information about health in magazines? Was this helpful?

What is the best way to give health information to Deaf people?

 (To the Interviewer) remember to say Thank you

Don't forget to ask the person to sign the payment/claim form. Make sure you have completed all questions

18. Appendix 3 Deaf Health Summary

Deaf people's health and Deaf people's access

A project funded by Big Lottery Fund with SignHealth and University of Bristol

Are Deaf people as healthy as hearing people? What happens when Deaf people go to the doctor?

We want to find out so that we can improve the services for Deaf people.

Three hundred Deaf people will have a free health check-up at the nearest BUPA centre. The project will provide BSL interpreters to make sure there is good communication.

A Deaf advocate (support person) will be there as well, to help out with explanations.

At each BUPA centre, there will be tests like weight, pulse, and blood pressure. There are also questions about health and access. There is a consent form to fill in to allow us to analyse the results. At the end, there is an explanation of the test results. The check-up and explanation takes about one and a half hours. The results can go to the GP as well.

All the information is confidential and is used only by the University of Bristol. We will not show information which lets anyone find out who has given the answers.

We will write a report for Health Authorities to help them to understand Deaf people's views. We expect to make the services better for Deaf people.

We will also have workshops and BSL information for Deaf people.

The project will finish in 2013.

More information: Dr Hilary Sutherland, Centre for Deaf Studies, University of Bristol, 8 Woodland Rd, Bristol BS8 1TN   www.deafhealth.org.uk