

A REPORT INTO THE HEALTH OF DEAF PEOPLE IN THE UK



**THE DEAF HEALTH
CHARITY
SIGNHEALTH**



FOREWORD

This report should be enthusiastically welcomed by the Deaf community and everyone who works in healthcare. It's the first time we've ever had such valuable information on the health of Deaf people. It really is long overdue.



I hope this report makes us all think carefully about what we can each do to end the unfairness and injustice. The research makes it clear that there is a lot to learn, and plenty to do.

The really good news is that the recommendations are inexpensive, simple steps which anyone can take. It just needs the health service to think about the needs of all patients, Deaf as well as hearing.

I'm only here because SignHealth and others are already working to make things better. Their online InterpreterNow service helped to save my life, when I needed to contact a doctor late at night, in an emergency.

Before that I had gone through eleven operations, a kidney transplant, a heart attack and a hernia, without ever having an interpreter.

Deaf people are the experts in the best way to communicate with deaf people, and we know what needs to be done. We will help to make the change easy.

This research shows that as Deaf people we face everyday barriers that the wider community simply wouldn't put up with.

Can you imagine forcing hearing people to walk to their GP's surgery to book an appointment? Can you imagine them having to explain their problems to a doctor who does not understand English, and who replies in another language?

The government and the NHS are already planning some changes which will benefit Deaf patients, but it's not enough and it's too slow. Online booking for appointments is a good example, it will be a huge help - but the deadline for doctors to make it happen has been delayed for years.

As the report points out, easier access is an important starting point, but it is not enough.

Everyone involved in health care, from government and commissioners to doctors and nurses, need to work with organisations such as SignHealth to find other ways to reduce these health inequalities.

Getting services right for Deaf people will be a big step towards making the health service fit for everyone. The changes we're talking about are important ... and I know that more than most.

Andrew McCafferty
Deaf Patient

25th March 2014

EXECUTIVE SUMMARY

The DeafHealth study is the largest and most extensive study of the health of Deaf people in the world so far. It set out to find out about Deaf people's experience of healthcare, whether Deaf people have poorer health than the rest of the population, to suggest reasons for any inequalities, and to identify practical measures that could reduce them.

The study found poorer health, poorer diagnosis and poorer treatment/management. These three problems were probably largely caused by poor access to services, poor communication, and poor access to information.

Issues with poor access and communication suggest the health service is at risk of harming Deaf patients. It is certainly not meeting the requirements of the NHS Constitution or the Equality Act.

Findings on medical care

- Deaf people have generally healthier lifestyles than the rest of the population in terms of smoking and alcohol, but are more likely to be overweight.
- High blood pressure was almost twice as common in Deaf people as in the rest of the population.
- Deaf people are twice as likely as hearing people to have high blood pressure which has not been diagnosed. They may also be more likely to have undiagnosed diabetes, high cholesterol and cardiovascular disease.
- Even when Deaf people have been diagnosed, they are less likely than hearing people to be adequately treated for these conditions (high blood pressure, high cholesterol, diabetes and cardiovascular disease).
- Under-diagnosis and under-treatment of potentially serious conditions is more common in Deaf people.
- Together these may put Deaf people at risk of **preventable** heart attacks and strokes, and diabetic complications such as kidney failure and blindness.
- As these conditions cause long-term ill-health, disability, and death, urgent measures are needed to address this marked health inequality.

Findings on access

- Deaf people are being denied access to health services.
- Services are not allowing Deaf people to communicate in their preferred language (BSL).
- Health information is not accessible to Deaf people.
- Most of the necessary actions are simple and cost-neutral, or cost-saving, in terms of improving access to services, communication with health staff, and improved management of long-term conditions.
- There is a large, avoidable cost to the NHS because of these health inequalities (in excess of £30m/year).

INTRODUCTION

Why do this research?

There are a lot of deaf people in the UK. With an ageing population, about one in seven people has some kind of 'hearing loss'.¹ There are an estimated 70,000 profoundly deaf people in the UK who were born deaf, or became deaf at an early age.² Their preferred language is usually British Sign Language (BSL), and they have their own culture and community. Most of this report focuses on this group, who are known as Deaf with a capital 'D' to distinguish them from people who are hard of hearing or severely deaf, and who usually have English as their first or preferred language. While our research has focused on Deaf people, many of the barriers faced and solutions suggested apply to all deaf people.

Deaf people face barriers accessing NHS services, and both Deaf people and healthcare staff have difficulties communicating in consultations.³ One UK study recorded that BSL/English interpreters were present at just 17% of GP and 7% of A&E consultations.⁴ Another study found that over three-quarters of Deaf patients had difficulty communicating with hospital staff. One-third left GP consultations uncertain about their condition and a third were unclear about how to take medication or had actually taken the wrong dosage. Most alarmingly, almost a third avoided booking to see their GP because of communication difficulties.⁵ Surveys in the US and Scotland have found lower understanding and knowledge of health issues among Deaf people.^{6,7,8}

SignHealth has supported countless Deaf people who are ill. Time and time again we were told appalling stories about poor levels of care. We felt sure that Deaf people had poorer health than hearing people, as well as poorer access to health services. There is strong evidence that Deaf people have poor access to healthcare and that they have about twice the prevalence of mental health problems as the rest of the population. However, there was very little research worldwide on the physical health of Deaf people.

Our hypothesis was that, given their poorer access to healthcare and health information, Deaf people would have poorer health than the rest of the population. The Deaf Health study is the most extensive study of the health of Deaf people in the world to date. This report is an attempt to fill the gap, examine the health inequalities between Deaf and hearing people, and to suggest steps to improve this.

¹ See the SignHealth website for a discussion of Deaf population estimates <http://www.signhealth.co.uk/about-deafness/deaf-awareness/>

² The term 'Deaf' is used throughout this report to describe people who were deaf before the age of five, prefer to communicate in BSL and see themselves as part of the Deaf community. The term 'deaf' is used for the broader deaf population (including those who became deaf later in life and who have English as their first language).

³ Alexander A, Ladd P, Powell S, 'Deafness might damage your health', *The Lancet*, Volume 379, Issue 9820, (2012), 979-981

⁴ Reeves D, Kokoruwe B, Dobbins J, Newton V. *Access to primary care and accident and emergency services for deaf people in the North West*, Manchester: National Health Service Executive North West Research and Development Directorate, 2004.

⁵ *A Simple Cure*, RNID, 2004

⁶ Woodroffe T, Gorenflo DW, Meador HE, Zazove P. 'Knowledge and attitudes about AIDS among deaf and hard of hearing persons', *AIDS Care* 1998; 10: 377-386

⁷ Kyle J, Allsop L, Griggs M, Reynolds S, Macdonald J, Pullen G. *Deaf health in Scotland: issues for deaf people in health promotion: report to the Health Education Board for Scotland*, Bristol: University of Bristol Centre for Deaf Studies, 1996

⁸ Barnett S, McKee M, Smith SR, Pearson TA. 'Deaf sign language users, health inequities, and public health: opportunity for social justice', *Prev Chronic Dis* 2011; 8: 1-6.

WHAT DID WE DO?

There were three stages to the research. An online survey, individual health assessments and semi-structured interviews. The second and third stages were funded by the BIG Lottery and done in partnership with the University of Bristol.

Online survey

This was the first major survey of its type in the UK and was open to all deaf people. It was carried out by Ipsos MORI, and mainly done online (by watching questions signed in BSL), but it could also be completed on paper. Five hundred and thirty-three Deaf people completed the survey, answering questions about their lifestyle, health, and access to health services.

Wherever possible the survey data has been compared with UK or England-wide comparative data drawn from large national surveys of the general population. Without any knowledge of the profile of the UK Deaf population it is not possible to calculate the extent to which survey respondents are *representative* of Deaf people, although efforts were made to ensure the survey was as inclusive as possible so that it is at least *reflective* of the UK Deaf population. The full findings from of the online survey can be found separately in *Research into the health of deaf people*.⁹

Individual Health Assessments

Standard Bupa health assessments were organised for 300 Deaf people selected using a simple sampling frame, so they were representative of the wider population in terms of age and sex. BSL interpreters and Deaf advisers were present and additional questions were asked about access. This gave us the first, quantitative clinical data from such a large group of Deaf people.

In-depth health interviews

Qualitative, semi-structured interviews were completed with 47 Deaf people. These people were selected because we knew from their health assessment that they had an interesting health story. For instance, we knew they had been in hospital for an operation, or had a chronic health condition. The aim of the interview was to understand more about the Deaf person's *experience* of their health and health services.

⁹ Research into the health of deaf people, SignHealth, 2014

LIFESTYLE

The survey found fewer Deaf respondents were in full-time work, more were in part-time work, and fewer had fully retired from work compared with data drawn from the 2009-2010 English Housing Survey.

Exercise

Most respondents did at least some regular physical activities. Seven in ten (69%) reported that they did housework; almost half (45%) reported they did some form of aerobic exercise (such as walking, running, swimming, cycling, dancing or a team sport) and a slightly smaller proportion (42%) reported doing gardening or DIY work. Seven per cent of respondents reported that they did not undertake any physical activity. Around a third of respondents (30%) reported exercising 3–6 times a week and a similar proportion (29%) reported exercising 1–2 times a week. This appears broadly similar to the general population.

Diet

Deaf respondents consumed a similar number of portions of fruit juice and a slightly greater amount of vegetables than respondents in the Health Survey of England 2008. However, Deaf respondents were more likely to eat fried food, and to eat it more frequently.

Smoking and Alcohol

Smoking rates appear to be lower among the Deaf population (8% compared to 20% of the general population). This mirrors a finding in an international study.¹⁰ Alcohol consumption was also lower among Deaf people (5.5 units/week for men and 3.4 units/week for women, compared to 15.9 and 7.6 for the general population).

¹⁰ Barnett S, Klein JD, Pollard RQ, Samar V, Schlehofer D, Starr M, Sutter E, Yang H, Pearson TA. Community participatory research with deaf sign language users to identify health inequities. *Am J Public Health* 2011; 101:2235-8.

HEALTH

- Deaf people have generally healthier lifestyles than the rest of the population in terms of smoking and alcohol, but are more likely to be overweight.
- High blood pressure was almost twice as common in Deaf people as in the rest of the population.
- Deaf people are twice as likely as hearing people to have high blood pressure which has not been diagnosed. They may also be more likely to have undiagnosed diabetes, high cholesterol and cardiovascular disease.
- Even when Deaf people have been diagnosed, they are less likely than hearing people to be adequately treated for these conditions (high blood pressure, high cholesterol, diabetes and cardiovascular disease).
- Under-diagnosis and under-treatment of potentially serious conditions is more common in Deaf people.

High blood pressure

More common in Deaf people

The study showed that over one-third of Deaf people (37%) had high blood pressure compared to 21.1% of the general population. This finding was particularly striking for men.

Not diagnosed

One in seven Deaf people (15%) had high blood pressure but were not aware of this, compared with 6% of the rest of the population. Although doctors pick up high blood pressure in people every day, undiagnosed high blood pressure was more than twice as common in Deaf people. Worryingly, over a third (34%) of Deaf people who were unaware they had high blood pressure had levels that were high or very high. As high blood pressure does not usually cause symptoms, these people would not know they had it and so would not be prompted to visit their doctor or alter their lifestyle. It therefore puts them at risk of complications such as heart attacks and strokes.

Not properly treated

Of those Deaf people who already had a diagnosis of hypertension, nearly two-thirds (62%) were still found to have high blood pressure, compared to 20% of the general population.¹¹ Only one-third (36%) were on treatment compared with 57% of the rest of the population. This suggests Deaf people's hypertension is not being properly treated and managed. This is worrying for a potentially serious condition.

High blood pressure is therefore both under-diagnosed and under-treated in Deaf people, putting them at higher risk of heart attacks and strokes.

¹¹ Quality Outcomes Framework (QoF), <http://qof.hscic.gov.uk/>

High cholesterol (blood fats)

This is also a risk factor for heart disease and strokes.

Nearly one-third (32%) of the Deaf participants had a higher than desired level of cholesterol, although this was less common than in the general population (57%). However, only one-third (31%) were taking cholesterol-lowering medication, compared to over two-thirds of the general population, suggesting that many did not know they had a condition which needed treatment.

Again, this suggests many Deaf people are not receiving the treatment needed to prevent the potential complications of high cholesterol, such as heart attacks and strokes.

Cardiovascular disease

Disease of the heart and blood vessels can lead to heart attacks and strokes.

- Deaf people reported much less cardiovascular disease than expected – about half that of the rest of the population (7% compared with 13%).
- More than half (55%) of the Deaf people who said they did have cardiovascular disease were not receiving appropriate treatment for it.

The lower prevalence of cardiovascular disease may be due to lower levels of smoking and cholesterol, despite more of the Deaf people having high blood pressure. However, the fact that more than half were not on appropriate treatment, raises the possibility that barriers to access and communication in the healthcare system could be contributing to the lower rate of diagnosis in Deaf people. It is worrying that over half of Deaf patients were not on appropriate treatment, and again suggests communication and access issues.

Diabetes

Undiagnosed diabetes

Diabetes can lead to cardiovascular disease, kidney failure and blindness. It usually develops gradually while the patient is unaware. About 2% of people in England have diabetes or pre-diabetes but have not yet been diagnosed. However, 7.6% of Deaf people had higher than normal blood sugar levels and were not aware of this, suggesting that undiagnosed diabetes may be more common in Deaf people.

Poor treatment

Deaf people had a similar rate of diagnosed diabetes as the rest of the population (about 6-7%). However, over half (56%) of those with known diabetes had high fasting blood sugar levels suggesting that their diabetes was not properly controlled.

There could be a number of reasons for this. Poor communication could be leading to medication errors, or inadequate patient education in diabetes self-management. Whatever the causes, it suggests clinicians need to ensure Deaf patients fully understand their condition, and how to manage it. This will involve communicating in the Deaf patient's preferred way, for example via a registered BSL/English interpreter.

In summary, as with high blood pressure and high cholesterol, under-treatment of diabetes puts Deaf people at increased risk of complications such as cardiovascular disease, kidney failure and, particularly devastating for people who rely on visual communication, blindness.

Weight

We know that obesity is an increasing problem in this country. However, it is even more of a problem in the Deaf community. A higher proportion of Deaf people were overweight (71%) or obese (30%) compared to the general population (61% and 25%). This was more common in Deaf people over 65, of whom 90% were overweight. Being overweight can increase the risk of heart disease, diabetes, arthritis and some cancers. Nearly half (48%) of the Deaf people in the study are at high or very high risk based on their BMI and waist circumference measurements.¹²

Deaf people consume slightly more vegetables and a similar amount of fruit juice to the general population, but more fried food. We found access to nutrition and activity information in BSL is limited, as is access to weight loss groups and gyms. We know that, following the health assessments, at least one person tried to attend a weight loss group. Unfortunately, no communication support was provided so they stopped attending.

Mental health

Although this study looked at physical, rather than mental health, Deaf people reported more depression than the rest of the population (24% compared with 12%), in keeping with previous studies.

Conclusions

Deaf people have generally healthier lifestyles than the rest of the population in terms of smoking and alcohol, but are more likely to have high blood pressure and to be overweight.

Many participants had results which suggested they should be receiving monitoring and/or treatment. But, until being tested as part of the research they were unaware that anything was wrong. This was the case with people with high blood pressure, and possibly also with high cholesterol and high blood sugars. This raises the question of whether Deaf people's illnesses are being routinely identified.

The other worrying finding was that a high proportion of people who had been diagnosed with a condition still did not seem to have it under control. This was the case with Deaf people with hypertension, cardiovascular disease, diabetes and high cholesterol. This raises questions about whether the diagnosis has been properly conveyed, whether clinicians are monitoring it sufficiently, and whether Deaf people are given information in an accessible format. We know from the in-depth interviews that many Deaf people were unsure about what they were taking medications for.

In both these instances, communication is vitally important, and appears to be letting down Deaf people. It should not be unreasonable to expect that all patients should know what conditions they have been diagnosed with and what is being done to treat them.

- Deaf people are more likely than hearing people to be unaware that they have conditions such as high blood pressure, and possibly also diabetes, cardiovascular disease and high cholesterol.
- They are also more likely to be on inadequate treatment for these conditions when they have been diagnosed.
- Together these may **preventably** put Deaf people at risk of heart attacks and strokes, and diabetic complications such as kidney failure and blindness.

¹² 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. <http://www.nice.org.uk/guidance/CG43> page 4 (Accessed 20/08/2012).

- As these conditions cause long-term ill-health, disability and death, urgent measures are needed to address this marked health inequality.
- Most of the necessary actions are simple and cost-neutral or cost-saving in terms of improving access to services, communication with health staff, and improved management of long-term conditions.
- The increased risk is unnecessarily costing the NHS £30m every year.¹³

¹³ Figure from analysis prepared for SignHealth by Health Economics Consulting, University of East Anglia.

ACCESS TO HEALTH SERVICES

Deaf people have poorer access to health services, poorer communication in consultations, and poorer access to health information.

The patient journey

Making an appointment

A shocking 45% of Deaf people go to their GP practice in person to book an appointment. For hearing patients, the telephone is used by the vast majority. Perhaps as a consequence, 44% of Deaf people said they found contact with their GP practice "difficult or very difficult".

Most Deaf people have a preference which GP they see, but interestingly they are less likely than a hearing person to get their preferred doctor (with the exception of Deaf people aged over 65). Most Deaf people preferred a particular doctor because they found communication easier. However, for older Deaf people, the preference for a particular doctor was based on the relationship built up over time.

It is worth mentioning the importance of receptionists. Health policy normally ignores receptionists and yet they play a crucial role as far as patients are concerned. Your experience of a health service can sometimes be decided by how good the receptionist is. This is particularly the case if you are Deaf and may have 'extra' contact with the receptionist, e.g. asking for an interpreter, being called from the waiting room, etc.

When the general population was asked about satisfaction with the receptionist, 8% said they were "not very helpful" or "not helpful at all". When Deaf people were asked this shot up to a massive 39.8%.

Not making an appointment

It is clear there is a marked disparity between the respondents to the GP Patient Survey where nine in ten (90%) people who had not visited a GP recently said this was because they had not needed to, compared with just 30% of Deaf respondents. That means that of the Deaf people who had not seen their GP 70% had wanted to but had not.

A similar picture appears with other health services. In the online survey, 41% of Deaf respondents said they had not been able to access other services. Of these, 56% reported not using health services because they had no interpreter to accompany them. One-third (33%) had not because they couldn't arrange an appointment easily. So, there is a sizeable group of Deaf people who need medical help but do not access a service because of the barriers faced.

Perhaps most alarmingly, just over a third (36%) didn't think it worth seeing their GP because the communication was poor. SignHealth has talked before about "barrier fatigue" because of repeated bad experiences of poor access and communication, and battles with the healthcare system. It is clear here that some people would rather risk being ill than face yet more poor communication. Deaf people's low expectations of healthcare are actually affecting their use of health services, potentially to their detriment.

The consultation

Having made it into the consulting room, it is clear the struggle is not over. Whatever the question asked, Deaf respondents reported a far poorer experience than the hearing population (compared to the GP Patient Survey). For instance, 49% of the general population said the clinician was "very good" at giving them enough time. For Deaf people this figure slumped to 18.7%. And when asked whether the clinician was good at listening to them, only 14.8% of Deaf people said they were very good, compared to 51% of

the general population. It was a similar picture for receiving test results and feeling involved in the decision being made. These are worrying findings.

Communication

The GPPS asks questions about communication because it recognises how central this is to the doctor-patient relationship and to health outcomes for patients.¹⁴ Unfortunately, we found that communication is broken as far as most Deaf people are concerned.

There was a big difference between how Deaf people wanted to communicate and what happened in practice. Most wanted to use BSL (about 80%), but few did (about 30%). In reality, many people (about 40%) were using spoken English and lip-reading, while only 3% chose to do so.¹⁵ A significant minority were relying on written notes passed between them and the doctor. Therefore, there is a complete mismatch between what the Deaf patient needs, and what actually happens.

Satisfaction and trust in the doctor

The poor level of communication probably explains the lack of trust Deaf people have in their doctor. Patients need to be able to trust their doctor. We put our life in their hands. The results show a stark difference between Deaf people and the rest of the population.

Asked whether they have "trust and confidence" in their doctor, only 24.6% of Deaf people said "Yes, definitely". This compares to 67% of the general population. Similarly, 18.3% of Deaf people said they had no trust or confidence at all, compared to just 4% of the general population.

The study did not look at specific hospital departments or professions. However, the in-depth interviews confirmed the suspicion that audiology and Ear, Nose & Throat (ENT) departments performed poorly in terms of awareness and access. These departments have more contact with Deaf people than other parts of the hospital. There is, therefore, a reasonable assumption that they will be more Deaf aware and will have mastered communication and access. Unfortunately, this does not seem to be the case. The medical model of deafness dominates. If hospitals want to start improving their services, these departments would be an excellent place to start.

Use of interpreters

The traditional response to these communication barriers has been to use some form of communication support. For most Deaf people this means a BSL/English interpreter. However, the study found that this is not the simple 'quick fix' it is often assumed to be. There is a structured training programme for people to qualify as professional interpreters. Unfortunately, there was a lot of evidence of unqualified interpreters being used. In other cases, professional interpreters were used, but they were still at a junior level and were being expected to interpret very important information. Members of staff with a low level of signing were also being used.

Even with a registered professional interpreter it is still not a level playing field because of the effect of the interpreter on the doctor-patient relationship. The Deaf patient still has to rely on an additional professional and both patient and doctor will be unaware of whether the conversation has been correctly interpreted. These are additional concerns for the Deaf patient on top of the health concerns that they arranged to see the doctor for.

¹⁴ McAlinden C., The importance of doctor-patient communication. *British Journal of Hospital Medicine* 2014; 75: 64-5

¹⁵ Lip-reading is, in most cases, unsatisfactory as the deaf person needs to fill in gaps and use guesswork. This can be particularly difficult when unusual words are being used. In general, levels of literacy are lower in the Deaf population. It should be remembered that many Deaf people have never heard English being spoken, and this is usually the first stage in learning a written language. Therefore, relying on written English is not usually satisfactory.

The effectiveness of the communication between doctors and patients is integral to patient education and understanding, compliance with treatment, and health outcomes.

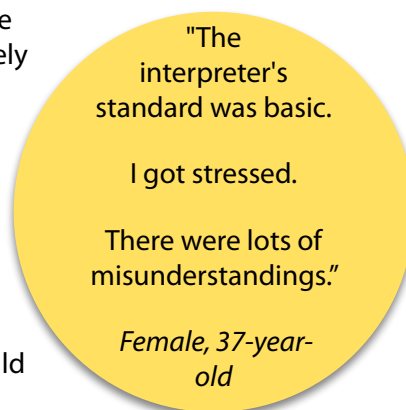
McAlinden C., The importance of doctor-patient communication. *British Journal of Hospital Medicine* 2014; 75: 64-5

Asking for an interpreter to be booked can be difficult. Many people do not like to ask, or ask but are told that one cannot be found. Sometimes patients have been told there will definitely be an interpreter, but then find that there isn't one. They are then faced with the difficult choice between re-arranging their appointment (procedure, or even operation), or trying to make the best of a bad situation, and risking miscommunication which could lead to medical error.

It should be noted that issues with interpreting were not limited to primary care. There was a lot of concern that no interpreters were provided during lengthy hospital admissions. This left people vulnerable, confused and sometimes unable to have their basic care needs met.

Deaf patients were also asked to use family or friends to interpret for consultations. As well as compromising the privacy and autonomy of the Deaf patient, this also risks errors in translation as the individual is unlikely to be at the level of a qualified interpreter. Just because a Deaf patient has had to rely on family or friends previously does not mean they chose to do this, and it is the responsibility of the provider, under the Equality Act 2010, to make the reasonable adjustment of booking a qualified registered interpreter. As always, the deaf patient should be asked what their preference is.

It is important that health care professionals realise the interpreter is as much for them as for the Deaf patient. Without the interpreter they would not be able to take a make a proper clinical assessment, explain the diagnosis and treatment, or discuss the patient's concerns.



Access to information

The in-depth interviews showed that access to health information was poor with clinicians often relying on written information. Similarly, NHS Choices has a huge library of information available in English and some foreign languages.

Unfortunately, most of this information is not easily accessible to Deaf people. They often need to rely on someone else to translate it for them, such as a friend. This would be bad enough for any information, but for something as personal and important as health it is unacceptable. Most hearing people would not be happy with having to ask a friend to explain what an information leaflet says.

Modern healthcare relies on people being given information and then making choices. For Deaf people to be informed, they need information that is accessible. As technology has progressed, the cost of putting information in BSL is now low. A national initiative is needed to put existing information into BSL. And all information provided in the future should be assessed to see how it can be made accessible.

Conclusions

Deaf people have poorer access to health services, poorer communication in consultations, and poorer access to health information.

Access

System seems almost deliberately difficult: from booking an appointment, to requesting an interpreter, to making a complaint. At no stage are things made easy **or equal** for a Deaf patient. Systems should be reviewed with deaf patients in mind. And deaf people must be asked what they would like to see happen.

Communication

Good communication is essential for any human interaction. Unfortunately, it is clear from this study that communication is inadequate for Deaf people. Providing a BSL/English interpreter seems to happen rarely despite the Equality Act. It should be the norm.

All clinicians need to ensure they have understood their patient, and that their patient has understood them. How is that possible without good communication?

Information

The NHS Choices website is used by a lot of hearing people to get information. It gets 27 million visits a month. It has embraced video, and has at least 890 videos on the site. Of these, ten are available in BSL. So, while most of the population has a wealth of information, Deaf people having almost nothing. This cannot be right. Deaf people need the same access to information as everyone else.

Deaf people reported feeling excluded, marginalised and disenfranchised by the healthcare system, findings barriers at every step preventing them taking control of their health.

CONCLUSIONS

- Deaf people have generally healthier lifestyles than the rest of the population in terms of smoking and alcohol, but are more likely to be overweight.
- High blood pressure was almost twice as common in Deaf people as in the rest of the population.
- Deaf people are twice as likely as hearing people to have high blood pressure which has not been diagnosed. They may also be more likely to have undiagnosed diabetes, high cholesterol and cardiovascular disease.
- Even when Deaf people have been diagnosed, they are less likely than hearing people to be adequately treated for these conditions (high blood pressure, high cholesterol, diabetes and cardiovascular disease).
- Under-diagnosis and under-treatment of potentially serious conditions is more common in Deaf people.
- Together these may put Deaf people at risk of **preventable** heart attacks and strokes, and diabetic complications such as kidney failure and blindness.
- As these conditions cause long-term ill-health, disability and death, urgent measures are needed to address this marked health inequality.
- Deaf people are being denied access to health services.
- Services are not allowing Deaf people to communicate in their preferred language (BSL).
- Health information is not accessible to Deaf people.
- Most of the necessary actions are simple and cost-neutral or cost-saving in terms of improving access to services, communication with health staff, and improved management of long-term conditions.
- There is a large, avoidable cost to the NHS because of these health inequalities (in excess of £30m/year).

This study is clear that in some respects Deaf people have poorer health than hearing people despite having a similar lifestyle.

A pattern seems to emerge of poor diagnosis and poor treatment. For some Deaf people, their assessment suggests they may have a particular condition that they didn't know they had.

For other Deaf people, they have told us that they have a particular condition, but their results suggest it is not being well controlled. For example, people who know they have hypertension but are still showing a high blood pressure reading. Some of these conditions can lead to life threatening or life changing disease.

We therefore have evidence of poorer health, poorer diagnosis and poorer treatment.

If all the Deaf people who kindly took part in the study went to the same GP practice and used the same hospital, change would be inevitable. Staff would realise there was a problem and they would hopefully do something about it. But the Deaf population is spread across the country, with most GPs only having a

handful of Deaf patients. Because of this, the true picture remains hidden and no action is taken to address it.

It has been calculated that this poor diagnosis and treatment might be costing the NHS at least £30m every year. If the Deaf community lived in one geographical area this unnecessary cost would be identified and addressed.

The reasons for poor health will vary from person to person. But the in-depth interviews point to some of the likely reasons for Deaf people, as a group, having their health harmed by their experience of the NHS.

Deaf people are facing barriers which most hearing people would not put up with. They find it difficult to navigate around the system: booking appointments, getting results, being 'called' from the waiting room. While these barriers are obvious to deaf people, most health staff are hearing and these barriers are invisible. This highlights the importance of Deaf Awareness training for staff.

The crucially important contact between the Deaf person and the clinician is deeply worrying. The poor communication Deaf people experience is clearly not fair. But more importantly it may be putting them at risk. If the clinician–patient communication is not working, then it is not surprising that some problems are not being diagnosed, and conditions which have been diagnosed are not being well managed. If it is the patient's preference then health staff should be using BSL/English interpreters. Interpreters are not for the Deaf patient, they are **for the clinician** and the patient. Without an interpreter, how can the clinician confidently make a diagnosis or provide treatment, advice and information?

The other large barrier remains access to information. A person's health is exactly that – it's theirs. We are all encouraged to learn more about our health and to take part in the decisions about it. Unfortunately, as the amount of publicly available health information has increased in recent years, it has not been made accessible to Deaf people. And because it is more difficult for Deaf people to get 'incidental' health information (from the radio, TV, etc.) this poses a real problem.

In each of these cases, the barriers can be removed with very little effort and will actually save the NHS money. The first important step is for health services to realise they exist, and accept they need to remove them. Some recommendations are included at the end of this report. We suspect most services in the country could easily take a few small steps which would make a huge difference.

Until they do, Deaf people will continue to be sick of it.

WHAT CAN YOU DO?

- All staff can take simple steps which make a big difference to Deaf patients
Just being aware that Deaf patients face barriers is a good start.
- Try and put yourself in the Deaf patient's shoes – for example, imagine being ill on holiday abroad and trying to communicate with a doctor who does not speak or understand English. It's not so different for Deaf patients every day in their own country.
- Getting communication right is the key.
- Simply read the general learning points and recommendations below, and then look for the page which applies to your role in the NHS.

FOR ALL NHS STAFF

General learning points that apply across the health service

- Deaf people have different communication preferences. What works for one deaf person will not necessarily work for another. Preferences may include whether a male or female interpreter is used.
- For many Deaf people, English is a second language they have never heard. Therefore, written communication is not always appropriate, (and would not count as a "reasonable adjustment").
- Communication support, such as an interpreter, is not **for** the Deaf patient. The clinician needs communication support to be able to understand and communicate with their patient.
- Deaf people are the experts on how to communicate with Deaf people.

General recommendations for health services

- All health staff should ask each deaf patient how they would prefer to communicate.
(*NHS Constitution*)
- Patient record systems should be able to record and code whether a person is Deaf. At the moment, most health bodies cannot say how many Deaf patients they have, or what their preferred language and communication is.
(*Putting Patients First, The Power of Information, Public Health Outcomes Framework*)
- A communication plan should then be agreed, recorded and flagged in the patient's record. This should include not just communication in a consultation, but how the person will be 'called' in the waiting room, how results can be given, etc.
- All staff should have Deaf Awareness training.
- Deaf patients should be able to contact services using SMS or e-mail.
(*The Power of Information*)
- Information should proactively be made available in BSL (with subtitles).
(*NHS Constitution, The Power of Information, Public Health Outcomes Framework*)
- Deaf people and groups should be approached as part of patient and public involvement initiatives.

PRIMARY CARE

Learning points

- Almost all Deaf people are currently dissatisfied with the way their GP communicates with them.
- Systems for booking appointments are often difficult for deaf patients.
- Systems for booking communication support appear disjointed and confused. This situation has probably become even worse since CCGs replaced PCTs.
- In many instances, technology could help remove some barriers faced by deaf patients, e.g. e-bookings, e-mail and SMS.
- Most Deaf patients do not have trust or confidence in their GP.

Recommendations

- As primary care embraces the 'paperless NHS' it should ensure that new systems are accessible for deaf people.
(*The Power of Information*)
- Each practice should have a system in place for booking communication support, and all staff should be aware of it.
- Book a double length appointment.
- Efforts should be made to establish a positive relationship with deaf patients, and staff should try to understand why confidence may be lacking.

SECONDARY CARE

Learning points

- Systems for booking appointments are often difficult for deaf patients.
- Systems for booking communication support appear disjointed, inconsistent and staff unaware of how to make a booking and where to find this information.
- In many instances, technology could help remove some barriers faced by deaf patients, e.g. e-bookings, e-mail and SMS.
- Secondary care often seems unprepared for deaf patients (even in audiology departments).

Recommendations

- Hearing aids should be checked on admission.
- Where 'Choose and Book' is used, the patient should be asked whether they would like communication support (this exists within the system as a screen which can be enabled).

- Book a double length appointment for outpatient clinics
- Hospitals could start to make changes in the audiology and ENT departments. This would generate some in-house expertise. Deaf patients should be involved to lead this change.

PUBLIC HEALTH

Learning points

- Deaf people have the same health needs as other members of society, but they may need to be addressed in different ways. Public health officials work to improve the health of other marginalised groups. Addressing the health needs of the Deaf community is long overdue and can no longer be ignored.
- With the exception of two parts of the country, we could find no attempt by public health officials to look at the Deaf community.

Recommendations

- Efforts should be made to record Deaf 'activity' within the health system.
(*Power of information, Everyone Counts, Public Health Outcomes Framework 3.16*)
- Public health officials should engage with Deaf people to learn more about the specific issues faced by the community.
- Joint Strategic Needs Assessments should include the Deaf community.
(*Public Health Outcomes Framework—domains 2 and 4*)
- Consideration should be given to programmes that could make health information and services more accessible for Deaf people.
(*Public Health Outcomes Framework*)

COMMISSIONERS

Learning points

- Levels of satisfaction in the general population may hide dramatic differences for some groups, such as Deaf people. Unfortunately, because the Deaf community is small there is a danger their views and experiences are missed and ignored.
- Commissioners rarely collaborate when it comes to Deaf services. Consequently, each CCG has a small Deaf population. This means steps to address the needs of Deaf people are not taken because the numbers involved are small.

Recommendations

- Commissioners should test the quality of services by seeing how they work for Deaf people. If services are good for Deaf people, they will probably be good for the general population.
- Commissioners should collaborate more. Areas of joint work could include: contracting for interpreting, funding accessible health information, providing community support workers, etc. Each of these initiatives is more effective (and cheaper) when done 'at scale'.
(A Framework for Collaborative Commissioning Between CCGs)

DEAF PEOPLE

Learning points

- We have rights under the Equality Act 2010. The providers of your health service should be making "reasonable adjustments" such as offering communication support. Many participants were unaware of this.
- Deaf participants in this research had low expectations of healthcare because of previous poor experiences. It is perfectly reasonable to complain when communication or access is poor.
- We hope that as a result of this research, the NHS will become more 'deaf-friendly', but improvements are likely to happen gradually over a number of years.

NHS ENGLAND AND GOVERNMENT

Learning points

Efforts to reduce health inequalities are hindered because information on 'deafness' or BSL as a preferred language is so rarely requested. The GP Patient Survey is the only place where people are routinely asked whether they are deaf and whether they use BSL.

- Apart from the *Towards Equity and Access* report on the mental health of Deaf people in 2005, there has been no real national attempt to address the health of deaf people. Deafness does not seem to be high on the agenda for any health organisation.
- There is no national guidance or best practice which can be pointed to and used to improve services.
- The fact that it has taken until now before any research has been done into the health of Deaf people tells us something.
- Despite high levels of common mental health problems, access to psychological therapies is a postcode lottery.
- Inequality for Deaf people may be costing the NHS £30m every year.

Recommendations

- Whether a person is Deaf or uses BSL should be routinely collected data.
(Public Health Outcomes Framework, Power of Information, Putting Patients First)
- Clear standards are required so that Deaf people (and providers) know what is expected in terms of access. The Information Standards Board is developing a new Standard and its implementation should be supported. However, there are areas not addressed by the Information Standard where additional guidance will still be needed.
- More research is needed into the knowledge and attitudes of Deaf people in relation to health.
- A 'Deaf Health' network should be formed which can assist health services to reduce the health inequalities faced by Deaf people.
- Psychological therapies for Deaf people should be commissioned nationally.

APPENDIX – policy review

Many strategy, policy and guidance documents contain a section on health inequalities and how important it is that these are ended. However, few refer to the specific problems faced by deaf people. As programmes like NHS 111 show, policies are not adequately considered from a deaf perspective before being introduced. This is a pity as it means solutions for deaf people are not incorporated from the start.

Below are some of the most important recent documents.

The Health & Social Care Act 2012	Places a statutory duty on the Secretary of State and CCGs to “reduce health inequalities”.
The NHS Constitution	<p>1. The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status.</p> <p>4. The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment.</p> <p>The NHS also commits to offer you easily accessible, reliable and relevant information in a form you can understand, and support to use it. This will enable you to participate fully in your own healthcare decisions and to support you in making choices. This will include information on the range and quality of clinical services where there is robust and accurate information available (pledge).</p>
The Mandate	<p>Numerous references that apply, including:</p> <p>1) The Government’s ambition for excellent care is not just for those services or groups of patients mentioned in this document, but for everyone regardless of income, location, age, gender, ethnicity or any other characteristic. Yet across these groups there are still too many longstanding and unjustifiable inequalities in access to services, in the quality of care, and in health outcomes for patients. The NHS is a universal service for the people of England, and NHS England is under specific legal duties in relation to tackling health inequalities and advancing equality. The Government will hold NHS England to account for how well it discharges these duties.</p>

NHS Outcomes Framework	Enhancing quality of life for people with long-term conditions. Indicator 2.1 “The proportion of people feeling supported to manage their condition.”
Putting Patients First	This includes numerous actions on health inequalities. It also says efforts should be made to examine outcomes based on ‘protected characteristics’.
Equality and Diversity System 2.0	This is a complete programme which health trusts are encouraged to follow to meet their requirements under the Equality Act, and the Public Sector Equality Duty.
A Promise to Learn – A Commitment to Act (The Berwick Report)	
Liberating the NHS: no decision about me, without me	“Shared decision-making involves a patient and their clinician(s) working together to clarify options and goals for their care, treatment and self-management, sharing information about those options and aiming to reach agreement on the best course of action. Shared decision-making is fundamental throughout the entire healthcare pathway irrespective of setting.”
The Francis Report into the Mid Staffordshire NHS FT Trust	“The patients must be the first priority in all of what the NHS does. Within available resources, they must receive effective services from caring, compassionate and committed staff, working within a common culture, and they must be protected from avoidable harm and any deprivation of their basic rights.”
Patients First and Foremost	This praised the ‘See It My Way’ programme set up at the Royal United Hospital in Bath, as an excellent way of changing staff attitudes and practice. The programme consists of events in which patients tell their stories of healthcare directly to staff.
The Power of Information (The Health Online Programme)	We have stressed how the human relationship between the patient and clinician is so important. It is perhaps ironic that the most promising area of health policy for Deaf people seems to be coming from technology. Moves towards the ‘paperless NHS’ could provide a huge opportunity. Key aims from the programme which could have benefit include: electronic booking of appointments, online access to health records, online repeat prescriptions, online secure communication between patient and GP, and support for information providers to communication in the most meaningful way possible. These steps may remove certain barriers, but could also raise new ones.

Putting Patients First

Scorecard 6

Ensuring that people have a positive experience of care; improving patient experience of primary and hospitals and community mental health care.

Scorecard 8

We will also be accountable for making progress in reducing health inequalities in access and across all domains of the Outcomes Framework where inequalities are identified, through the services we commission directly and in our work to support local commissioners.

As a first step we will measure, assess and publish information on each of the protected characteristics (as set out in the 2010 Equality Act) and inequalities dimensions across all the domains and indicators in the NHS Outcomes Framework for which information is available.

Promoting equality and narrowing inequalities in access and outcomes will be highly challenging and we will need to deepen our understanding of the role the NHS can play across the breadth of its remit. We will publish an equality and health inequalities strategy which will form part of the Board's broader strategy.

Compassion in Practice

Patient and service user choice and clear communication with patients and the people we care for is crucial to ensure they are partners in their care and they share decision making with the team providing their care. All the people in our care need to have a voice, choice and control.

Communication is central to successful caring relationships and to effective team working. Listening is as important as what we say and do and essential for "no decision about me without me". Communication is the key to a good workplace with benefits for those in our care and staff alike.

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SignHealth is a voluntary sector organisation that works to improve healthcare and achieve equal access to healthcare services for Deaf people. The organisation works with the Deaf community, health services, other charities and policy-makers in order to realise this aim.

signhealth.org.uk