

Deaf Health

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

Executive Summary

Research Funded by Sign Health & the BIG
Lottery

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the Health of Deaf People,*

carried out by
Centre for Deaf Studies,
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The starting point

Deaf people are known to have difficulties in *access* to health services, but there is a lack of research evidence concerning their health *outcomes*. In order to improve services for this group of the population, it is essential that we understand the extent of the problem and the issues which need to be addressed in order to reach equality of service delivery for Deaf sign language users. A study of Deaf Health in the UK was commissioned by Sign Health between 2010-13 from researchers at the University of Bristol and the Deaf Studies Trust. The study was funded by the Big Lottery.

The key issues

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

The aim

The aim of the Deaf Health study was to assess the current health of a representative sample of the Deaf, sign language 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 study

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 local 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, Nottingham, Manchester, Cardiff, and Glasgow. In each session they were accompanied by signing Deaf advisers and BSL interpreters. The structured health assessment consisted of the standard well-person health check provided by a Bupa health adviser and an interview with a Deaf adviser (to collect data on use of GP services). This data could then be directly compared with health survey data for the general population, using routinely collected GP data in England (eg the GP Patient Survey – GPSS; Health Survey of England, HSE 2011).

Health assessments for 298 Deaf sign language users, aged 20 to 82 years

Health Outcomes

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 HSE 2011, the Deaf respondents reported higher rates than the general population of hypertension (HT), 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%).

*Self report:
higher rates for
hypertension,
asthma, epilepsy
and depression*

Participants were asked about their use of medication and this was used to determine the rates of treatment for illness. 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. Even excluding those who did not drink at all, the extent of alcohol use by Deaf drinkers was less than the general population.

*...90% of those
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Deaf are more
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population*

The medical examination in the health assessment calculated the BMI for each participant. This revealed high rates of 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. 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%. The obesity problem is greater among Deaf people.

We also considered waist circumference (recommended as an additional measure by NICE- National Institute for Health and Clinical Excellence) and combined it with the BMI figures. These are jointly considered to be predictors of illness (coronary heart disease, Type 2 diabetes, osteoarthritis and some cancers). 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.

*One third of
Deaf
participants
had elevated
levels of
cholesterol*

Self-reported cardiovascular disease (CVD) is less common among Deaf people (7%) than among the general population (16%). However, nearly one third of Deaf participants had elevated levels of cholesterol, which was more prevalent in women (41%) than men (23%). The levels of LDL and the cholesterol/HDL ratio were also high, but the gender differences were less marked. However, we do need to note that elevated cholesterol levels were higher in the general population (over 50% compared to Deaf 32%) suggesting a greater problem in the community as a whole.

*... 25% had high
blood pressure
and 12% very
high blood
pressure.
Fifty percent were
undiagnosed and
untreated*

All participants had their blood pressure (BP) measured, and 25% were found to be high (140/90 -159/99) and 12% very high (>160/100). Hypertension was significantly greater among the Deaf participants than in the general population (47% as compared to 18%). Very high blood pressure was more common among Deaf men (16%) than among Deaf women (8%). In addition, there was poor correlation between the measured BP and the self-reported awareness of hypertension, or the taking of anti hypertensive medication..

The national *detection* rates for hypertension 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). There are some caveats here and the difference is statistically significant only for Deaf men.

If we use the recorded presence of medication, as the indicator of treatment then the treatment rate is even lower for Deaf people at 36% overall (32% male and 40% female) compared to the HSE 2011 which has males at 54% and females at 59%

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 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 HSE 2010.

In relation to diabetes Deaf participants were marginally more likely to be diabetic than the general population and were likely to be less aware of the problem.

Calculating Risk

One important aspect is the need not only to determine health now but to try to predict health in future. This is usually expressed as “risk”. On the Bupa calculations for heart problems and diabetes, Deaf people seem to have lower risk than does the general population. This appears to be due to their lower rates of smoking, lower cholesterol and the difficulty in determining family history. However, given that the risk factors in the population are already worrying, we remain convinced the levels of hypertension and obesity (BMI & waist circumference) are sufficient on their own as warning signs for future Deaf health.

Use of GP services

The structured interview with the Deaf adviser collected data on use of GP services, and found widespread difficulties with communication between Deaf people and professionals in primary and secondary care. In virtually, all measures, Deaf levels of satisfaction with GP were significantly lower (statistically) than those of the general population. Nevertheless, Deaf people go to the GP more often than do the rest of the population – 80% had seen the doctor in the last 6 months.

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 32% of the general population who (of course) also used the telephone (89%). 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 respondents to the GP Patient Survey (GPPS) were *actually more likely* to see their preferred doctor than the Deaf patients, with exception of older Deaf people who saw the doctor they preferred a lot of the time (80%).

..25% thought the GP was 'poor' or 'very poor' in involving the Deaf patient in decisions about health

Compared to the GPPS, the Deaf respondents reported much higher rates of dissatisfaction with the doctors' explanation of their condition or tests. Only 11% of Deaf participants thought their GP 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 GPPS). The preference of the vast majority was for the use of signing with the doctor. Only 16% of respondents thought they communicated very well with their GP. In the general population, 64% said that 'definitely' they had trust in the doctor while only 25% of Deaf people expressed this degree of trust. Eighteen percent of Deaf people asked whether they had confidence and trust in the GP, said 'no, not at all' (compared to only 4% of the general population).

... Confidence and trust in the GP? "no, not at all" said 18% of Deaf people

Not surprisingly the preference of the vast majority was for the use of signing with the doctor (95%) and this coincides with a rejection of the use of English (speech, lip-reading and writing down) - only 5% said they wanted this. It was the case that when asked about their usual communication, 46% said that they used signing in some form. However, overall, an interpreter would usually be involved less than 30% of the time. Even so this might seem like some progress but when we probed further in the follow-up interviews, it was often the case that the Deaf participant did not understand the interpreter (or other "signer").

Some improvement in the provision of interpreters but Deaf often said they did not understand

Deaf people's experiences

As well as determining the pattern of Deaf people's health and their attitudes to the health service, we also needed to know about Deaf people's experiences in health care and their own beliefs about the nature of health. In this second part of the investigation of Deaf health, 47 Deaf people who had taken part in health assessments were interviewed. At the same time, we set up workshops in 5 locations to feedback to participants and to elicit their own responses to the health information. These two elements have been separately analysed from the Deaf researchers' perspective.

The 47 interviewees were chosen from the original sample of 298 people as individuals who would have considerable experience of contact with the NHS, with a range of diagnoses in priority areas in public health. Each person was interviewed individually in their chosen location close to their home. The interviewer was Deaf and used British Sign Language (BSL).

The video recordings of the semi-structured interviews were subjected to qualitative analysis in BSL. Categories of response were established and themes were extracted from the data in *discussion in BSL*. Only in the final stage was this English text report prepared, in order to protect the BSL integrity of the data and the analysis. These in-depth accounts were then compared with Deaf people's experiences after their health assessment. The analysis identified particular themes of great significance to Deaf people.

"Interpreters are good IF.... those Deaf people know how to use them." Most do not." Male in 50s

The presence of interpreters

This topic of interpreting came up again and again. There were difficulties in obtaining interpreters for consultations, problems with the quality of the interpretation and lack of awareness of the difficulties Deaf people were facing in the interaction. Doctors had almost no means to judge whether information was getting through to the Deaf person nor whether it was culturally appropriate. There were almost no instances of the Deaf person

*"I walked out... had no confidence in the interpreter"
Female 73 yrs*

complaining during the interaction with the doctor and as far as we can tell no official complaints have been lodged about problems in the interaction when there was an interpreter present.

Interpreters usually arrive before the appointment and then ask the Deaf person for information on the problem as preparation for their “assignment”. One Deaf person reported this as intrusive and inappropriate when feeling unwell or anxious. The interpreter then accompanies the Deaf person into the appointment, confirming the perception of role as the ‘interpreter *for* the deaf’ and not as an independent mediator for hearing and for Deaf. This was seen by Deaf people as creating inequality. The Deaf person viewed the interpreter as another hearing person and at times felt outnumbered.

Dealing with the receptionist

There was almost unanimous agreement that interacting with the practice or hospital receptionist was stress-producing and upsetting. This interaction would normally be done without the aid of an interpreter. Nearly 40% of all the Deaf people who had health assessments thought the receptionist were not very helpful.

The problems of failure to record that a person in the waiting room was Deaf, failure to book interpreters, lack of Deaf awareness were repeated in accounts and presented as significant barriers to engagement with health provision.

Dealing with the doctor

Many commented on the pressure to continue with an appointment even when there was no interpreter. One Deaf person found this led to misunderstanding and recourse to writing down.

“In attempt to improve the dynamic and elicit further information I produced a paper and pen and requested that the GP write down what he had been attempting to tell me. After giving me a long, exasperated look he summed up the entire conversation with writing down two words, 'fatty liver'. He then looked at me and said he did not think this was a problem. Needless to say I left the surgery feeling extremely confused and uncertain” Deaf woman in her 50s

Where Deaf people expressed satisfaction, it was due to the development of a personal relationship with a doctor over a period of time. They reacted negatively when there were different doctors each time they attended.

Privacy

There are considerable issues surrounding privacy, and often Deaf people will determine whether or not to use an interpreter based on their decision on whether the matter will be confidential, private or even personal. These are different concepts in sign language and these affect the way in which a Deaf person might approach the health provider. An interpreter may be brought in for a confidential appointment, but if the content of that strays into the private or personal area, the Deaf person will be very uncomfortable.

The name for the illness does not act as a key to information in the way it does for a hearing person.

“...when the Bupa adviser explained to me about being 'fat' I was shocked. The GP had never said anything to me. So I have to do something about it.” Female 62

Control

There were clear issues of managing the control of one's health which all interviewees found difficult. When given a diagnosis, hearing patients may be re-assured and when given a treatment they will exercise their own right to follow and to monitor that treatment. The provision of a name for an illness acts as a key to further information and may in itself be comforting. However, that name has limited value to Deaf people who do not use English. The diagnostic process which has been multi-layered for hearing people, simply becomes one-dimensional for Deaf people since they have limited access to the "keys" supplied by the English-based diagnosis. At no point does the process come within the Deaf person's control.

Health and identity

All health transactions for Deaf people take place in a hearing-led context where speech is the dominant interaction mode. Not surprisingly, Deaf people see this is something of an alien world and feel that health decisions are not within their grasp. As a major overarching theme, we consider that Deaf people experience a dissociation of their health transaction in the health centre or hospital from their inner person and identity. This separation arises from the need to preserve their own inner well being when external information is inaccessible and when efforts to deal with it are ignored by the community and the health professionals. Deaf people then have difficulty in acting on advice or following treatment regimes when they do not relate these instructions to their own inner wellness.

Conclusions

This study has raised major concerns about the state of Deaf people's health.

Our health assessments carried out on a typical sample of deaf adults in the UK showed significantly higher rates than the general population of obesity, and hypertension. Many of the Deaf participants were unaware of the health problems they had and most seemed unclear about the implications of the problem, the nature of their treatment and the prognosis. Deaf respondents' self-reported rates of smoking and alcohol consumption were lower than those of the general population.

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

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

Health takes place in a hearing world – separate from Deaf control and Deaf thinking

Major concerns about obesity and hypertension in the Deaf community

We need to reformulate the role of the signing interpreter as a positive participant in the process, acting for equality of access

As a result of the incomplete engagement of Deaf people with the NHS, there is a separation in Deaf people's thinking between their Deaf self and the 'person' who has to engage with health practitioners and interpreters in a hearing world. This dissociation leads to problems being undiagnosed and even when treated, the problems can remain uncontrolled. The net result is diminished health care delivery to Deaf people and later on, potentially increased health care costs because conditions have deteriorated.

Recommendations

It is relatively easy to take the headline figures and to suggest that we tackle the symptoms of these health conditions and the indications of the access problem. Undoubtedly some progress would be made with a universal right of access to interpreting in all consultations. Although we may be satisfied with the short term gains which might accrue, we do not believe that we would be tackling the inherent problem of a speech-dominated Health Service which views Deaf people as separate and disabled by hearing loss. More interpreters would be an advantage, but this would be without much change in the approach of health care staff because responsibility for communication would simply be passed to interpreters. This would not lead us to a model of *cultural competence* in health care delivery and it would not bring Deaf people into a position where they took responsibility for their own health.

We recommend that resources and action be directed at the training of health practitioners and interpreters in particular, to understand the Deaf view of the health interaction and to work towards a three-partner collaboration rather than a detection and treatment model. Such training also needs to promote flexibility in interaction during assessment and treatment, bearing in mind the particular problems of Deaf people in hospital, in A&E and other settings where an interpreter may not be available immediately.

For Deaf people, we consider it vital that Deaf-led groups be encouraged to form in order to begin to define their health issues and evolve an awareness of the actions needed to avoid illness or actions needed in the case of illness or injury.

We suggest that that Deaf health monitors/mediators/ coordinators will have a role to this transition in order to change awareness of the nature of health in Deaf adults and to create a framework through which Deaf health needs can be expressed to those providing health services to the community..

Training for "cultural competence" in health care delivery could make an enormous difference in the health transactions

Deaf-led groups for transition to responsibility for own health