



NHS Accessible Information Consultation: Volunteer Organizations/Patient Groups

A Voice for Accessible Information and Deaf Health Education



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Introduction

For decades, Deaf people have suffered inaccessibility to health professionals and clear health education.¹ This dire situation results from serious knowledge and participation blockages in public health. The majority of Deaf adults are only literate to the reading age of a nine-year-old, haven't heard 'common knowledge' conversations around them, and most information is not available in BSL.² These all install a significant knowledge barrier very early in adult life.

To overcome this, BSL interpreters are often used as a very expensive, short-term measure. This service can facilitate some translation of what is being said in a patient-doctor environment, however, rarely does it convey understanding, meaning, or ameliorate the lack of fundamental health knowledge. Health Deafinitions have found that the Deaf community lacks the typical knowledge a hearing person has about health as an outcome of their social involvement and education. These factors impact Deaf patients' participation in NHS services and taking control of their own health.

At Health Deafinitions, we are a Deaf-led organization and have built our social enterprise on several years of research and conversation with the Deaf community, who have had input at every stage of development. As such, we have learnt of the many difficulties and health inequalities that are unnecessarily burdening the community. We are responding to this demand for fair and equal access to healthcare and education by developing high quality DVDs in BSL. These productions are Information Standard approved, and presented in BSL with in-depth, 3D graphic videos and glossary terms.³ These not only facilitate Deaf people's understanding of health, but also empower individuals to more fully manage their own well-being, breaking down decades of health inequalities faced by the Deaf community. Therefore Health Deafinitions aims to work with the NHS to clearly define health for the community.

This information packet is a response to the recent Voluntary Organization consultation, offering our unique perspective as a Deaf-led organization on information accessibility.

¹ It is general convention to capitalize "Deaf" when referring to those who are more often profoundly deaf, use BSL as their first language and culturally identify with the Deaf community; this differs from "deaf" as a more general range of audiological conditions.

² Alys Young and Ros Hunt, "Research with d\Deaf people: improving the evidence base for adult social care practice," *National Institute of Health Research*, Methods Review 9, available at http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/SSCR%20Methods%20Review_9_web.pdf

³ For more on The Information Standard please see <http://www.theinformationstandard.org/>

Our Organization: Questions 1 & 2

Health Deafinitions is a uniquely Deaf-led social enterprise that works both with the Deaf community and for it by developing high quality educational videos on various health topics, such as cardiovascular disease, smoking cessation, obesity and diabetes. We have held consultations across England with over 2,500 Deaf people to assess need, understanding, and appropriate information formats. In response, we are developing these videos made by Deaf people for Deaf people, using fluent BSL as the primary mode of communication but including world-class 3D animated views of internal images to aid visual learning and understanding. Among our majority of Deaf employees are Deaf presenters and actors to convey this information in a way that is culturally relevant and relatable. Health Deafinitions has also been accredited with The Information Standard quality mark, which means we follow stringent procedures to ensure the information is medically accurate, clear and unbiased. We aim to empower the Deaf community with necessary tools to manage their own health, and further NHS commitments to patient participation and Outcomes of preventing premature death, improving long-term health conditions, and ensuring positive experiences with care.⁴

⁴ NHS Outcomes Framework, 2014/15, *Department of Health*, available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256456/NHS_outcomes.pdf

Challenges Facing Patients and Providers: Our Experience: Questions 3 & 4

The key challenges faced by the Deaf community are the lack of comprehensible information and limited nature of interpretation services. Easy read and pictographic pamphlets do not reach the 250,000 Deaf people in the UK, for whom English is not their first language and often have the literacy of a nine-year-old.⁵ Additionally, many Deaf people, fluent in their own language find these materials unhelpful and even demeaning, as well as culturally inappropriate. In our conversations with the Deaf community less than 1% recognized or understood the term artery; furthermore no BSL sign existed for this term. How, then, can the majority of Deaf patients understand any written or interpreted description of ‘hardening of the arteries’?

This deficiency has serious consequences for the community. In 2009, Dr Jeetesh Patel in the West Midlands found that deafness indicated profound increases in risks for cardiovascular disease.⁶ These findings were evidenced by high levels of poor literacy and education, which has made simple tasks such as incorrectly following medication labeling a life-threatening mistake, or not understanding what ‘healthy eating’ entails. The NHS does not offer any in-depth and comprehensive health education to this disadvantaged community in its native BSL. Where materials are provided in BSL they are usually translations of English, not directly BSL and certainly not culturally appropriate. Consequently, there can be a significant delay in Deaf people recognizing earlier symptoms of serious conditions because they have missed out on the ‘common’ knowledge and public health adverts by not being able to hear and understand them.

This education barrier results in further challenges. For example, a patient will attend an appointment with a GP (with or without an interpreter) and seem to agree with any information or diagnosis presented, however, they will actually have very little understanding of the meaning or application of the latter to their own well-being or long-term health. Many lack the confidence needed to impose on either the doctor or interpreter to take the time to truly explain what was discussed.

“My Doctor tells me about taking the medication, but I couldn’t read his mouth pattern so I don’t understand what he’s saying. I just nod, pretending I

⁵ The British Deaf Association estimates that there are at least 250,000 Deaf people who consider BSL to be their first language.

⁶ J. V. Patel, P.S. Gill, and J. Chackathayil, et al., “Short-term effects of Screening ofr cardiovascular risk in the deaf community: a pilot study,” *Cardiology Research and Practice* 2011, available at <http://www.hindawi.com/journals/crp/2011/493546/>. *BBC News*, Deaf People ‘High Heart Risk’, available at <http://news.bbc.co.uk/1/hi/england/7964020.stm>

understand him. But when I get home with my prescription, I admit I began to feel unsure of the medication because I don't know what he's said to me – what benefit the medication has, the purpose of it and what it does to make me better. The doctor tells me very short information but I don't fully understand it. It could be the wrong medication, and maybe make me worse because I might have given wrong information. That could be dangerous if I'm being misdiagnosed. It could lead to health complications and I may worsen or die from wrong treatment. To have proper language that is accessible to my needs is so vital."

Deaf woman, Health Deafinitions consultation, Doncaster 2010

Reliance on interpreters as the main connection between the NHS and tackling Deaf health inequalities holds various points of communication breakdown and medically limits the quality of information and understanding. Consider a scenario where a patient is being asked, through the interpreter, whether or not they are taking a prescribed medication correctly, and if it is having specific effects. If the interpreter is not able to accurately convey the medical nuances of the medication, then how is the patient able to understand? Further, if the interpreter is able to convey the right medical terms, many Deaf patients will not even understand these, as they lack crucial health knowledge.

NHS professionals undertake years of training, which is followed by continuous adaptation to workplace and scientific advancements. BSL interpreters do not have a remotely comparable level of medical knowledge. cursory searches of groups like Association of Sign Language Interpreters shows that very few of the required professional development courses cover medical terminology in a Primary Care setting. Compare this with any police or Ministry of Justice interpreter, who is legally obligated to be specifically trained in these environments and appropriate terminology.⁷ This is concerning in an environment where standards like that of the Care Quality Commission are so vital to a successful and safe NHS.

The overall lack of health education for Deaf individuals means that increased interpreter services is not the kind of transformation needed. Calls for more, certified interpreters would only prolong the problems caused by the absence of in-depth health education for Deaf people. According to our research, appointments

⁷ *National agreement of arrangements for the use of interpreters, translators and language service professionals in investigations and proceedings within the criminal justice system, as revised 2007*, Ministry of Justice, available at http://www.justice.gov.uk/downloads/courts/interpreters/National_Agreement_on_Use_of_Interpreter_s-August_2008.pdf

with an interpreter take place for an average of 15 minutes, but cost over £200.⁸ Factoring the above communication and knowledge limits of a Deaf patient, it increasingly seems that money is being thrown at this problem, to provide a temporary 'access', in place of a long-term change. This also jeopardizes key NHS Outcomes for the Deaf community,

- from being increasingly put at risk for premature deaths,
- misunderstanding long-term health conditions and being unable to improve self-care,
- and not having positive care experiences.

The doubtful achievement of these Outcomes is also demonstrated in Deaf perceptions of healthcare professionals. In 2008, we were invited to conduct a Health Needs Assessment of deaf patients in the Wakefield, West Yorkshire PCT. It was revealed that 64% of respondents did not feel respected by their hospital doctors, with another 44% feeling the same way about their GPs. The patient-doctor relationship is left wanting for Deaf people because they do not understand much of what is discussed, due to the lack of health education.⁹ This variety of concerns also casts a shadow over the fulfillment of NHS responsibilities articulated in both the Equality Act and the Health and Social Care Act.

⁸ We have further anecdotal evidence of many Deaf people who have booked interpreters who do not show-up, and where younger children or other family members have to translate for their Deaf family member.

⁹ Health Deafinitions, *Health needs assessment of the Deaf and Partially Deaf Community Report*, NHS Wakefield District, October 2009.

Yunus Lorgot (1971-2013) died prematurely as a result the long-term health inequalities that face many Deaf people. Active in the Deaf community, he worked for the National Deaf Children's Society and set-up local support groups for Asian deaf people. After losing his job due to untreated depression and difficulties with hearing colleagues, he withdrew from friends

and the community. Yunus was outside of the reach of the NHS network that could have saved his life, because he was unaware of the kind of treatment that was available to him.



(Left) Yunus (Top, middle) was an avid football player as a young man, (Below) Yunus shortly before his passing



Our Feedback and the Deaf Community's Demand: Questions 5 & 6

Having shared our innovative trial productions with both the Deaf community and many healthcare professionals, we have been greeted with overwhelming support and demand for these Information Standard approved videos. It is this kind of contribution to Deaf people's health that can fulfill above referenced NHS Outcomes and responsibilities in providing equal access and comprehensible information. Our videos all use Deaf, BSL presenters and in-depth 3D graphics which map and visualize the inside of the body describing essential biological functionality with accurate medical terminology. Accompanying these presentations are video glossary terms that establish BSL appropriate medical terminology and new signs where previously they have not existed. These features work together to breakdown health conditions such as diabetes or cardiovascular disease that are otherwise complex and confusing. This then aids Deaf patients in understanding preventative measures, causes and symptoms, tests for diagnoses, treatment options and self-care advice.

These presentations are designed to empower the patient with knowledge, which can enhance healthcare experiences, and in the long-term, save lives. Future meetings with GPs, hospital doctors and other NHS staff, facilitated by interpreters, could then approach more of the equal access and format of information that the Deaf community is demanding, and the NHS is endeavoring to provide. Having demonstrated to doctors and other medical professionals we have found welcoming support for the potential this innovative tool holds for making Deaf patient participation robust and meaningful.

"We do try to give everyone health education, it's not just about tablets. However, with Deaf patients it is harder because their level of understanding of health matters may not be that good in the first place. I am very supportive of your bid to try and produce and disseminate educational materials in BSL about common health problems. One of the key outcomes for patients is their level of understanding and ability to assert their needs. An informed patient is an empowered patient."

Dr. Mike Lawson, Horton Park Surgery, Bradford.

Accessible Information Public Consultation

Health Deafinitions have also formally responded to Sarah Marsay regarding the missed opportunity in the public Accessible Information consultation. The survey, although translated into BSL, carried heavy and misleading assumptions about the effectiveness of interpreters being sufficient communication aids for Deaf patients, and other types of information provided to the Deaf community by the NHS. Again, what is currently on offer does not adequately meet the needs expressed to us by the community, and perpetuates long-term health inequalities.

Through our community liaison we have also been fervently working with the Deaf community members we are in touch with and encouraging them to respond to the Accessible Information consultation through the survey provided, if at all possible, but also through more accessible means, such video or short letter comments. We have received significant feedback already, stating dissatisfaction with the survey itself and concern about the general lack of health education for Deaf patients. The following are examples of some direct responses.

"I book an interpreter, but there is no provision. There is no help from a social worker. I bring my cousin as a 'makeshift' interpreter, but the information is still not clear as the doctor converses directly with my cousin. My cousin says 'its all right'. I am suspicious about that, because I have some doubt. Is it really all right?"

Response of a male, mid-forties, profoundly Deaf

"I get given information. I read it but I don't understand it, I then look at the picture and understand a little bit. I ask my mum and she explains it to me. My doctor explains the problem but I don't understand it so my mum explains it to me but I still don't understand it so she repeats herself until I know what it means. I do usually use my mother but she has a health problem, so I don't use her as much I end up stuck, because I don't have access to interpreters."

Response of a female, mid-forties, Deaf

Conclusion

In a fair and equal society, a Deaf person's difference to a hearing person should not define their health or understanding of how to better manage it. The community clearly demands more and is rightfully entitled to accessible information. However, they often lack the voice and audience to fully articulate these concerns. As a Deaf-led organization, we strive to provide such a platform to the community. We see a way forward in bridging these gaps by providing health education. The videos that we develop, using 3D graphics and BSL presenters is an important step in the journey bringing patients and professionals together for a more successful, fair, and equal NHS. With this kind of empowerment through education Deaf people could be then live longer, healthier and happier lives.

Please do contact us if you wish to view a demonstration of the videos, read more feedback we have received from the Deaf community and healthcare professionals, or have any other questions.