



## Preferences for communication in clinic from deaf people: a cross-sectional study

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### Abstract

**Aims and objectives** To explore the preferences of deaf people for communication in a hospital consultation.

**Methods** Design – cross-sectional survey, using a structured, postal questionnaire. Setting – survey of readers of two journals for deaf and hard of hearing people. Participants – 999 self-selected individuals with hearing loss in the UK, including those who use sign language and those who use speech. Main outcome measures – preferred mode of communication.

**Results** A total of 11% of participants preferred to use sign language within everyday life, 70% used speech and 17% used a mixture of sign and speech. Within a clinic setting, 50% of the sign language users preferred to have a consultation via a sign language interpreter and 43% indicated they would prefer to *only* have a consultation directly with a signing health professional; 7% would accept a consultation in speech as long as there was good deaf awareness from the health professional, indicated by a knowledge of lip-reading/speech-reading. Of the deaf speech users, 98% preferred to have a consultation in speech and of this group 71% indicated that they would only accept this if the health professional had good deaf awareness. Among the participants who used a mixture of sign language and speech, only 5% said they could cope with a consultation in speech with no deaf awareness whereas 46% were accepting of a spoken consultation as long as it was provided with good deaf awareness; 30% preferred to use an interpreter and 14% preferred to have a consultation directly with a signing health professional.

**Conclusions** The hospital communication preferences for most people with deafness could be met by increasing deaf awareness training for health professionals, a greater provision of specialized sign language interpreters and of health professionals who can use fluent sign language directly with clients in areas where contact with deaf people is frequent.

### Introduction

There are approximately nine million deaf and hard of hearing adults in the UK, which equates to one in seven of the population [1]. Estimates of the number of sign language users range from 50 000 [1] up to 250 000 [2]. Given the high prevalence of hearing loss it is likely that health professionals in all disciplines within the

National Health Service (NHS) will frequently meet with deaf and hard of hearing patients.

The term 'deaf' is generally used by those with a pre-lingual, profound deafness and 'hard of hearing' by those with a post-lingual, usually moderate or severe hearing loss. 'Deaf' (uppercase D) is used by those deaf people who use sign language as their first or preferred form of communication, do not perceive their

deafness as a medical disability and define themselves as part of a cultural and linguistic group [3] often referred to as the Deaf community. The wider 'deaf community' (lowercase d) in this work refers to all people with any hearing level or perception of deafness (which includes those who perceive their deafness from the medical model as well as those who perceive it from the cultural or linguistic model). For ease of language we use the term 'deaf' throughout to refer to people who call themselves deaf, Deaf, hard of hearing, deafened and hearing impaired.

There are numerous studies which report that health professionals lack an awareness of how to communicate effectively with deaf patients [4–10]. The effect of this is that communication between health professional and deaf patient is often inappropriate and exchanged without knowledge or understanding of the deaf person's communication needs or preferences. It might be assumed that a deaf speech user is content with a consultation in speech and a deaf sign language user would prefer to use a sign language interpreter. However, as we will show in this paper, there are more subtleties to be considered here. For example, is speech on its own sufficient or can the deaf speech user only cope if the health professional also uses deaf awareness skills? Would sign language users actually prefer to conduct their consultation directly in sign language with the health professional rather than through an interpreter? These are issues we explore in more detail. Despite repeated calls to improve the communication exchange between health professionals and deaf patients [4–10], there are no large-scale studies which specifically investigate the preferences of deaf and hard of hearing people for mode of communication within a hospital consultation.

Because British Sign Language (BSL) has a grammar that is different from written and spoken English [11–14] a consultation which is provided only in spoken English, requires the native BSL user to translate the words into sign language. Such a process leaves space for misunderstanding if the patient's fluency in written English is imperfect, as it often is. For details and a discussion of the consequences, see [15–19]. Therefore, it could be considered dangerous to assume that a deaf sign language user can 'get by' with a hospital consultation in speech and therefore there is a particular need to ensure that communication requirements are met for this group as well as for others.

Previous research has shown that existing health care services for d/Deaf and hard of hearing people often leave much to be desired [5,6,9,20–22]. Examples of some of the difficulties that deaf people experience include meeting with a consultant who just shouted when 'all that was needed was to speak slowly and clearly', p. 3 [20] or not being able to express the symptoms of clinical depression because the doctor knew no sign language [23]. Research has shown that deaf sign language users have, for example, taken too much or too little medication because they were unsure of the instructions from their doctor [20]. Deaf people face inequality in accessing health services [6], which could be due to communication difficulties [5] as well as lack of deaf awareness from health professionals.

In 2004, the Royal National Institute for Deaf people (RNID), the UK's largest deafness charity, indicated that 'urgent action' was needed to improve the accessibility and communication for deaf and hard of hearing people using the NHS. They also recommended that all front line NHS staff should have deaf awareness training [20]. Broadly speaking, 'deaf awareness' covers practical

information on how to communicate effectively with deaf and hard of hearing people, that is, to speak clearly to enhance lip-reading, not shouting nor exaggerating lip patterns as well as knowing how to set up a consultation room to ensure clear communication and knowing what sort of sign language interpretation is appropriate. It also covers a more general sensitivity to the needs of deaf and hard of hearing people, including an understanding of how words might be translated from spoken English into signed language as well as an awareness of the social norms of the Deaf community and the impact on everyday life of having a hearing loss.

A recent article in the *BMJ* [23] highlighted the inadequacies of current health care services for deaf patients and indicated that medical students needed to be better trained in deaf awareness and knowledge of sign language. Despite such calls there have been no large-scale surveys which specifically assess how deaf language sign and deaf speech users wish to communicate with health professionals.

The objectives of this study are to report on the preferred mode of communication for deaf sign language users and deaf speech users for a hospital consultation. As this is an exploratory study there were no pre-specified hypotheses. The data presented are part of a larger study on the attitudes of deaf people towards genetic counselling services.

## Participants and methods

The study population consisted of people with a personal hearing loss who used either speech or sign language as their main form of communication. Recruitment was via two UK-based magazines, 'Sign Matters' (now named the British Deaf News) and 'Hearing Concern'. Both magazines are targeted towards men and women and a whole cross-section of ages. 'Sign Matters' is published by the British Deaf Association and focuses on issues relevant to deaf sign language users. 'Hearing Concern' is published by a charity of the same name. It is targeted towards people with late-onset deafness, to include deaf and hard of hearing speech users. All copies of one issue of each magazine had a questionnaire included together with an invitation to participate in the study; questionnaires were distributed and collected in 2006. Thus the questionnaire was sent to 5250 potential participants of varying ages and with varying audiological levels, perceptions and experiences of deafness.

A total of 1098 people returned a completed questionnaire. Informed consent was deemed implicit if participants chose to return the questionnaire; they could complete this anonymously or voluntarily leave their name and address if they wanted more information or have an interview. Participants defined themselves as deaf, Deaf, hard of hearing, hearing impaired, deafened or having a specific level of hearing loss, and included those who were born deaf, those who had lost their hearing progressively throughout adulthood, as well as those who had lost their hearing as they approached their older years (e.g. aged 50+). No hearing people participated.

We compare the attitudes of those who use signed language and those who use speech or a mixture of sign and speech as their main form of communication. The age of onset of deafness contributes to determining the profile of these groups used in the analysis. For example, those participants who were born deaf were more likely to use sign language as their main form of communication;

whereas those who had lost their hearing later on in life (after the development of speech) were more likely to use speech. Inevitably, those who lost their hearing later on in life were more likely to be older when they completed the questionnaire. It is therefore possible that there may be a confounding age factor on their views towards communication in a clinic setting. However, we have not explored this here as it seems likely that speech users prefer to have a clinic consultation in speech because this is their first language rather than *because* they are older.

The non-standard questionnaire was generated via discussions with deaf people and experts in deaf studies as well as after a review of the medical, social sciences and deaf studies literature. Our research team and Steering Group consists of Deaf, hard of hearing and hearing academics, clinicians as well as D/deaf lay representatives, and all contributed to the design of the questionnaire. The questions were piloted extensively with deaf sign language users and deaf speech users as well as with experts in sign language. The questionnaire was checked specifically for ease of translation into signed language [including BSL and Signed Supported English (SSE)]. It was also checked for cultural sensitivity so that it was appropriate for people who identify with the Deaf community. It was tested for readability and also checked for face-validity using experts working within health service delivery for people with deafness.

Responses to two questions are reported here:

‘What language do you find most comfortable to use?’

‘I use .....’

- Signed Language
- Spoken language
- Mixture of signed and spoken language
- Other, please give details: .....

‘If all communication methods were possible when you go for a hospital appointment, what language or communication would you prefer to use? (you can tick several boxes)

‘I prefer the consultation to be in . . . . .’

- Sign language directly with the health professional
- British Sign Language with a hearing interpreter
- Sign Supported English with a hearing interpreter

- Spoken language, with an awareness of lip-reading/speech-reading
- Spoken language on its own
- Notation using speech to text reporting
- Other, please give details:’

The latter question gave participants the opportunity to indicate a difference between the acceptance of a consultation using speech alone with no deaf awareness on the part of the health professional and a consultation in speech where the health professional had an awareness of lip-reading/speech-reading (which represents ‘deaf awareness’).

The above question was also deliberately structured to allow people, if they so chose, to give more than one response. For those who were adamant that only one option was suitable, there was also the option that they could give just once choice, that is, demonstrate their ‘preference’ by ticking one box only. We have only presented the data here for those participants who ticked one box and thus demonstrated their ‘preferred’ communication method (as seen in Table 1). Participants also had the opportunity to leave free-text comments on their answers to this question.

The questionnaire as a whole contained 32 questions; we present here the findings from two of these as given above. The remaining questions covered various issues relating to deafness (e.g. questions about family history and membership of the Deaf community), attitudes towards communication with GPs, understanding of genetic counselling and interest in having genetic counselling. While the questions are placed within the context of genetic counselling, the findings should be equally applicable to other health care contexts for deaf people. For example, free text comments given by participants refer to general communication problems within interactions with health services, and not just in relation to attending a genetics clinic. The data were coded and analysed using the software package, SPSS 14.0.

For ease of language, we present the views of ‘deaf’ people in our study and do not draw distinctions between levels of deafness nor whether respondents regarded themselves as culturally Deaf or not. The study population consists of participants who self-define their language use.

**Table 1** Preference of different communication methods within a hospital consultation related to main language use

	‘What language do you find most comfortable to use?’		
	Sign Language (n = 60)	Spoken language (n = 609)	Mixture of signed and spoken language (n = 123)*
‘I prefer the consultation to be in’ (results given for those who ONLY ticked one box)			
ONLY sign language directly with the health professional	26 (43%)	0 (0%)	17 (14%)
ONLY sign language through a hearing interpreter	30 (50%)	1 (0%)	37 (30%)
ONLY spoken language, with an awareness of lip-reading/speech-reading	3 (5%)	427 (70%)	57 (46%)
ONLY spoken language on its own	1 (2%)	171 (28%)	6 (5%)
ONLY notation using speech to text reporting	0 (0%)	10 (2%)	6 (5%) <sup>†</sup>

\*There are 18 missing values in the question on most comfortable language; there are no missing values in the question about consultation communication.

<sup>†</sup>The percentages are based on column data, that is, numbers of each consultation preference per language the participants felt most comfortable using.

Multi-centre Research Ethics Committee approval was granted for the study.

## Results

A total of 5250 questionnaires were distributed to subscribers of 'Sign Matters' ( $n = 1750$ ) and 'Hearing Concern' ( $n = 3500$ ).

A total of 1098 questionnaires were returned (Sign Matters  $n = 209$  and Hearing Concern  $n = 790$ ). Of these the data on 99 were either uninterpretable or returned too late for the coding, leaving 999 for analysis. All respondents had a personal hearing loss and resided geographically within the UK.

In total, 68% of respondents were female (median age was 63 years, range 16–94 years and for men the median age was 68 years, range 24–102 years).

The overall frequencies of responses to the two questions were: Most comfortable language:

Signed language 11% (106)

Spoken 70% (702)

Mixture signed and spoken 17% (173)

Other (to include finger-spelling, note writing) 2% (18)

Communication with a health professional (respondents could choose more than one response):

Sign language directly with the (signing) health professional 11% (111)

Sign language with a hearing interpreter (BSL or SSE) 15% (148)

Spoken language, with an awareness of lip-reading/speech-reading 62% (615)

Spoken language on its own 24% (244).

Notation using speech to text reporting 7% (74/999).

Table 1 relates to those participants who only ticked one box (even though they *could* tick more than one if they chose); the percentages are based on the number of people in each language group. For example, there were 60 people whose most comfortable language was sign language in day-to-day life and who chose only one clinic communication option. Of these, 43% (26/60) said they would only accept a consultation directly with a health professional in sign language; 7% (4/60) indicated they could manage a consultation in speech, the remainder indicated that some level of sign language would be necessary.

Of the 609 participants whose comfortable language was spoken and who only chose one clinic communication option, 98% (598/609) indicated that only a spoken consultation would suffice. Of those wanting a spoken consultation, 71% (427/598) would *only* accept a consultation with an awareness of lip-reading/speech-reading (i.e. deaf awareness), 29% (171/598) did not necessarily need a consultation that involved deaf awareness.

Of the 123 who were comfortable to use a mixture of sign language and speech, 51% (63/123) ticked only the boxes to indicate a preference for a spoken consultation and of these only six individuals said they could cope with a consultation in speech that did not involve an awareness of lip-reading/speech-reading, that is, 90% (57/63) of this group required some level of deaf awareness in a speech only consultation. A total of 49% (60/123) indicated no acceptance for a speech consultation and only preferred to have a signing consultation, either through an interpreter or directly with a health professional and 14% (17/123), by choice, would *only* want a consultation directly with a health professional who could sign.

## Discussion

Given that one in seven of the population have some level of hearing loss [1], health professionals within the NHS will encounter deaf sign language and deaf speech users frequently. The objective of our study was to help health professionals plan their services by offering information to help determine the preferences of deaf sign language users and deaf speech users for mode of communication within a hospital consultation. This study reports on the attitudes of members of the UK deaf population (including those who use sign language and those who use speech) on two important matters. These include specific issues in relation to a lack of 'deaf awareness' as well as a need for qualified signing interpreters. In addition new data are offered on the preference for hospital consultations to be conducted with signing health professionals.

Population studies of the deaf community are methodologically challenging because of ambiguities surrounding definitions of deafness and the absence of a population register [24,25]. The pragmatic solution used here almost certainly did not deliver a 'representative' sample. The data have therefore been analysed using frequency data with a cross-tabulation and the results taken as the best answer available. Where percentages are given they should be taken only as an aid to understanding the data, not as population estimates. We have attempted to address this major limitation to some degree within the larger project from which these data derive through different forms of external validation. The quantitative data have been qualified by gathering extensive interview data in BSL; these results will be presented elsewhere. The study results have also been considered for face validity by members of the larger deaf community attending a national workshop on genetics and deafness. The workshop delegates voted on issues relating to the research and indicated that the findings seemed reasonable. However, despite this it still remains impossible to determine exactly how generalizable the results are. Ideally, future research projects in this area could be conducted using a representative study sample and a longitudinal research design.

Through considering the different ways of interpreting the results about communication in a hospital consultation, it can be seen that only a minority of respondents indicated they could manage a consultation using speech on its own without knowledge of how to enhance lip-reading/speech-reading. The majority of speech users required a consultation in speech accompanied by a good level of deaf awareness on the part of the health professional in order to be able to follow the consultation satisfactorily. Therefore, large numbers of deaf and hard of hearing patients may feel they misunderstand/mishear information and be unable to follow a conversation in its entirety, unless there is consideration of specific communication needs. Solutions to this situation are simple and relatively inexpensive. Thought needs to be given to ensuring that communication is clear, is presented appropriately and in several different ways to facilitate uptake of information and that the health professional checks frequently with the patient for feedback and understanding [26].

Participants who were bilingual, in that they were comfortable using both sign language and speech in their everyday lives, gave responses to the clinic communication question which reflected the same bilingual approach. It is possible that most medical



practitioners would assume that if a person has some level of speech that it would automatically be acceptable to offer a health consultation in speech. However, our results report otherwise, in that 14% would prefer a consultation directly with a signing health professional. It appears, if sign language is part of a person's communication repertoire that, for some, this may be the language they feel most comfortable using when discussing health information. If this is their preferred language it is entirely logical; even more so if the consultation involves distressing or complicated information. It has also been reported elsewhere that when asked about access to mental health services, deaf sign language users have indicated they would prefer to have consultations directly with deaf, signing health professionals [5,24]. It is also known that bilingual English/Welsh speakers often prefer to have health consultations in Welsh and research has suggested that medical and dental services in Wales should be offered in Welsh to accommodate this [27]. Within the sign/speech bilingual group some did, however, feel comfortable enough to accept a consultation in speech; however, again, the vast majority would only accept this with deaf awareness on the part of the health professional. This indicates the importance of the health professional having such skills when working with deaf bilingual patients.

Among monolingual sign language users, only a very small minority indicated that using speech was a possibility in a hospital consultation. The vast majority preferred to have a hospital consultation in sign language: most indicated that they were accepting of a consultation using an interpreter; however, just under half of the monolingual sign language users said they would prefer a consultation if it was *only* with a signing health professional. Free text comments indicated that some participants were concerned that the introduction of an intermediary compromised the privacy of their interaction with the professional and that private medical information would be shared by the interpreter with others. Other participants, however, indicated that they would rather see someone who was not part of their Deaf community, for discussing private medical issues, and for such consultations, using a professional hearing interpreter was acceptable and indeed preferable. Certainly the use of unqualified interpreters perhaps with only BSL Level 1 or 2 conversational skills, or signing family members, is inappropriate within a hospital consultation [28,29] and the professional status of sign language interpreting services has, in part, been motivated by the wish to eradicate such compromises [30].

At present there are no plans to train health professionals, en masse, in BSL and this highlights a disparity between patient preferences and the reality of the services that are available in the UK. Despite attempts by the UK government to offer patient choice and a willingness to meet the communication needs of patients, the reality is that it is ineffective, cost-wise, to train health professionals to the level required to conduct a consultation fluently, if the health professional sees only a handful of patients using this language per year. Therefore in the absence of health professionals who can sign adequately, access to qualified sign language interpreters is paramount. However, for those health professionals routinely working with deaf sign language users, everyday or even weekly, for example within specialist mental health services for the deaf or in audiological services, it becomes more obvious that staff should be able to converse directly in the language used by their patients. Indeed there are several specialist

psychiatric centres in the UK where care is provided by deaf and hearing staff in BSL [31]. Also, in the US there are generic clinicians who use sign language directly with their deaf patients [7].

Access to suitable interpreters has been highlighted as a problem in services for the deaf. It is thought that there is one fully qualified interpreter in the UK for every 275 deaf people who need one [1]. Interpreters will often favour working in certain settings, for example, law, theatre or medical. This narrows down the availability of suitable interpreters for use within the health service. Most hospitals in the UK use an agency of registered interpreters, or alternatively local freelance interpreters and thus the practicalities of working with different interpreters on an infrequent basis can be challenging for health professionals. If such work were more integral to the infrastructure of the health service, for example, by having to demonstrate use of an accredited interpreter before consent can be considered informed [32], then quality and access issues might begin to be addressed.

Given the high prevalence of hearing loss in the population, it is not unreasonable to suggest that NHS staff dealing with the public everyday should have deaf awareness training. Indeed this is recommended by the Department of Health: 'Primary Care and Hospital Trusts [are] to include deaf awareness training in their training and development curricula for all front line staff'. p. 5 [33]. Therefore, even if direct training in BSL is impractical for all NHS staff; deaf awareness training at least, should be a priority. We feel this should not just apply to front line staff but to all health care staff who interact with patients, to include reception and administration staff. Our results are in keeping with other research indicating that those with hearing loss feel there is a lack of deaf awareness among health professionals [6,21,22]. Corrective action has been taken in the teaching of medical students [23,26], but this has a long lead-time for the general medical population.

In thinking about the study limitations, we are aware that those people who use sign language as their first language have written and spoken English as their second language. This means that written English is not necessarily easy to access when translations are needed into BSL. Great consideration was given to this in the design of the questionnaire. It was piloted extensively and also checked for readability and face-validity with members of the Deaf community, teachers of the deaf and sign language experts. The sentence construction was changed in light of this to make it as accessible as possible to those readers whose first language was sign language. However, it is acknowledged that the most monolingual BSL users are the people least likely to respond to a postal questionnaire. For this reason we have taken a mixed-method approach for the larger research project from which this data derives. The quantitative data has been qualified by gathering extensive interview data in BSL; these results will be presented elsewhere.

There are no standard, validated questionnaires for use with the deaf community for gathering attitudes towards issues surrounding communication within the health service. If this research were to be repeated it may be useful to present the question on hospital communication differently. Allowing participants the option of ticking more than one box put limitations on knowing exactly which mode of communication was the most preferable. Future studies could either consider asking participants to rate their responses, that is, they could indicate which option was their first

choice, their second, their third etc. Alternatively, the question could be completely closed and participants could be asked to indicate only one option, with no choice to tick more than one box. When the questionnaire was originally written this is how this question was structured; however, results from the pilot work indicated that even though participants were asked to tick only one box they still repeatedly ticked more than one, indicating that it was difficult to limit their choice. It was these pilot results that led to the change in question format.

The question about preference for communication in a hospital consultation asked people to consider their response on the assumption that all communication methods were available. One of the options – having a consultation in sign language directly with the health professional – is not currently available for the vast majority of health consultations. This being the actual situation, it is therefore possible that participants answered the question by considering what services are currently available and what are likely to be available (as opposed to considering their views if ALL forms of communication were available). Those who said that they would prefer their hospital consultation to be with a hearing interpreter may have given this response because they knew that using an interpreter was feasible in a practical sense within the current NHS services. However, if they genuinely thought that it would be possible to have a consultation directly in BSL with a health professional then it seems possible (and indeed logical) that this would be their preference.

In summary, our results suggest it is most appropriate for all NHS staff dealing with the public to receive some level of deaf awareness training and for those regularly seeing deaf sign language users (e.g. on a daily or even weekly basis) focussed training for specific staff in sign language should be a priority, so that consultations can be conducted directly without an interpreter. Both deaf speech users and sign language users require good deaf awareness skills from their health professional and it is evident that there is a lack of this currently within individual consultations in the health service. Efforts to raise deaf awareness would have benefits for all staff and patients and may increase uptake of health services among deaf people. If we truly are working within a health service that offers choice to patients, then adequate communication services must be available.

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