Deaf and hard-of-hearing people's access to primary health care services in North East Essex

A report for North East Essex Primary Care Trust

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Abstract

This study examines the issues surrounding access to primary health care services for deaf individuals resident in the NE Essex area. Two groups of deaf participants were interviewed about their experiences accessing primary care services in the area: individuals whose primary method of communication was British Sign Language (BSL) and individuals whose primary method of communication was English. Furthermore, in order to obtain a comprehensive overview of the situation in NE Essex, a number of individuals involved in treating and working with deaf individuals were also interviewed, namely health professionals and BSL interpreters.

The main issues facing deaf individuals in accessing primary care services in the local area were lack of deaf awareness, difficulty in booking appointments via telephone and difficulty in communicating with health professionals. This study shows that the PCT needs to consider providing comprehensive deaf awareness training and clear guidelines for staff on communicating and treating deaf patients. This would lead to an improved and more homogenous primary care service for deaf individuals in the NE Essex area.

Glossary

RNID	Royal National Institute for the Deaf
BSL	British Sign Language
RAD	Royal Association for the Deaf
HoH	Hard of hearing
DED	Disability Equality Duty
DRC	Disability Rights Commission
DDA	Disability Discrimination Act
PCT	Primary Care Trust
PALS	Patient Advocacy and Liaison Service

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1. Introduction

1.1. Background

It is estimated that there are around 8.5 million people in the UK who have some form of hearing loss (RNID, 2009). The degree and severity of hearing loss varies across individuals, ranging from those who primarily use spoken English as their main method of communication to those who are considered culturally Deaf (with a capital 'd') and use British Sign Language (BSL) as their main method of communication. The majority of people who have a hearing loss in the UK are categorised as 'hard-of-hearing' (HoH) and use hearing aids; around 8.2 million people have a mild to moderate hearing loss (RNID, 2009) and approximately 580,000 people are severely to profoundly deaf. Of these, there is estimated to be around 50,000–70,000 Deaf people whose first or preferred language is British Sign Language (BSL) (Brien, 1992). In this report, the capital letter 'D' is used for 'Deaf' when it relates to individuals whose first/preferred language is BSL, and hard-of-hearing used for individuals whose first/preferred language is English.

1.2. Deafness and access to health care

The impact of deafness on access to health care is variable and depends on many factors. One of the main issues is barriers in communication with health professionals (Reynolds, 2007). Deaf and hard-of-hearing people typically employ a range of communication methods with health professionals, including BSL, spoken English, lip-reading and written English (Reeves, Kokuruwe, Dobbins and Newton, 2003).

1.2.1. Communication methods in health settings

BSL was recognised by the UK government as an official British language in 2003, and is a language in its own right. Sign language users tend to have little or no speech and use the services of professional sign language interpreters when communicating with hearing people.[1] However, research shows that professional sign language interpreters are only used in a minority of medical consultations (Reeves et al., 2003). For example, Dye, Kyle, Allsop, Dury and Richter (2001) investigated 236 Deaf BSL users across the UK and found that only 19% of Deaf individuals in this sample who had been to see a GP within the previous two weeks had used an interpreter for the consultation.

[1] Fully qualified sign language interpreters should be Members of the Register of Sign Language Interpreters (MRSLI). Other categories of registration are Trainee Interpreters (TI) and Junior Trainee Interpreters (JTI).

Chilton (1996) argues that effective communication in medical settings can be achieved only through the use of a qualified sign language interpreter. As Reynolds (2007) points out, many studies have indicated that not using sign language interpreters results in communication problems which, in medical settings, can have a negative impact on the health of the Deaf population as a whole. Indeed, some studies have illustrated that deaf sign language users may experience poorer health than their hearing counterparts as a direct result of lack of information and communication barriers. For example, recent investigations undertaken by doctors from Sandwell and West Birmingham PCT in cooperation with the Healthy Hearts Institute (http://www.healthy-hearts.org.uk) and Sandwell Deaf Community Association showed that Deaf patients are at higher risk of developing cardiovascular problems. Moreover, SignHealth's recent report on the GP Patient Survey show that Deaf respondents to the survey tended to state that they had poorer health more often than their hearing counterparts (SignHealth, 2009).

Deaf people may not use interpreters for medical consultations for a number of reasons. Firstly, there is often a shortage of qualified interpreters available; it is estimated that the ratio of fully qualified sign language interpreters to sign language users is 1 to 275 in the UK (RNID, 2009). Secondly, some sign language users are reluctant to use interpreters in medical settings because of issues surrounding confidentiality, privacy and independence (Naish & Clark, 1998; Reynolds, 2007). As the Deaf community is a closed community, interpreters tend to be well known within the community, leading to some concerns about confidentiality. Some sign language users value the privacy and confidentiality of one-to-one consultations above all else even if it means that communication is poorer because of it (Reynolds, 2007), and there is some degree of mistrust between Deaf individuals and BSL interpreters as far as medical consultations are concerned (Naish & Clark, 1998). Even though interpreters are bound by professional rules of confidentiality, Naish and Clark (1998) found that some Deaf individuals often did not fully trust interpreters to keep the nature of the consultation confidential. Furthermore, Reynolds (2007) found that Deaf individuals often stated their independence and thus felt that they did not need to use an interpreter. However, many sign language users tend not to realise how useful and beneficial it can be to have an interpreter to gain full access to medical consultations. It may also be that for these individuals, health professionals' lack of awareness about working with interpreters has led to less than positive experiences using interpreters for medical consultations in the past (e.g. Reynolds, 2007).

Instead of using qualified sign language interpreters, Deaf patients frequently attend consultations with no communication support, relying on the written word to communicate with health professionals (Ebert & Heckerling, 1995), or they are accompanied to consultations by a friend or family member who is able to interpret for them (e.g. Huntingdon, Warburton & Ubido, 1995; Naish & Clark, 1998). There are distinct disadvantages in both these methods of communication support. Using written English with Deaf patients is problematic because sign language users often have lower levels of literacy than their hearing peers (e.g. Barnett, 1999; Dye, Kyle, Allsop, Denmark, Dury & Ladd 2000). Lower levels of vocabulary and an inability to express and understand health-related concepts puts sign language users at a considerable disadvantage in medical settings. For example, Huntingdon et al. (1995) found that words such as 'bowel', 'penicillin' and 'smear' were unfamiliar to people whose first language is sign language. As a result, many may come away from consultations not having properly understood what has happened or what treatment they may need to undergo. Furthermore, the consequences of this reach beyond the actual consultation; Deaf patients may delay going to see their doctor because of inadequate communication support, and may also feel unable to ask for further information on their condition or treatment (Reeves et al., 2003). Lower literacy levels also present problems with understanding prescriptions; Ludders (1987) found that the sign language users only understood 59% of medical prescriptions. Problems with understanding treatment options and written prescriptions may also lead to these patients taking the wrong dosages of medication (Reeves et al., 2003).

Using friends or family members as interpreters is also problematic. While having a trusted person to interpret in health settings is advantageous for sign language users, there are two main areas of concern when friends or family members act as interpreters. Firstly, their signing skills may not be the required standard to enable translation/explanation of complex medical terms or consent forms, and secondly, they are not impartial and can be unreliable in conveying all the information, particularly negative news, to the Deaf patient. In addition, they have a tendency to interject their own conclusions (e.g. Davenport, 1977; Reeves et al., 2003; Reynolds, 2007; Wright 1993).

Those who prefer communicating in English rather than sign language (referred to here as hard-of-hearing) typically have higher levels of literacy and presumably better health knowledge than sign language users and are able to communicate effectively using speech. However, this is not to say that this group does not also

experience problems accessing health care services because of communication issues. While they may be able to express themselves adequately using speech, this does not mean that they can understand what is being said to them by a health professional.

This group typically relies on lipreading and written communication with health professionals (e.g. Huntingdon et al., 1995). While written communication presents fewer problems than for sign language users, lipreading is not a failsafe method of communication. As Reeves et al. (2003) point out, lipreading can be quite limited because many words in the English language can be quite difficult to distinguish from one another by mouth movements alone. This issue is exacerbated if the speaker has a particularly strong accent or does not speak clearly. Moreover, general lack of deaf awareness among health service staff compounds problems experienced in lipreading; staff may make basic errors such as standing in front of a window when speaking, not speaking clearly or shouting instead of speaking more slowly at a normal volume (e.g. Huntingdon et al., 1995)

A further point is that many hard-of-hearing people are aged 70 or above and may have additional issues such as poor eyesight or arthritis in the hands or wrists, rendering written communication more difficult.

1.2.2. Other issues in accessing health care services: making appointments

Deaf and hard-of-hearing individuals are also disadvantaged in other respects. Making appointments, for example, can be difficult, particularly as far as GPs are concerned.

Deaf people cannot use the telephone to make appointments, so rely on either going in person to make an appointment at the surgery, or use textphones (also known as minicoms; the terms are more or less interchangeable) and a service known as the RNID Typetalk service. Textphones are special machines that enable Deaf and hard-of-hearing individuals to communicate via landline networks without using voice telephones. They consist of a screen and keyboard and function in a similar way to instant messaging services on the internet; textphone users can write messages on their textphone to another textphone user who can see the message in real time. To communicate with hearing people, textphone users can use Typetalk, which is a three-way telephone service involving an operator. Textphone users dial the number they want to call from their textphone with a specific prefix that enables a Typetalk operator to be contacted. Once the Typetalk operator is connected, the call can go

ahead. The Typetalk operator then types what the hearing person says so that the Deaf or hard-of-hearing person can read it on his/her textphone. When the Deaf or hard-of-hearing person wants to respond, he/she types the message on the textphone, and this is read out by the Typetalk operator to the hearing person on the other end.

While it is possible to make appointments this way, it is quite cumbersome. GP surgeries and dental practices often do not possess a textphone, so the call has to be made through Typetalk. There is often a lack of awareness about Typetalk among health service staff, and sometimes connections between the user's textphone and Typetalk are not successful, and the person called often tends to hang up. Moreover, a recent report by the charity SignHealth stated that the growing use of automated switchboards can also cause problems, not just for Typetalk connections, but simply in being able to contact the surgery (SignHealth, 2009).

The other issue in making appointments is the current system of booking GP appointments. New government targets introduced in 2000 specified that all patients in England should be able to see a GP within 48 hours by 2004. In order to achieve this target, the Advanced Access appointment system was introduced, which divides appointments into 10 minute slots, with the majority bookable only on the day of the appointment. There are several issues with this system, primarily that to book an appointment, you have to telephone first thing on that day, and booking appointments in advance can be difficult. For patients who already have difficulty using the telephone to make appointments, this system puts them at a considerable disadvantage.

1.2.3. Other issues in accessing health care services: waiting rooms

One particular issue facing Deaf and hard-of-hearing patients at GP surgeries and hospitals is knowing when their health professional is ready to see them. Traditionally, patients are called by voice announcement, e.g. over a tannoy when their doctor is ready to see them. This presents obvious difficulties for those with hearing loss, leads to a considerable degree of frustration and anxiety and may cause them to miss their appointment (Lomas, 1998; SignHealth, 2009).

1.3. Legal responsibilities of Primary Care Trusts: The Disability Discrimination Act (1995, 2005) and Disability Equality Schemes

The Disability Discrimination Act (1995), which was extended by the Disability Discrimination Act 2005 and the Equality Act 2006, is aimed at ending discrimination

faced by many disabled people in the United Kingdom. It gives disabled people specific rights in relation to employment, education and access to services, as well as requiring public bodies to promote equality of opportunity for disabled people. A disability is defined as “a physical or mental impairment which has a substantial and long term adverse effect on [a person's] ability to carry out normal day to day activities” (DDA, 1995). Deafness is considered to be one such disability under this Act.

The DDA is there to ensure that disabled people cannot be treated less favourably (i.e. cannot be treated differently because they have a disability) and services and organisations, such as the police, are required to make reasonable adjustments for disabled people, e.g. ensuring a BSL interpreter is present if required by a Deaf person, or providing physical access to a building for those in wheelchairs.

In addition, public sector organisations in England, Scotland and Wales have been legally required since December 2006 to promote equality of opportunity for disabled people. As part of this, organisations across the public sector, including NHS trusts, local authorities, schools and universities, are legally subject to the Disability Equality Duty (DED). This requires them to publish a Disability Equality Scheme which demonstrates that they have paid due regard to the following list of duties outlined by the Equality and Human Rights Commission (formerly the Disability Rights Commission, or DRC):

- promote equality of opportunity between disabled people and other people
- eliminate discrimination that is unlawful under the Disability Discrimination Act
- eliminate harassment of disabled people that is related to their disability
- promote positive attitudes towards disabled people
- encourage participation by disabled people in public life
- take steps to meet disabled people’s needs, even if this requires more favourable treatment.

(DRC, 2006)

A central part of producing a Disability Equality Scheme is the requirement to actively involve disabled people in planning and producing the scheme, and to provide practical steps and action plans to improve access for all disabled people.

1.4. Current developments in access to healthcare for Deaf and hard-of-hearing people

As many NHS Primary Care Trusts are currently in the stage of collecting data for Disability Equality Schemes, it is difficult to assess whether the DDA and DED have improved access for Deaf and hard-of-hearing people overall; this will only become apparent in the next few years once Disability Equality Schemes are properly and fully implemented. However, the DDA and DED have meant that some improvements in access can already be seen. For example, many Primary Care Trusts have installed visual display boards for Deaf and hard-of-hearing people so these patients know when it is their turn to see a doctor. Portable hearing loop systems are also in use for those who wear hearing aids; these typically consist of a microphone worn by the person speaking and amplify sound for users whose hearing aids have a so-called T-switch or T-position. If the hearing aid is switched to the T-position and the loop system is turned on, sound can be picked up by the hearing aid user.

Thanks to the charity SignHealth, there has also been some progress in developing online services specifically aimed at Deaf people. There is currently a move to implement a new online system for GP surgeries in the UK, called the EMIS access system. This allows patients whose surgeries participate in the EMIS scheme to book and cancel appointments online, as well as change their address and order repeat prescriptions. SignHealth has developed software for this platform called SignTranslate GP.

SignTranslate has two components: first, it contains pre-defined medical questions which have yes/no answers. The health professional operates the software and can click on a button to generate a video clip of the question in BSL for the Deaf patient. It is not intended as a replacement method of communication but is rather a tool to aid communication. Second, SignTranslate also allows direct access to a fully qualified BSL interpreter through a webcam. This eliminates the need to book and have interpreters physically present in consultations as there is always an interpreter available through the SignTranslate system at the touch of a button. This service is charged to the health professional but is free to the Deaf person. Currently, SignHealth estimates that 20% of PCTs have a SignTranslate licence. The software also enables text messages to be sent to Deaf and hard-of-hearing patients reminding them of their appointment times. A SignTranslate version for hospitals has also been recently developed and is currently being offered to hospitals.

For BSL users, there are also other, non-NHS based, services available, including advocacy services (such as those offered by SignHealth), particularly in the area of mental health. Deaf advocates can help Deaf patients understand their treatment by relaying information from the health professional and providing it as clear information (in BSL) to the Deaf person, as well as informing Deaf individuals about their rights and choices (Collier, 2000). Their role is different to that of an interpreter; advocates are there to help ensure that the Deaf person understands exactly what the information being conveyed really means.

Other deafness charities, such as the RNID, are also active in improving healthcare services for Deaf and hard-of-hearing people. The RNID is currently running a mental health service project to develop specific mental health services for Deaf people, including a separate mental health unit. In addition, some areas run health promotion talks for Deaf people, such as the Healthy Deaf Minds group in London. A more recent initiative has been set up by Deaf Connections in Glasgow, which works with both health professionals and members of the Deaf community to improve Deaf people's access to health services. The Healthy Living Centre for Deaf People (http://www.deafconnections.co.uk/The-Glasgow-Healthy-Living-Centre-for-Deaf-People/) provides deaf awareness training and practical advice on making health information more 'Deaf friendly' whilst providing a range of advice and information on a wide range of health issues to the Deaf community. The Healthy Living Centre is a local initiative funded by the Greater Glasgow NHS Board and Glasgow City Council. Initiatives such as these go some way towards rectifying the gaps sign language users have in health knowledge.

Finally, a further service is currently being developed which is aimed at providing information in BSL for Deaf individuals: the SignBytes project (http://www.deafway.org.uk/index.asp?pg=1001). This project involves taking information leaflets that are in written English, translating them into BSL, and making them accessible to anyone in the UK who has access to a computer and an internet connection. This is not just restricted to health-related information, but it does provide a practical solution for filling in gaps in Deaf people's health-related knowledge.

2. Methodology

2.1. Introduction

The Royal Association for the Deaf (RAD), based in Colchester, was commissioned by NE Essex PCT to undertake a brief study looking at Deaf and hard-of-hearing people's access to primary care services in the area as part of the PCT's Disability Equality Scheme. RAD then recruited two researchers from the Deafness, Cognition and Language Research Centre (DCAL) at University College London to undertake the study and produce a final report.

2.2. Geographical area and current disability provisions

NE Essex PCT was set up in 2001 to cover the areas previously covered by Colchester and Tendring PCTs (see Fig. 1 below). Around 155,000 people are resident in the Colchester district and 140,000 in the Tendring area. Combined, these areas cover an approximate 65,000 hectares and 72 wards (NE Essex PCT, 2009).

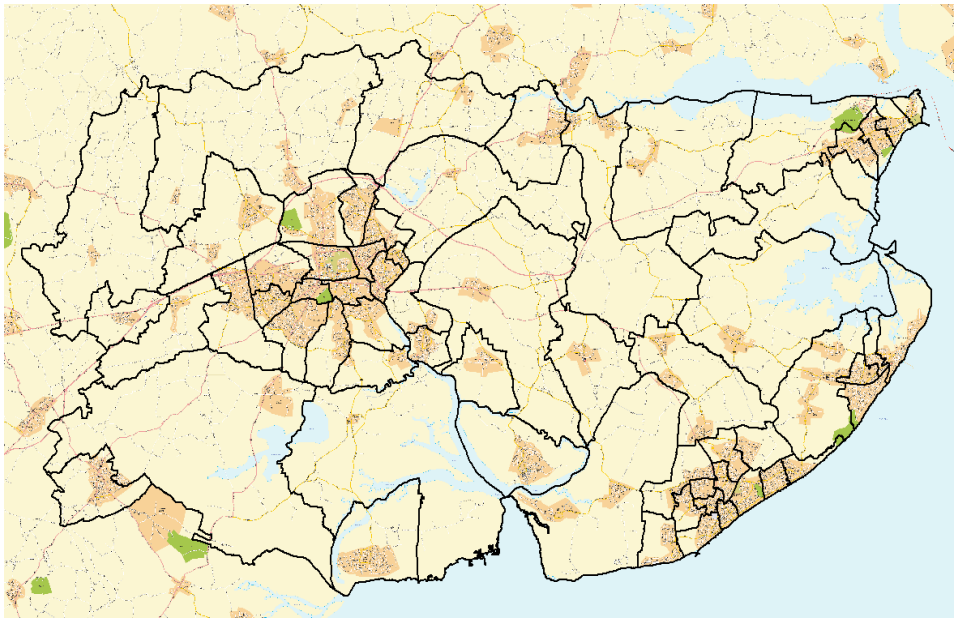

Figure 1: Map of area covered by NE Essex PCT

At the last estimate, there was a total of 291 registered Deaf and hard-of-hearing individuals (146 HoH, 145 Deaf), and 342 unregistered in the Colchester area. In the Tendring district, there was a total of 282 registered Deaf and hard-of-hearing individuals (159 HoH, 123 Deaf), and 185 unregistered.

The PCT is responsible for providing a wide range of health services for the local community, including district nursing, health visiting, primary care clinics, Clacton and

Harwich community hospitals and Cornerstone, which is a health information service. The Trust has published its first Disability Equality Scheme (2006-2009) in compliance with the DED, outlining guidelines and proposals for ensuring local disabled people have access to health services provided by the PCT, and a timetable is in place for its implementation. In addition, the PCT states that a sign language interpreting service is currently available in cooperation with RAD.

2.3. Services investigated

Although the PCT offers a wide range of health services, this study focuses on Deaf and hard-of-hearing people's access to primary care services. Consequently, this study examines access to the following specific services:

- GP surgeries
- NHS dentists
- Colchester walk-in centre
- Clacton minor injuries unit
- Out-of-hours doctors
- Cornerstone health information and advisory service (Colchester)

2.4. Design of study

As Deaf and hard-of-hearing people's needs vary depending on level of hearing loss and method of communication, it was necessary to gather data from individuals with varying degrees of deafness and different methods of communication. In addition, although the primary focus of this study is on Deaf and hard-of-hearing people's access to primary care services, it is also important to include those treating and working with Deaf and hard-of-hearing individuals (e.g. doctors and BSL interpreters); improving health services for Deaf and hard-of-hearing individuals can only be successful if all parties involved understand how to work together and what each other's needs are.

To cover the broadest range of views on the current state of access to NE Essex health services, four groups were devised from which to collect data:

1) Deaf individuals with BSL as their primary method of communication
2) Hard-of-hearing individuals with English as their primary method of communication
3) BSL interpreters
4) Health professionals, e.g. doctors, practice managers

2.5. Data collection

Questionnaires were devised for each of these groups, focusing on the main steps that Deaf and hard-of-hearing patients have to navigate in order to use primary health care services, particularly those that have been highlighted in the literature as problematic (see Section 1), as well as awareness of rights and responsibilities. The questionnaires covered the following main issues:

- making appointments
- Deaf and hard-of-hearing people's communication with frontline staff
- waiting rooms
- Deaf and hard-of-hearing people's communication with health professionals
- understanding outcomes of appointments
- booking and working with BSL interpreters if needed
- awareness of services and equipment available
- awareness of rights and responsibilities under the DDA

Questionnaires were devised for each of the four groups based on these main issues so that the data collected from each group could be compared and contrasted. Pilot studies were undertaken with each of the four groups in order to test the efficacy of the questionnaire.

Data was collected in a variety of ways, depending on the group in question; these are outlined below.

2.5.1. Deaf individuals with BSL as their primary method of communication

Deaf individuals were recruited from the local area and Deaf club through a contact person at RAD. As BSL was the primary method of communication for this group, interviews were conducted individually face-to-face in BSL in order to ensure individuals fully understood the purpose of the interview and were able to give as much information as possible about their experiences. Interviews were held either at RAD's premises or other locations in the centre of Colchester.

2.5.2. Hard-of-hearing individuals with English as their primary method of communication

It is difficult to recruit individuals who fall into this category simply for the reason that many are aged 70 or over and less able to travel to specific interview locations. As Colchester has a local hard-of-hearing group that meet once a month, a focus group session on the topic of access to primary care services in the area was held with this group.

2.5.3. BSL interpreters

Interpreters were recruited through RAD, both internally and via RAD freelance interpreter contact lists. Interpreters were e-mailed and asked to fill in an online survey about their experiences working in health settings in the area. The questionnaire was set up via the SurveyMonkey online facility (http://www.surveymonkey.com).

2.5.4. Health professionals

Health professionals were interviewed after the interviews for the Deaf and hard-of-hearing individuals had taken place. The Deaf and hard-of-hearing individuals were asked which GP surgery/dental practice they used so that a mixture of health professionals could be contacted: those whose surgeries had definitely had contact with Deaf or hard-of-hearing patients and those who might not have done. Permission was sought from the PCT prior to contacting these health professionals, and all surgeries were informed in advance about the reasons behind the study and that they would be contacted and interviewed by telephone.

3. Results: Deaf individuals with BSL as their primary method of communication

3.1. Introduction

Nine Deaf participants were interviewed about their access to primary health services in the area. Four participants were male and five female. Five belonged to the 18-35 age group, one to the 36-50 age group and three to the 51-65 age group. The communication preferences of this group of participants varied, but the majority (66%) expressed a preference for using British Sign Language as their main method of communication with family and friends. All the participants were resident in the NE Essex area, predominantly in and around Colchester, including Colchester itself, Wivenhoe, Wix and St. Osyth (see Appendix 1 for overview of these data).

3.2. Deaf people's access to primary care services in the NE Essex area

3.2.1. Usage of primary care services in the local area

Participants were asked whether they had used the following primary care services in the last 12 months:

- GP surgery
- NHS dentist
- Colchester walk-in centre
- Clacton minor injuries unit
- Out-of-hours doctors
- Cornerstone health promotion services

Table 1 shows that all nine participants said they had visited their GP surgery in the past 12 months, and eight said they had visited their dentist. Only three participants had made use of the other primary care services investigated: one had used Clacton MIU and two had used out-of-hours doctors, but significantly none of the participants had used Cornerstone services. In addition, some participants were not aware that services such as Colchester walk in centre or Clacton MIU existed.

	Used in past 12 months	Had not used in past 12 months (but aware of)	Did not know about service
GP surgery	9	0	0
Dentist	8	1	0
Colchester walk-in centre	1	5	3
Clacton minor injuries unit	1	0	8
Out-of-hours doctors	2	5	2
Cornerstone health promotion services	0	3	6

Table 1: Usage of primary care services in NE Essex

3.2.2. General access to GP surgeries and NHS dentists in the local area

Participants were asked questions on the typical stages of making and attending appointments at GP surgeries and dental practices. This included booking appointments, attending appointments and communicating with the GP/dentist and reception staff. This section focuses mainly on experiences with GP surgeries because although all the participants were aware of dental services in the area and the majority had seen a dentist in the last 12 months, six participants were unsure whether their dentist was NHS or private, and two stated that their dentist was private.

3.2.3. Booking appointments

Participants were asked how they usually booked appointments at their GP surgery and NHS dentist. The majority of participants (55%) said a (hearing) friend or relative telephoned for them, usually their parent or spouse. Two of these participants also said that they would go in person to make an appointment if the person they normally relied on to phone for appointments was ill or unavailable.

One participant said he was able to hear well enough on the phone to be able to make an appointment via voice telephone, and the remaining 2 participants said they made their appointments using a textphone and the Typetalk service or via a BSL interpreter (see also Section 1.2.2).

Participants who used or had used textphones in the past to contact their GP surgery or dentist were asked if they had had any problems using this method of contacting their health service provider. Three participants cited a lack of awareness among staff about how to receive Typetalk calls. As there is often a delay between the caller making the call via Typetalk and a Typetalk operator being connected to the call, two said that the surgery often hung up, presumably because they thought it was a prank call. Participants also cited a general lack of awareness among staff about how to communicate with patients via Typetalk.

3.3. Communication before, during and after appointments

3.3.1. Communication with frontline staff (e.g. receptionists).

There were mixed views on the ease of communication with frontline staff (receptionists, etc.) at GP surgeries and dentists. The majority of participants (77%) stated that they preferred to communicate with frontline staff using either BSL, spoken English or written English/gestures. None of the participants stated that they used BSL interpreters or other service providers such as lipspeakers to communicate with frontline staff, but three participants (in the 18-35 age bracket) did say that one of their parents attended appointments with them to facilitate communication.

Overall, participants' views of ease of communication with frontline staff at GPs and dentists were mixed. Four stated they found communication with frontline staff difficult, and the remaining five found communication easy (one very easy). It should also be pointed out that communication with frontline staff in local hospital A&E departments can be just as problematic; one participant recalled a particular problem she had with a member of staff who was not deaf aware:

"Last August I hurt my foot and it was getting worse and worse, I couldn't walk. I went to A&E, arrived at reception and she was talking. I said, I'm deaf, I lipread and sign. She kept looking down and looking up and looking down, asking me questions and it was difficult to understand what she was saying. When she got to question 4, I really could not understand what she said. I asked her to repeat again and again and still could not understand. She then said "Oh don't worry" and went on to question 5. But question 4 could have been really, really important! And then in the end she just wrote down on a piece of paper "What is your problem?". By this time, I was pretty stressed and rather upset. I was also very embarrassed as everyone in the waiting room could hear what was happening. I appreciate that she was referring to what was wrong with me, but clearly what she wrote could be taken in the wrong context."

3.3.2. Waiting rooms

Participants were asked how they knew when their doctor or health professional was ready to see them. The results were interesting because nearly all the participants

(77%) stated that their GP surgery had an electronic display board that displays the name of the patient and the number of the room they should go to when their doctor is ready to see them. The remaining two participants, whose surgeries do not use the display boards, said that either someone came to fetch them or they had to keep checking with the receptionist.

The situation with dentists is slightly different; none of the participants said that their dentist had a similar system. Dentists instead prefer traditional voice announcements or relying on the nurse to fetch the patient.

Participants were also asked whether they had ever missed an appointment due to difficulties in knowing when the doctor was ready to see them. Eight said they had never or rarely missed an appointment because of this, and one stated that he had sometimes missed appointments because of not knowing when his name was called. This is not surprising given that the majority of participants stated that their GP surgery had an electronic display board.

3.3.3. Communication with health professionals, outcomes of the appointment and general satisfaction with communication

The participants use a number of different methods to communicate with health professionals. The main methods of communication cited by the participants in this study were as follows:

- spoken English only (both the Deaf person and the health professional speak, and the Deaf person lipreads the health professional): **33%**
- written English only (both the Deaf person and the health professional write their questions and answers on paper): **22%**
- a mixture of spoken and written English (the Deaf person speaks and the health professional writes his/her responses down on paper): **22%**
- Family member acts as a BSL interpreter: **22%**

There are some additional issues that should be pointed out here. Although participants stated they could speak to the health professional, this is based on self-assessment as all our interviews were conducted in BSL. It is therefore unclear whether the level of spoken or written English that the participants have is sufficient for them to communicate with their health professional or understand what the health professional is trying to communicate. As noted in Section 1, many Deaf individuals whose first language is BSL tend to have poor skills in understanding and writing English. In addition, having family members act as interpreters is also not an ideal

solution. The participants who stated that their family members had interpreted for them in the past felt that they lost some degree of independence because of this, particularly as family members are not impartial. One participant stated that she felt that family members did not pass on full information when interpreting while she was in hospital for complications with her pregnancy, but rather they conveyed only the positive aspects of her treatment. She felt that having access to a fully qualified independent BSL interpreter would have given her full access to all the information, as well as more privacy and independence:

"There were lots of problems with communication at the beginning of the pregnancy and I asked the midwives if it was possible to have an interpreter. They didn't seem very aware of what an interpreter was and asked me if any of my family could come with me to communicate with me. I said no, but my fiancé said yes, his mother could sign. I felt a bit unsure, but they said "oh she can do it". It was a bit difficult really, I wanted an interpreter for independence but at the time I didn't know my rights so I just went along with it, but I'm a bit disappointed because, OK, I wasn't aware of my rights, but they should have been. They should have said, yes, fine, you can have an interpreter. It was fantastic having family but it didn't make me feel independent."

There was a mixed level of overall satisfaction with communication at appointments, with 2 participants stating that they were very satisfied with communication at their last appointment, 2 stating they were quite satisfied, 3 who said they were somewhat satisfied and 1 who said he was not at all satisfied. What is perhaps of greater concern in this regard is that only 3 participants said that they always understood what their health professional had said or advised during their appointments, while the remainder said that they only sometimes understood what had happened. Overall, however, participants did feel that their health professional had some degree of deaf awareness and did try to understand their communication problems, particularly GPs (1 said her GP was always deaf aware, 6 said their GPs were sometimes deaf aware and 2 said their GP was rarely deaf aware).

3.4. Use of BSL interpreters

None of the participants stated that they used qualified BSL interpreters for GP appointments in the last 12 months even though six participants said that BSL was one of their preferred main methods of communication in everyday life. Participants were asked whether they thought that their appointments would be improved if a qualified BSL interpreter was there. Four said that they would like a BSL interpreter to be present, and the remainder said that they would not want or did not need an interpreter. There is also a more complex set of issues at stake here concerning interpreter provision. There was some degree of misconception among participants in this study concerning access to BSL interpreters, similar to those noted in Section

1. Participants in this study sometimes expressed anecdotal concerns about confidentiality and the fact that they felt appointments were too short to justify booking an interpreter. Instead they stated they preferred to try communicating using spoken/written English. However, as only 3 participants in this study stated that they always understood what had happened in appointments, the current methods of communication are clearly unsatisfactory. It appears that Deaf individuals not only need better access to their health care services, but also need more information on exactly how having an interpreter could enhance their access to health services.

As none of the participants had used a BSL interpreter for GP or dental appointments in the past 12 months, they were also asked if they had ever used BSL interpreters for health-related appointments in the area and whether there had been any problems in booking interpreters. Five stated they had used BSL interpreters in the past, mainly for hospital appointments and sometimes for GP appointments. Two said that there were no problems booking interpreters for appointments, but the remaining three said that they had experienced a variety of problems. The main issue appears to be that primary care/hospital staff are unaware of how to book interpreters for appointments. In one case, a GP refused to book an interpreter.

Participants were also asked if they knew about SignTranslate, a new computer-based BSL phrasebook/interpretation service (see also Section 1.4). Five of the participants had never heard of this service and four said they had heard of it but had not used it.

3.5. Information about health services in the area and awareness of rights

All the participants stated that they would like more information on services in the area, particularly Cornerstone, preferably via the internet and in BSL. In addition, all the participants wanted more information on services specifically aimed at Deaf people in the local area, while four participants said that they would like to see a support group set up for Deaf BSL users that would give them information on health related issues, access and service provision. None of the participants were aware of any existing groups for Deaf people in the local area.

While all participants apart from one were aware of the Disability Discrimination Act, there was little awareness as to exactly what the PCT should be providing for Deaf patients. All the participants stated that they thought the PCT should ensure that all staff are deaf aware, and five stated that they thought it was the PCT's responsibility to provide a qualified BSL interpreter or lipspeaker for appointments. All the

participants but one wanted more information about the DDA and what it means for them as patients, particularly in so far as interpreter provision is concerned. There is also a mixed degree of awareness on how to provide NHS staff with feedback on service provision and who to approach if there are any problems. Five stated they knew how to provide feedback and four said they did not know how to provide feedback. The five who stated they did know how/who to approach all stated that they would approach the practice manager initially (internal feedback), but only one (a deaf awareness trainer herself) knew how to provide feedback externally, e.g. with the help of the Patient Advocacy and Liaison Service (PALS) or to NHS managers.

3.6. Recommendations

Participants stated that they would like to see the following improvements made to primary care services in the area:

- Staff should know basic BSL, particularly frontline staff and GPs (n = 9)
- Staff should be more deaf aware (n = 7)
- It should be possible to make and confirm appointments and obtain results by e-mail and/or text message, or even a secure online system (n = 9)
- There should be an electronic display board in all GP surgeries and NHS dental practices to inform patients when the health professional is ready to see them (n = 9)
- BSL users should be offered the option of communicating in BSL (via a qualified interpreter) (n = 9)
- Extended appointment times for Deaf people to allow for extra time needed for interpreting (n = 9)

4. Results: Hard-of-hearing individuals with English as their primary method of communication

4.1. Introduction

A focus group session was held at the local hard-of-hearing club (non-BSL users). The group were asked similar questions to the Deaf participants (how they booked appointments, what the problems were, etc.).

All participants were asked to fill in a brief background questionnaire about where they lived and their preferred method of communication. Table 2 shows that six were female and two male and all cited spoken English as their main communication method with family and friends (see also Appendix 2). In addition, all the participants were resident in the Colchester area and all were aged over 66.

Gender	
Male	2
Female	6
Preferred method of communication	
English	8
BSL	0
Other	0

Table 2: Background data for hard-of-hearing participants

4.2. General access: booking appointments

All the participants except one use the telephone to make appointments with GPs and dentists. All expressed difficulty with using the telephone to make appointments, primarily for two reasons:

i) Many surgeries have automated phone systems where callers have to go through a process of listening to automated messages and pressing one particular number to get through to a particular person. These automated systems are extremely difficult for hard-of-hearing people who cannot hear that well on the phone because it is difficult for them to distinguish between different numbers. Many members of the group are also quite elderly and they felt these systems are too complex for them to navigate.

ii) Staff who answer the telephone often do not speak clearly or slowly enough and it is difficult to understand them even when using a T-switch on hearing aids. In addition, there is often a lot of background noise, such as a radio being played that makes it hard to hear staff on the telephone.

4.3. Attending appointments: communicating with staff and waiting rooms

The majority of participants stated that their GP surgery was helpful but all the participants said that they would like staff to be more deaf aware. One participant felt that she constantly had to remind staff that she is deaf and to speak clearly and slowly.

As with the BSL users, many GP surgeries used by the group have the electronic display boards which the group found very helpful. However, again, dentists do not tend to have these boards which the group said makes dental appointments more problematic for them. In addition, many members of the group cited hospitals as being the worst places for attending appointments.

Although hospitals are not being investigated in this report, they are worth mentioning because this group's experiences in hospitals contrast sharply with their experiences at GP surgeries: names are often called out, with no electronic display board system, and some members of the group had missed hospital appointments because of this. One participant stated:

"Recently I attended A&E with a suspected broken bone. I waited 6.5 hours but did not receive any treatment. I could not hear my name being called out. I've also had to attend Essex County Hospital several times which entailed sometimes waiting in outpatients where a nurse comes out and calls your name. Fortunately on these occasions I had a hearing companion to help me. This is a real problem for deaf and hard-of-hearing patients. There should be some visual indication in outpatient departments."

In contrast to the BSL users, the group felt that they did understand everything that happened during doctors' appointments and if they did not understand something, their GP was happy to write it down for them. However, this group has English as their first or preferred language and therefore tend to have no problem with writing or understanding the language.

4.4. Information about health services and awareness of rights

Like the BSL users, the group stated that they would like more information about health care services in the area, particularly within the scope of a hard-of-hearing

support group to give them information not only about health issues, but also about specific services for hard-of-hearing people in the area (e.g. technological assistance, health campaigns, etc.).

There was mixed awareness of the DDA. Some participants felt that deafness is often not recognised as a disability, and few of the participants knew exactly what their rights were under the DDA with regard to access to health services.

As with the BSL users, the group were largely unaware of how to provide NHS staff with feedback on service provision and problems. Some had approached the practice manager at their local surgery after experiencing problems and stated that this had helped resolve matters. Again, none of the group was aware of how to make external complaints to, e.g. NHS managers. All the group members wanted more information on how to provide feedback and resolve problems. The importance of providing positive, and not just negative, feedback to NHS staff was also underlined.

What is particularly interesting is that in contrast to the BSL users, this group was all aware of other health services in the area, particularly Cornerstone. This is unsurprising to some extent as group members said that they often went there to get their hearing aid batteries changed. Cornerstone was singled out for particular praise, with many members of the group saying that staff there are always helpful, more so than the local audiology department. Experiences using Colchester walk-in centre were mixed: one group member said she had had a particularly bad experience there, and staff were not very deaf aware. However, another group member said that she had had a very good experience at the walk-in centre and staff were very helpful.

4.5. Recommendations

The group suggested that the PCT could improve their access to local NHS primary care services in the following ways:

- ensure a greater level of deaf awareness among staff
- create a hard-of-hearing support group for health-related issues
- provide more information about the DDA and what it means for them as patients
- provide more information on how to provide staff with feedback.

5. Results: Interpreters' experiences in health settings

5.1. Introduction

Fourteen interpreters (10 based at RAD and 4 freelance interpreters) were asked to fill in an online survey about their experiences working in health settings in the NE Essex area. Nine interpreters responded (a response rate of 64%). The respondents were mostly RAD-based interpreters, but three freelancers also responded.

Table 3 shows that respondents' backgrounds and levels of experience were mixed (see also Appendix 3 for an overview of these data). Four were male (three RAD-based and one freelancer) and five were female (three RAD-based and two freelancers). Four had worked as an interpreter for 1-5 years, two for 5-10 years and three for more than 10 years. One respondent was a Junior Trainee Interpreters (JTI), four were Trainee Interpreters (TI) and four were fully qualified Members of the Register of Sign Language Interpreters (MRSLI).

	RAD	**Freelance**
GENDER		
Male	3	1
Female	3	2
INTERPRETING EXPERIENCE		
Less than 1 year	0	0
1-5 years	3	1
5-10 years	1	1
More than 10 years	2	1
QUALIFICATIONS		
Junior Trainee Interpreter (JTI)	1	0
Trainee Interpreter (TI)	3	1
Member of the Register of Sign Language Interpreters (MRSLI)	2	2

Table 3: Interpreter background data

Respondents were also asked how often they worked in a health setting in the NE Essex area and who mostly booked their services. The majority of respondents (66%) worked in a health setting around once a month or less often, and 88% stated that their services were booked mainly by an agency on behalf of a client.

5.2. Particular issues when interpreting in health settings

Eight of the nine respondents (88%) said that their experiences interpreting in a health setting were positive overall. However, all the respondents had experienced some problems when interpreting in a health situation. All the respondents were asked to state which problems they had encountered when working in a health setting. These are listed below in order of importance:

- All respondents had experienced health professionals who had little or no deaf awareness
- 77% of respondents stated that they had come across health professionals unfamiliar with using interpreters
- 77% of respondents said that the time booked for appointments is too short to allow enough time for responses and questions to be relayed and interpreted
- 22% stated that they had come across problems with booking follow-up appointments for Deaf clients (e.g. an interpreter cannot be booked or found for a follow-up appointment)
- 22% said lack of advance information about the interpreting assignment was an issue.

5.3. Use of SignTranslate

Respondents were also asked whether they had interpreted for the SignTranslate service before but none of the respondents had done so.

5.4. Recommendations

77% of respondents thought that the PCT could do more to improve access for their Deaf clients, with the following specific recommendations:

- provide deaf awareness training and ensure greater deaf awareness among staff, particularly frontline staff
- make sure staff are 'interpreter aware'. In other words, ensure staff how to work with interpreters to get the best possible access for Deaf people, which means, e.g. ensuring the Deaf person is directly involved by talking directly to the Deaf patient and not the interpreter

- provide clear guidelines and training for staff on how to book interpreters, provide a list of contact numbers for booking interpreters and ensure staff know rights and responsibilities if an interpreter is needed or requested for a Deaf patient
- ensure that interpreters can be booked for any follow-up appointments
- provide advance information on assignment for interpreters. Interpreters often do not have access to advance information on the nature of the appointment (e.g. what particular field the appointment covers, such as oncology, surgery, etc.). However, giving advance information such as department name and name of doctor/consultant to interpreters would be useful for two main reasons:
    - it would enable the interpreter to make an informed choice on whether to accept an assignment based on their level of experience in a particular medical field
    - it would allow the interpreter to prepare before the appointment in order to ensure full access for the Deaf person and help him/her to work to the best of his/her ability.

6. Results: Health professionals' experiences working with Deaf and hard-of-hearing patients

6.1. Introduction

Thirteen GP surgeries in the area were asked to participate in a telephone interview asking about their services for Deaf and hard-of-hearing patients and what they felt could be improved (see Appendix 4). Eight agreed to participate in this study and five either could not be contacted or chose not to take part (see Appendix 4 for specific reasons). The surgeries were located across the NE Essex area, including Colchester, Clacton-on-Sea and Manningtree. Cornerstone and Clacton Minor Injuries Unit were also contacted, but neither agreed to participate (see Appendix 4 for specific reasons). At six of the eight surgeries which agreed to take part, we spoke to the Practice Manager, and at the remaining two, we spoke to a receptionist.

6.2. Number of Deaf and hard-of-hearing patients

Participants were asked how many Deaf and hard-of-hearing patients were registered at their surgery and how many Deaf and hard-of-hearing patients had attended appointments at the surgery within the last 12 months. None of the participants were absolutely sure how many Deaf and hard-of-hearing people were registered at their surgery. Six could not give an answer at all, one stated "under 30", and one said 2-3 Deaf and hard-of-hearing patients were registered at her surgery. When asked how many Deaf and hard-of-hearing patients had attended the surgery in the past 12 months, four said 0-5 patients, two said 5-10 and one said more than 20.

6.3. Communication with Deaf and hard-of-hearing patients

Participants were asked about various aspects of communicating with Deaf and hard-of-hearing patients, including how appointments are booked and how health professionals communicate with these patients.

6.3.1. General access: booking appointments

Overall, 87% of participants stated that Deaf and hard-of-hearing patients booked appointments at the surgery either in person or they got a friend or family member to ring for them. Only 4 of the 8 participants stated that their Deaf and hard-of-hearing patients used the phone to contact them (primarily elderly hard-of-hearing patients via voice telephone). One practice manager stated that one patient at her surgery used faxes to communicate with the surgery.

All participants were asked if they either already provided or would consider providing Deaf and hard-of-hearing patients with the opportunity of booking appointments via e-mail, text message or the internet (e.g. via an online booking system). Although only one practice currently offers e-mail booking, the overall response was positive for all three methods. Six of the seven remaining participants said they would be happy to consider allowing Deaf and hard-of-hearing patients to make bookings via e-mail, and two said that this was currently being looked into but not yet available. One practice manager said that an e-mail address was available for patients to ask for repeat prescriptions, but not for booking appointments.

The general response for text message booking was slightly less positive, with one practice manager saying it would be more difficult to implement, and two practices saying that they currently do not have a mobile phone available at all. One practice, however, had a mobile phone available for patients to contact them out of hours, so there are some possibilities for implementing a text message system. Overall, six practices said they would consider this or were currently looking at ways to implement such a system.

With internet systems, one practice said they did not currently have a website at all, and one said that they were currently waiting for the clinical system to be upgraded, and that the old system would not be any good for internet booking. One practice said they did currently have an web-based booking system, and five stated they would either be happy to consider setting up such a system or were currently considering it.

6.3.2. Awareness of communication equipment

In order to test awareness of various communication equipment, participants were asked to explain what they thought minicoms/textphones, Typetalk and hearing loop systems were. There was a considerable lack of awareness among participants about these systems: only one participant could fully explain what a minicom was, while two were vaguely aware that it was linked to some sort of relay system but were not sure exactly how it worked. The remainder did not know what a minicom was; one suggested that it was the same as a hearing loop.

The results were a little better for Typetalk. When asked to explain Typetalk, three were able to fully explain what this system was, while one knew about it but was not aware of what it was called. Two further participants were aware that it was some

sort of typing/messaging system but were unaware of how to use it, and two were completely unaware of Typetalk. What is particularly interesting is participants often confused Typetalk and minicoms, saying that minicoms were a relay system and Typetalk a system for seeing written telephone messages.

As far as hearing loop systems were concerned, there was greater awareness of these. Five participants said they knew what a loop system was and were able to explain how it should be used. Two were not aware of loop systems and one had heard of them but was unsure what they were.

6.3.3. Communication with Deaf and hard-of-hearing patients

Participants were asked how they and others at their surgery would communicate with Deaf and hard-of-hearing patients. The majority (62%) stated that they use written English and/or gestures to communicate. Two participants stated that they would use BSL if a BSL interpreter was booked, although one said that her surgery had never been asked to book an interpreter; instead, the Deaf signer who uses her surgery brings along a family member to interpret for him. In addition, another participant said that one member of staff at her surgery has basic signing skills. One pointed out that her surgery has a touchscreen system for checking in for appointments which eliminates the need for patients to talk to frontline staff.

Participants were also asked how their surgery informs Deaf and hard-of-hearing patients when their health professional was ready to see them. All the participants said their surgery had an electronic display board that comes up with the name and room number.

6.3.4. Awareness of responsibilities and training

Participants were asked whether they knew about the DDA and the PCT's obligation to provide Deaf and hard-of-hearing patients with full and equal access. Seven of the eight participants said they were aware of the DDA, but there did appear to be some confusion surrounding obligations to provide patients with a disability with equal access. For example, participants were asked whose responsibility they thought it was to book a BSL interpreter if one is requested by a patient. While four stated correctly that it was the surgery's responsibility, three stated that they thought it was the patient's responsibility. Five stated they would not know how to book a BSL interpreter, while three were able to explain how to book interpreters. The number of Deaf and hard-of-hearing patients seen on average in these surgeries appears to be quite low, so it is possible that staff have not come across Deaf or hard-of-hearing

patients before or have not had to book an interpreter. However, it does highlight that there may be a general lack of awareness on guidelines and procedures concerning Deaf and hard-of-hearing patients.

All participants but one felt that their practices would benefit from deaf awareness training, all of whom cited the need to learn how to communicate with Deaf and hard-of-hearing patients and what problems to be aware of. One practice manager suggested deaf awareness training would be best suited to receptionists and clinical staff, as these are the staff come into contact with these patients more often than, e.g. the practice manager. Another issue highlighted was training staff on an individual basis, particularly where learning basic signs is concerned. For example, if only one staff member is trained to use basic signs, it is highly possible that that particular staff member may not be on duty if a Deaf BSL user comes in.

6.4. Recommendations

The following main recommendations were made by the health professionals interviewed:

- provide comprehensive deaf awareness training, including basic signs
- provide clear guidelines on staff responsibilities with regard to PCT requirements and legal responsibilities under the DDA.

7. Summary and Recommendations

7.1. Summary

In summary, this study has produced some very interesting data regarding Deaf and hard-of-hearing people's access to primary health care services in North East Essex. Although the sample sizes for this study are relatively small, the data collected is commensurate with that outlined in previous literature (see Section 1), particularly concerning problems with booking appointments, communication during appointments and general lack of deaf awareness, as well as uncertainty regarding how to work with BSL interpreters. It is also important to note that this study also highlighted some positive aspects regarding access to primary care in this area. For example, a high proportion of GP surgeries have installed electronic display boards, and the majority of health professionals either tried to provide good access for their Deaf and hard-of-hearing patients or at least expressed great interest in improving the standard of deaf awareness in their practice.

As stated above, this study concentrates primarily on Deaf and hard-of-hearing people's access to GP surgeries and other local health services such as Cornerstone and Clacton MIU. Although the health professionals interviewed for this study were all from GP surgeries, it should be noted that NHS dental practices are also an important part of primary care. Deaf and hard-of-hearing participants' experiences at dental surgeries have been noted in this report where possible, but these should be taken with a degree of caution as many participants were unsure whether their dentist was a private or an NHS dentist. However, many of the problems encountered by Deaf and hard-of-hearing patients in GP surgeries are very similar to those encountered when they visit a dentist (making appointments, waiting rooms, etc.) and thus recommendations made in the following section are equally applicable to local NHS dental services as to local GP surgeries and other primary health services.

Furthermore, it was only possible to interview one representative person from each GP surgery, thus data collected from health professionals may not be completely representative of deaf awareness among staff in each surgery, particularly of GPs who might have received deaf awareness training as part of their medical degrees. However, it does provide an overall view of quality of access provided in each surgery.

Finally, although larger sample sizes would be needed to provide a comprehensive overview of Deaf and hard-of-hearing people's access to local primary health care services in the NE Essex, these findings form a good basis for recommendations on how to improve services. Recommendations for better practice are outlined in the following section.

7.2. Overall recommendations to improve access to primary health care services in the NE Essex area

This study has shown that a number of overall recommendations can be made, which if implemented by the PCT would improve Deaf and hard of hearing people's access to healthcare in the NE Essex region. These are as follows:

7.2.1. What the PCT can do for primary health care staff and local primary care services:

1) **Provide deaf awareness training for all primary health care staff**, but particularly frontline and clinical staff. This training should be provided by a qualified and experienced deaf awareness trainer and should include:
    - how to communicate appropriately with all Deaf and hard-of-hearing patients and recognise their varying communication needs
    - awareness of technology and equipment used, e.g. Typetalk, hearing loop systems
    - basic BSL and encouragement to use BSL
    - how to work effectively with BSL interpreters and provision of advance information to BSL interpreters on the nature of the booking.

Collective training is important. Providing training for just one or two people per practice or department is not effective as that person may not be on duty when a Deaf or hard-of-hearing person attends an appointment.

2) **Provide staff with clear and simple guidelines on staff responsibilities** as far as Deaf and hard-of-hearing patients are concerned, particularly:
    - What the PCT expects staff to provide for Deaf and hard-of-hearing patients, e.g. when/how BSL interpreters should be provided and who funds these

- Comprehensive information on the DDA, DED and what staff members' legal responsibilities are under the DDA.

3) **Provide a simple guide to booking BSL interpreters**, e.g. a simple A4 poster that can be put up in reception for the whole surgery to read as and when required.

4) **Ensure that BSL interpreters can be booked easily and quickly as and when required.**

   It can be difficult to book interpreters at short notice, particularly given the current system of booking appointments on the same day. **SignTranslate** may provide a possible workaround and also provide some BSL access for Deaf patients in appointments.

5) **Ensure senior and managerial staff, e.g. practice managers are aware of Deaf and hard-of-hearing patients who attend their practice or service and that a patient's deafness is clearly noted in their medical records.**

   This study indicates that many practice managers may currently be unaware of the number of Deaf and hard-of-hearing patients attending their surgery and have had little deaf awareness training. They need to take a more active role in ensuring equal access is provided for these patients and that staff are adequately trained in deaf awareness.

7.2.2. What the PCT can do for Deaf and hard-of-hearing patients

1) **Introduce systems for booking/cancelling appointments online, by e-mail or by text message. Reduce reliance on automated telephone systems.**

   Many Deaf and hard-of-hearing people would benefit from being able to book appointments online, by e-mail or text message as contacting health services by telephone/Typetalk is problematic. In addition, automated telephone systems are extremely difficult for older hard-of-hearing individuals to navigate.

2) **Offer and introduce extended appointment times** to facilitate successful communication and ensure patients understand the outcomes of the appointments.

3) **Ensure all GP surgeries and dental practices have electronic display boards** informing patients when it is their turn to see their health professional.

4) **Provide Deaf and hard-of-hearing individuals with more information on the DDA.** This should include:
    - Clear information about services the PCT provides for Deaf and hard-of-hearing individuals as part of their requirements under the DDA, e.g. BSL interpreter service, in both BSL and English
    - Simple information on patients' rights under the DDA and what they should expect of their health professional in both BSL and English.

5) **Provide Deaf and hard-of-hearing patients with more information on PCT services in general.**

    There is currently a lack of awareness about services available, particularly among Deaf individuals. The PCT needs to provide simple information in both BSL and English on services such as Cornerstone, how they can be used and what facilities these services provide.

6) **Provide Deaf and hard-of-hearing patients with more information on health-related issues and health promotion.** For example:
    - Provide BSL versions of information leaflets using e.g. SignBytes or provide information in BSL on PCT website
    - Set up specific Deaf and hard-of-hearing groups/meetings (possibly through Cornerstone) to provide information on health-related issues and health promotion, and also technology available.

7) **Provide information on how Deaf and hard-of-hearing patients can provide positive and negative feedback on services, as well as a simple guide on who to contact if patients experience problems.**

    Provision of feedback is crucial to improving services. Patients should be encouraged to provide positive as well as negative feedback to health professionals. This would encourage positive attitudes towards Deaf and

hard-of-hearing access to health care and motivate staff to improve services further. This could be arranged through the Patient Advocacy and Liaison Service (PALS).

7.3. Conclusions

North East Essex PCT needs to consider providing a more homogenous service for Deaf and hard-of-hearing patients. Currently, access provision and the level of deaf awareness varies from service to service and across individual health professionals, which means that individual Deaf and hard-of-hearing patients can experience vastly differing service levels even within the same GP practice.

Following and implementing these recommendations would considerably improve access for Deaf and hard-of-hearing individuals in the NE Essex area, particularly provision of deaf awareness training. In addition, NE Essex PCT has an obligation under the DED to ensure equal access for these patients, as well as make sure that all patients are able to make informed choices about their treatment.

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Appendix 1: Results for Deaf group

1. Background

Participant	1	2	3	4	5	6	7	8	9
AGE									
18-35				✓	✓	✓		✓	✓
36-50							✓		
51-65	✓	✓	✓						
66+									
-									
GENDER									
Male		✓	✓			✓			✓
Female	✓			✓	✓		✓	✓	
COMMUNICATION									
BSL			✓	✓		✓	✓	✓	✓
Signed English	✓	✓	✓		✓				
Spoken English			✓	✓	✓		✓		
Other									
AREA	Colchester	Colchester	Wivenhoe	North Colchester	Colchester	Wix	St Osyth	Colchester	Colchester

2. Access to health care

	1	2	3	4	5	6	7	8	9
Last 12 months, have you used:									
GP surgery	✓	✓	✓	✓	✓	✓	✓	✓	✓
NHS dentist	Not used	✓	✓	✓	✓	✓	✓	✓	✓
Colchester walk-in centre	✓	Not used	Not used	Heard of but not used	Heard of but not used	Never heard of	Heard of but not used	Never heard of	Never heard of
Clacton minor injuries unit	Never heard	Heard of but not used	Never heard of	Never heard of	Never heard of	Never heard of	Never heard of	Never heard of	Never heard of
Out-of-hours doctors	✓	Heard of but not used	Heard of but not used	Heard of but not used	✓	Never heard of	Heard of but not used	Heard of but not used	Never heard of
Cornerstone health promotion	Heard of but not used	Heard of but not used	Heard of but not used	Never heard of	Never heard of	Never heard of	Heard of but not used	Never heard of	Never heard of
BOOKING									
Telephone		✓		✓	✓				
Friend or relative phones	HoH husband phones as its quicker		Easier to go in myself rather than call			My mother rings for me	Hearing husband phones as its quicker	Mother-in-law phones for me	Mother phones for me

I visit GP myself							If husband is ill I will pop in and make the app myself	If MIL not available	
Friend or relative visits GP									
Other					I use Typetalk, in work hours I use BSL interpreters				
MINICOM PROBLEMS		n/a		n/a		n/a	n/a	n/a	n/a
No-one answered									
Called party hung up	✓				✓				
Staff did not know how to use minicom/typetalk			✓						
ATTENDANCE: COMMUNICATION									
Sign	✓					✓	✓		
Speech	✓	✓	✓	✓	✓				
BSL interpreter									
Lip speaker									
Written English/gestures			✓				✓	✓	✓
Other						Mother comes with me		Mother-in-law often comes with me	Mother often comes with me

ARRIVAL: RECEPTIONIST									
Very easy				✓					
Easy	✓	✓	✓		✓				
Difficult						✓	✓	✓	✓
Impossible									
HOW KNOW DR. READY?									
Someone fetches me									
System e.g. loop, pager, board	✓	✓	✓	✓	✓	✓	✓		
Voice announcement								✓	
Keep checking with receptionist									✓
Never know when ready									
EVER MISSED AN APPT?									
Always									
Often									
Sometimes									✓
Rarely				✓	✓			✓	
Never	✓	✓	✓			✓	✓		
COMMUNICATION IN APPOINTMENT	Speak/write	Speak	Speak/write	Speak	Speak	Mother comes with me and interprets	Speak/write usually. Husband comes to interpret if serious or use a BSL interpreter	Write	Write

AFTER THE APPOINTMENT									
Always		✓		✓					✓
Sometimes	✓		✓		✓	✓	✓	✓	
Rarely									
Never									
GP/DENTIST DEAF AWARE?									
Always			✓						
Sometimes	✓			✓	✓		✓	✓	✓
Rarely		✓				✓			
Never									
SATISFACTION WITH COMMUNICATION AT LAST APPT?									
Very		✓	✓						
Quite	✓				✓				✓
Somewhat				✓			✓	✓	
Not at all						✓			

IF BSL INTERPRETERS ARE USED	Not used	Not used	Not used for GP, have used at hospital in past	Not used, interpreters not confidential enough. Prefer to write down. Father is a retired GP. Ask him for info.	Not used	Not used		Used one throughout my pregnancy	Not used
GP							✓		
Agency								✓	
Booked self									
ANY PROBLEMS WITH BOOKING INTERPRETERS?		n/a		n/a		n/a		n/a	n/a
Yes	GP forgot to inform hospital				✓				
No			✓				✓		
WHAT WERE THE PROBLEMS?		n/a	n/a			n/a	n/a	n/a	n/a
GP/Dentist refused to book					✓				
There was no interpreter available									
GP/Dentist did not know how to book	✓								
Other									
APP BETTER WITH INTERPRETER?		n/a		n/a	n/a	n/a			n/a

Yes	✓		✓				✓	✓	
No									
WHY?									
HEARD OF SIGN TRANSLATE?									
Yes	✓		✓	✓			✓		
No		✓			✓	✓		✓	✓
IF USED THE SERVICE, WAS IT USEFUL?	Not used, would like access	n/a	n/a	Not used, worried about security of using online.	n/a	n/a	Not used service before	n/a	n/a
Yes									
No									
OTHER PRIMARY CARE SERVICES	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
WANT MORE INFORMATION ABOUT HEALTH SERVICES IN LOCAL AREA?	Yes, not sure what they do?	Yes, would be useful	Yes	No	Yes	Yes	Yes	Yes	Yes
HOW WANT TO KNOW ABOUT SERVICE?									
Via the internet			✓	✓	✓	✓		✓	
Via GP		Leaflets from GP	If not enough info from internet		✓				
Via email									✓

Other	Deaf group						Deaf group	Deaf group	Deaf group
OTHER SERVICES?	Not aware of	RAD?	No	No	No	No	No	No	No
HOW KNOW ABOUT SERVICES	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
WOULD YOU LIKE MORE INFO RE HEALTH SERVICES FOR DEAF PEOPLE?	Yes	Yes	Yes	No, can ask my father for advice.	Yes	Yes	Yes	Yes	Yes
HOW WOULD LIKE TO LEARN ABT SERVICES?		Various ways							
Via the internet				✓				✓	✓
Via GP									
Via email									
Other	Deaf group		Deaf group	✓	Deaf group	Deaf group	Deaf group	Deaf group	Deaf group
AWARE OF DDA?	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes
AWARE THAT PCT RESPONSIBLE UNDER DDA FOR EQUAL ACCESS TO APP?	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No
WHAT SHOULD THEY BE DOING?									
Staff should be deaf aware	✓	✓	✓	✓	✓	✓	✓	✓	✓
Should be able to use minicom/typetalk									
Should provide a registered BSL	✓					✓	✓	✓	✓

interpretert/lipspeaker									
Other									
PROBLEMS WITH GP ETC? KNOW HOW TO COMPLAIN?									
Yes	✓			✓	✓			✓	✓
No		✓	✓			✓	✓		
IF NO, WHY NOT?	n/a			n/a	n/a			n/a	n/a
Did not want to/did not want to upset anyone									
Did not know how to		✓	✓			✓			
Did not get around to it							✓		
WANT MORE INFORMATION ABOUT THE DDA?									
Yes		✓	✓	✓	✓	✓	✓	✓	✓
No	✓								
RECOMMENDATIONS									
Staff should be more deaf aware	✓	✓		✓	✓	✓	✓	✓	
Staff should know how to use Typetalk/sign translate	✓								
Staff should know basic BSL	✓	✓	✓	✓	✓	✓	✓	✓	✓
Other									
MAKING APPOINTMENTS									
Telephone									
Minicom (dedicated									

textphone line)									
Email	✓	✓	✓	✓	✓			✓	✓
Text message on mobile		✓		✓	✓	✓	✓	✓	
Via the internet (online booking system									
Other									
WHEN READY FOR APPT, HOW KNOW?									
Member of staff (e.g. receptionist)									
Electronic system (vibrating pager/board)	✓	✓	✓	✓	✓	✓	✓	✓	✓
Other									
IF HAD OPTION, COMMUNICATION WOULD BE									
BSL		Basic BSL would be helpful		Basic BSL would be helpful	Basic BSL would be helpful				
BSL interpreter	✓					✓	✓	✓	✓
Spoken English									
Written English									
Other									

Appendix 2: Results from hard-of-hearing group (background data)

Participant	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
66+	✓	✓	✓	✓	✓	✓	✓	✓
GENDER								
Male							✓	✓
Female	✓	✓	✓	✓	✓	✓		
COMMUNICATION								
Spoken English	✓	✓	✓	✓	✓	✓	✓	✓
Signed English								
British Sign Language								
Other	Lip reading with difficulty		Lip reading					
AREA	Colchester	Colchester	Colchester	Colchester	Colchester (Stanway)	Colchester	Colchester	Colchester
How old when became deaf?	48 yrs	28yrs	52yrs	9yrs	50yrs	50yrs	20yrs	40yrs

Appendix 3: Results for BSL interpreters group

1. Background

RESPONDENT	1	2	3	4	5	6	7	8	9
GENDER									
Male			✓	✓	✓		✓		
Female	✓	✓				✓		✓	✓
QUALIFICATIONS									
JTI									
TI								✓	
MRSLI	✓	✓	✓	✓	✓	✓	✓		✓
LENGTH OF TIME WORKING AS INTERPRETER									
Less than 1 year									
1-5 years		✓	✓		✓			✓	
5-10 years	✓			✓			✓		
More than 10 years						✓			✓
HOW OFTEN DO YOU WORK IN HEALTH SETTING IN NE ESSEX?									
Once a month	✓		✓	✓		✓			✓
2-3 times a month		✓			✓			✓	
3-5 times a month									
More than 5 times a month							✓		
HOW ARE YOUR SERVICES MAINLY BOOKED?									
Client books me directly									
Booked by agency on behalf of client	✓		✓	✓			✓	✓	✓
Booked by NHS service on behalf of client		✓			✓	✓			

2. Experiences

RESPONDENT	1	2	3	4	5	6	7	8	9
RAD or Freelance?	**RAD**	**RAD**	**RAD**	**RAD**	**RAD**	**RAD**	**Freelance**	**Freelance**	**Freelance**
Are your experiences working in health setting:									
Mostly positive	✓	✓	✓	✓		✓	✓	✓	✓
Mostly negative					✓				
What are reasons for any negative experiences? You can tick more than one answer									
Lack of information about the assignment			✓					✓	
Not enough time with healthcare professional	✓				✓		✓		✓
Booked time is too short	✓	✓			✓	✓	✓	✓	✓
Problems booking follow-up appointments					✓		✓		
Lack of deaf awareness among health professionals	✓	✓	✓		✓	✓	✓	✓	✓
Health professionals unfamiliar with using interpreters	✓	✓	✓		✓	✓		✓	✓
Do you have experience with SignTranslate?									
Yes									
No	✓	✓	✓	✓	✓	✓	✓	✓	✓

Appendix 4: Results for health professionals group

1. Background for surgeries that responded

GP PRACTICE	1	2	3	4	5	6	7	8
AREA	Stanway	Wivenhoe	Colchester	Stanway	Clacton-on-Sea	Holland-on-Sea	Wix	Colchester
Responded	✓	✓	✓	✓	✓	✓	✓	✓
If not, why not?								
Respondent's job title	R	PM	R	PM	Assistant PM	PM	PM	PM
No. of deaf patients registered	under 30	not sure	2 – 3	not sure	not sure	not sure	not sure	not sure
No. of deaf patients seen in last 12 months								Not sure
0 – 5	✓	✓	✓	✓				
5 – 10					✓		✓	
10 – 20								
More than 20						✓		

Key: PM = practice manager

2. Background for surgeries that did not respond

GP PRACTICE	9	10	11	12	13	14	15
-							
AREA	Great Bentley	Clacton-on-Sea	Manningtree	Thorpe-le-Soken	Clacton-on-Sea	Cornerstone	Clacton MIU
Responded							
If not, why not?	Could not get through	Could not get through	PM not there, receptionist refused to answer	PM not there, receptionist refused to answer	PM not there, receptionist refused to answer	Called party refused to answer questions, PM did not return calls	Called party refused to answer questions

3. Access for Deaf and hard-of-hearing patients

GP PRACTICE	1	2	3	4	5	6	7	8
How do your deaf patients make appt.?								
Phone					✓	✓	✓	✓
In person	✓	✓	✓		✓	✓	✓	✓
Friend or family member rings for them	✓		✓	✓	✓	✓	✓	✓
Other (please state)		Fax (one patient)						
COMMUNICATION SYSTEMS								
Do you know what a minicom is?	No	Yes, same as loop	Relay system	3-way system	Heard of it, but not sure	No	Yes	No
Do you know what Typetalk is?	Yes	No	On phone, not sure how to	typing messages	Know about system but didn't know what it was	No	Yes	Yes

			use		called			
Do you know what a hearing loop system is?	No	Yes	No	Yes, have in surgery but charged to use	Heard of it, but not sure	Yes	Yes	Yes, have one available
COMMUNICATION WITH PATIENTS								
Speak to them	✓				✓	One member of staff has basic signing		
Sign to them							If booked	Have receptionist who can sign
BSL interpreter								
Written English/gestures		✓	✓		✓		✓	✓
Other		Also have touchscreen system for checking in		Family member comes with, never been asked for interpreter				

When a deaf patient attends appt., how do you let them know when health professional ready to see them?								
Someone fetches them	✓							
System (pager or board)	✓	✓	✓	✓	✓	✓	✓	✓
Voice announcement								
Other (please state)								
If BSL interpreter needed, whose responsibility is it to book?								
Surgery	✓	✓		✓		✓	✓	
Patient			✓		✓			✓
Do you know how to book a BSL interpreter?								
Yes		Contact RAD or PCT direct		NHS interpreting service "The Big Word" agency, or RAD for advice			Via switchboard	
No	✓		✓		✓	✓		✓
Do you feel your surgery could benefit from deaf awareness training?								

Yes	✓	✓		✓	✓	✓	✓	✓
No			✓					
What would you like to learn about?	How to communicate better, basic signs	Like to be able to communicate, ensure reception knows how to communicate	n/a	How to communicate	Can't think of what. Problem is if one member of staff trained, deaf person comes in, that member of staff may not be there	Not sure, how we can help	How to communicate	How to communicate, be aware of problems. Appropriate for receptionists/clinical staff
Are you aware of the DDA?								
Yes		✓	✓	✓	✓	✓	✓	✓
No	✓							
Are you aware that the PCT is legally required to ensure full access to deaf patients?								
Yes	✓			✓	✓	✓	✓	✓
No		✓	✓					

Would you consider allowing deaf patients to make appts via:								
e-mail	Have for prescriptions, but not sure of policy	Possibly, would give email address out if necessary	✓	✓	Looking at this at the moment	Not currently but in future	✓	Yes, available now
text message	Possibly in future	Don't have surgery mobile but possibility	✓	surgery already has mobile used by hearing patients for out of hours	Looking at this at the moment	Would consider	More difficult	Don't have surgery mobile but possibility
via the internet	Not at the moment	Waiting for clinical system to be updated at present, old system no good for this kind of thing	✓	✓	If it was possible, but considering it at the moment	Don't have a website at the moment	Looking into this at the moment	Have online booking system, web-based