

**Improving access to
Health Care Services
for Deaf Patients
in Cumbria.**

December 2015

your
voice
counts

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Introduction

Healthwatch Cumbria (HWC) was contacted by the Deaf Health Champion Project (DHC) who asked if we could support them in highlighting issues affecting the Deaf community when accessing health and social care services. The main issues concerned access to GP surgeries, hospitals and problems with poor communication resulting in unsatisfactory patient experiences.

The Deaf Health Champion project (DHCP) is funded by the Department of Health and is delivered locally by Cumbria Deaf Association (Deaf Vision). It aims to identify gaps in access to services and raise awareness of the needs of all Deaf people who use BSL as their first or preferred language. The majority of big D Deaf people usually become deaf before or just after they learn to speak - through Meningitis, German measles, Whooping Cough. Very few are born deaf. The DHCP acts as a champion for change to improve access to health and social care services. In Cumbria the DHCP are working with members of the public who are Deaf and attend local support groups based in the Copeland, Barrow, Kendal and Carlisle districts of Cumbria that are run by Cumbria Deaf Association.

HWC is aware of the 'Accessible Information Standard 1605' and promotes it on the HWC website. This is a national initiative that the National Health Service (NHS) has introduced to overcome some of the communication issues affecting people with disability or sensory loss. *The Standard* seeks to ensure that all NHS or publicly funded adult social care services must identify and record information and communication needs with service users no later than April 1st 2016. The information we received from the DHC indicated that the service currently received by Deaf patients is at odds with this standard.

The findings from this work will inform healthcare providers in Cumbria of the views of the Deaf community as they work to implement *The Standard*.

SignHealth's National 'Sick of It' report (March 2014 page 2) stated that the ineffective access to services for Deaf people meant '*missed diagnosis and poor treatment is costing the NHS - £30m a year*'. The report suggested that lack of information, poor communication, and unnecessary difficulties in getting to a doctor make the Deaf population more likely to be overweight, twice as likely to have high blood pressure and four times more likely to be on the verge of diabetes:

'Our health system is failing Deaf people. It's gone on too long and we're sick of it'. SignHealth 'Sick of it' 2014 page 2.

HWC working in conjunction with DHC proposed to:

- Find out more about the experiences of the Deaf community when accessing GP and hospital services, including any perceived barriers to accessing and utilising these services.
- Find out from GP's in Cumbria how they currently work to assist Deaf patients in accessing their service.

The findings from this work will inform Cumbrian Healthcare providers of the views of the Deaf community as they work to implement *The Standard*.

Definition and population

It is important to note that the profoundly Deaf, whose first language is British Sign Language (BSL) are defined as Deaf with a capital 'D'; deaf people with a lower case 'd' are those who have once had full hearing but now have reduced hearing.

During this research HWC learned from members from the Deaf support groups that there are no up to date definitive numbers available of exactly how many Deaf people are living in Cumbria, however, colleagues from the Deaf support groups told us that an estimated figure in 2007 was around 450.

Methodology

To try and gain as broad an understanding as possible, the 4 support groups for the Deaf and 64 GP surgeries were approached with two separate surveys:

1. Deaf patient survey:

Designed to explore individual's experiences of accessing GP and hospital care in relation to barriers faced and how these could be overcome.

2. GP Surgery Access survey:

Designed to assess what provision surgeries currently have for Deaf patients.

Copies of both surveys can be seen in Appendix 1 & 2.

HWC in conjunction with HWC Deaf Ambassadors and the DHC lead agreed that a survey specifically designed in language appropriate for the Deaf to best understand would be the preferred option of engagement with the groups. This would allow us to gather experiences and views. or gathering experiences/views from the group's members about access to GP's and hospital services, with the aid of an interpreter. HWC devised the survey questions based on knowledge provided by the Deaf Ambassadors, DHC Project lead and research of a similar nature carried out by Healthwatch York and Wokingham. HWC wanted to gather both the experience of Deaf patients in accessing health services, and also learn from a service perspective the strategies, processes and devices implemented to assist Deaf patients in accessing the service.

Deaf Patient Survey

The patient survey consisted of 24 questions, split into two sections:

- i) GP and
- ii) Hospital.

These sections were subdivided into three areas:

- a) contacting GP/Hospital,
- b) waiting room for GP/Hospital,
- c) appointment with GP/Hospital.

The language used in the survey was designed in conjunction with two Deaf representatives from the DHCP (who are also Deaf Ambassadors for HWC) and the Deaf Health Champions project lead.



Survey Pilot:

A HWC member of staff attended the Deaf group, referred to on page 1, along with the lead from the DHC in Copeland where a pilot of the survey questions was undertaken with 7 members of the group. The DHC interpreted the survey questions for those members of the group who were unable to read the questions themselves. Their feedback was analysed and helped us to develop the wording and flow of the survey questions.

HWC along with the DHC lead and a registered interpreter visited the Deaf groups in Barrow, Kendal and Carlisle to complete the revised survey. In total HWC gathered a further 33 responses to the Deaf patient survey. This was made up of 14 Carlisle group members from the Barrow group, 12 members from the Kendal group and 10 members from the Carlisle group.

GP Surgery Access Survey

In a covering letter Practice Managers were given the option to either complete a paper copy of the survey to be returned by post to HWC or complete the survey online.

Following the initial mail out of the covering letter and survey, there was a very low response rate, with only 8 practices completing the survey. To encourage more practices to respond HWC contacted the NHS Area Team to enlist their support in promoting the survey to all GP practices in Cumbria. To do this they use an internal email system. This resulted in 3 more practices responding.

In total HWC received survey responses from 12 out of 64 practices.

HWC plans to work with GP surgeries, GP federations and the CCG to explore why there was a relatively low response rate and to consider ways of increasing this for further work.

Key Issues Identified from Patient Survey

A national report by SignHealth¹, stated that lack of information, poor communication, and unnecessary difficulties in getting to a doctor, make the Deaf population more likely to suffer from a range of medical problems including high blood pressure and weight problems.

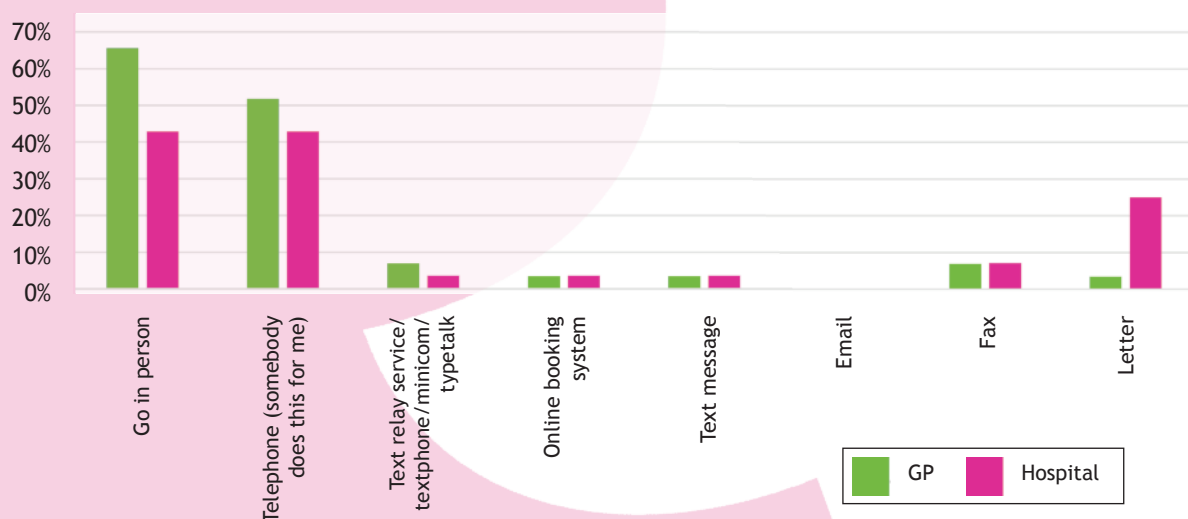
Accessibility

Our survey found a difference between how our Deaf respondents contacted their GP and national figures reporting how the general public contacted their GP. 66% of respondents reported that to make a GP appointment they would go to the surgery in person. 52% said that they would ask somebody to telephone the surgery on their behalf. These figures are in stark contrast to figures released by NHS England in 2014², they reported that 88.4% of all patients booked their appointments by phone and 29.3% booked them in person.

¹ SignHealth, 'Sick of It - How the Health Service is Failing Deaf People', 2014

² NHS England GP Patient Survey, 2014

How do you contact the GP/Hospital to make an appointment?

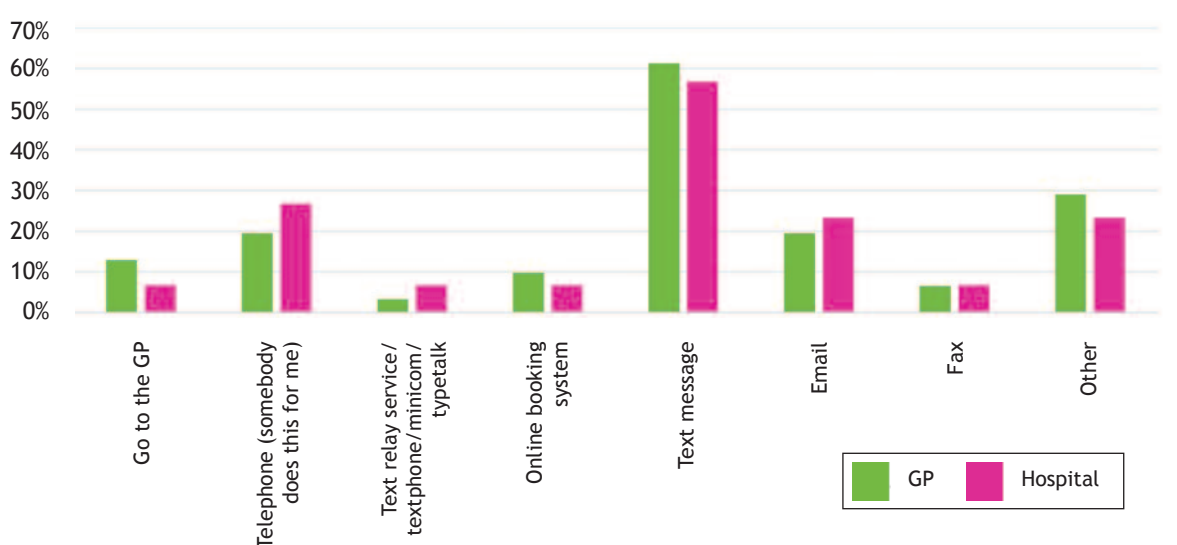


Respondents reported similar methods when contacting a hospital to make an appointment, although less respondents went in person and more made appointments by letter.

These figures suggest a disparity between ease of access for the Deaf community and the rest of the general population. Respondents told HWC that Deaf patients make the journey to their GP surgery to book an appointment and then make a second journey for the actual appointment, if the general population had to go through this process it could be assumed that many people would find this an unacceptable inconvenience.

When respondents were asked how they would want to make an appointment with their GP or hospital the majority said that they would like to use a text message system; sending an email was also a popular choice. This suggests a strong desire by Deaf patients to utilise technology to assist them in booking appointments. The benefits of this being twofold; firstly it would allow appointment booking to remain under the autonomy of the patient, and secondly it would be far more convenient than making an extra trip to the surgery in person.

How would you want to contact your GP/hospital to make an appointment?

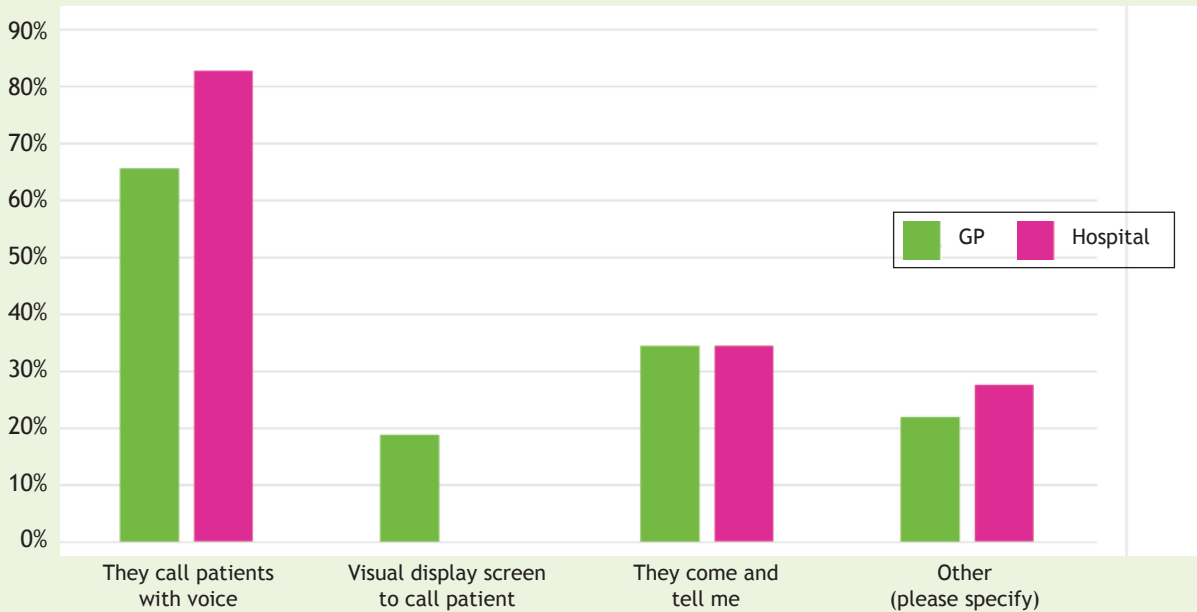


Communication/Interactions

81.25% of respondents said that communication problems put them off making an appointment with their GP, and 80% said communication problems put them off making a hospital appointment.

We asked how patients were called for their appointment in the waiting room. The majority of patients at the GP practices and hospitals were called by voice.

How are you called for your appointment?



Respondents explained how they felt when they were called by voice for their appointments:

‘Not Deaf aware, shouting for me doesn’t help, I can’t hear them.’

‘It’s embarrassing when they shout for me because I can’t hear them. If I’m sitting facing the doors I watch for them coming out but I can’t lip read well.’

Furthermore, 62.5% of respondents said that they have missed an appointment whilst sitting in a waiting room at a GP, and 60.71% had missed a hospital appointment:



‘When pregnant I missed an appointment due to missing name calling.’

‘It’s embarrassing if I’ve missed my appointment, that’s why I take someone if I can.’

Communication was not only a problem when being called for an appointment. Some respondents reported on issues communicating to staff throughout their visit to the GP surgery or hospital:

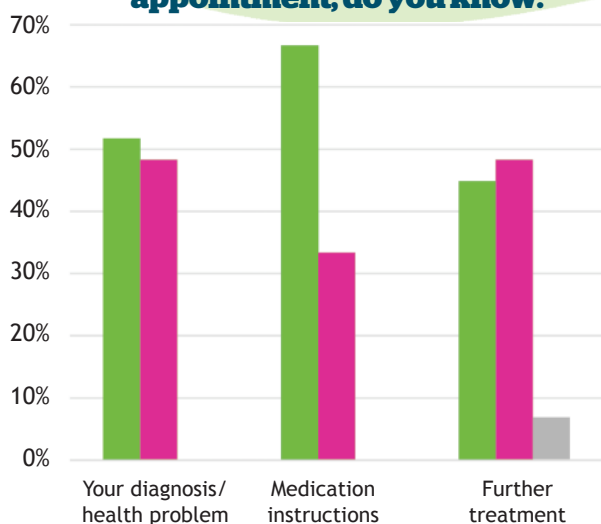
‘Very few surgeries do sign language or even attempt to talk directly to the profoundly Deaf preferring to talk to whoever is with them.’

‘General dissatisfaction with people answering phone and talking far too quickly.’

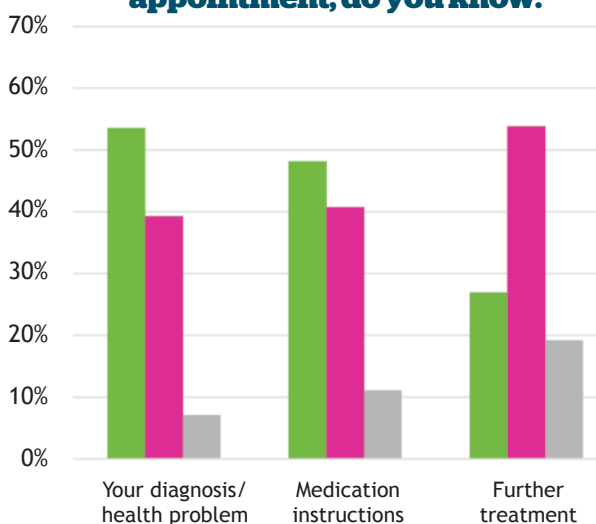
‘I tried to speak to the receptionist but he wouldn’t make face to face contact.’

Communication issues were found to lead to missed appointments, patient anxiety, and patients leaving with incomplete knowledge regarding their consultation. Further, respondents were asked if, following their GP or hospital appointment, they knew their diagnosis, their medication instructions and if they needed further treatment (if applicable).

After you leave your GP appointment, do you know:



After you leave your hospital appointment, do you know:



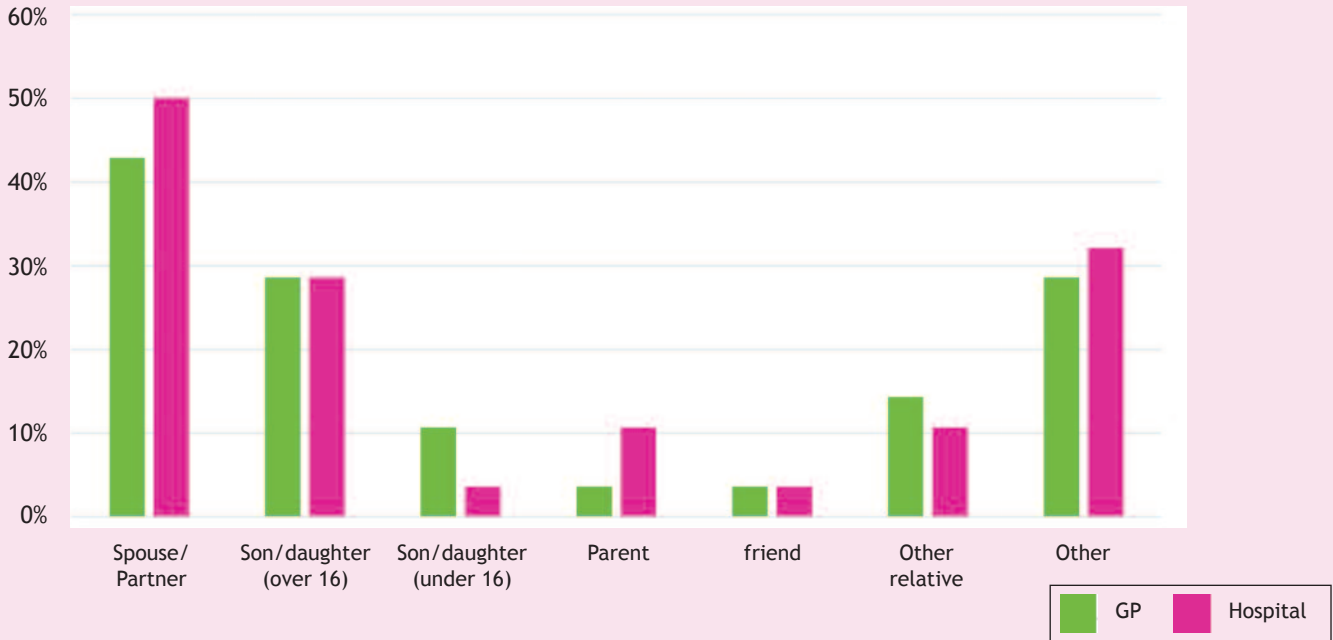
Whilst multiple factors may lead to a patient not leaving an appointment with a full diagnosis or knowledge of further treatment, the high number of respondents leaving without knowing their medication instructions is worrying and could obviously lead to very serious consequences. It is interesting to note that more knowledge is gleaned in this area from the GP interview.



Accompaniment to appointments

The majority of respondents stated that they either 'Always' or 'Sometimes' take someone with them for GP and hospital appointments. Of those the accompanying person was most commonly a spouse or partner, or a son/daughter over the age of 16. There were a small proportion of respondents who reported that they took a son/daughter under the age of 16.

Who do you take to appointments with you?



When asked why they took someone to their appointments with them, the most common reason was to help interpret. Others explained that they took someone with them for support and confidence. This raises the issue of patient confidentiality and also whether having the attendance of a family member, particularly a child, is appropriate in all situations.



Key Issues Identified from GP Practice Survey

Booking an appointment

When asked if the surgery knew how many Deaf patients were registered at the surgery:

- 8 out of the 12 surgeries that responded knew how many Deaf patients they had and also stated that they made a distinction between Deaf and hearing impaired patients
- 3 surgeries stated they did know how many Deaf patients they had
- 1 surgery thought the question was not specific enough

All of the surgeries that responded said their patient record system would flag up that a patient was Deaf. However, four surgeries stated that they did not have an agreed procedure to meet a Deaf patients, 'communication requirements. Of those surgeries that said that they did have a procedure to meet Deaf patient, 'communication requirements, answers included:

'I have an arrangement with one patient that she can email me when she needs an appointment.'

'We would organise interpreting (BSL) if required. I am not aware of such a request in the last 4 and a half years but I am conscious that we haven't publicised this very widely. I'm going to put it in our next newsletter.'

'Ring a specific number where the patient communicates with an interpreter who is speaking directly to the receptionist.'

Four of the twelve surgeries confirmed that they do have a text system in place whereby a Deaf patient can request an appointment. Another 4 surgeries stated that they had an alternative method to make an appointment, for example an email or an online system. Three surgeries stated that they did not have a text service, despite 2 of them having a text service for outbound messages



Staff Training

9 of the 12 surgeries stated that their staff team were not trained in basic British Sign Language (BSL) and/or had not received Deaf awareness training. The three remaining surgeries stated they had received Deaf awareness training, although only one surgery had a member of staff with BSL (level 1). One surgery spoke highly of the Deaf awareness training they had received:

‘All staff received Deaf awareness training at a session we requested. It was an excellent session! Three Lovely ladies attended - two interpreters and a Deaf lady and it really opened our eyes to the issues’

Accessibility

Three of the surgeries stated that they had visual indicators in waiting areas to alert Deaf patients that it was their turn; all three used screens. The remaining nine surgeries stated that they did not have any visual indicators and their practitioners would call or ‘fetch’ the patient from the waiting room. However, one surgery stated that although they did not have visual aids, they catered to their patients individually:

‘No. We are small single handed practice. We know all our patients individually and cater to their needs on a 1:1 basis.’

Interpreters

When asked if the surgery would provide an interpreter if requested, one surgery said that patients organise this themselves. The remaining 11 surgeries said they would do so. The surgeries were asked exactly how they would do this:

- 3 surgeries said they would use an interpreter service but did not specify which one
- 2 surgeries said they had a list of interpreter services in reception
- 1 surgery did not specify how they would do this
- 1 surgery said they would like to use an interpreter service, but did not know how to do this
- 1 surgery said they would use the Clinical Commissioning Group (CCG) provided interpreter service
- 1 surgery said they would contact Deaf Vision or Signtranslate
- 1 surgery said they would contact a local registered BSL interpreter
- 1 surgery said they would arrange an interpreter via the Cumbria Deaf Association

The surgeries were also asked if they had procedures for booking interpreters for an emergency appointment:

- 5 surgeries said that they did not
- 5 surgeries said that they did, although one surgery stated ,‘although last time it was a hassle,‘
- 2 surgeries said it would be the patients responsibility

The surgeries were asked if they would factor in additional support time into appointment length if an interpreter attended:

- 8 surgeries said they do
- 2 surgeries said they would if it was requested
- 2 surgeries said they do not

Communication

The surgeries were asked what methods the practice GP's use to check that a Deaf patient understands their diagnosis, treatment, medication (including dosage), potential side effects and next steps.]

- 9 surgeries said that they would ensure this was done by giving details in writing:
Written communication - part lip reading - patient information leaflets'
Would present visual information for patients, to some extent would rely on patient bringing another person with them for support
- 2 surgeries said they would speak slowly so the patient could lip read or request a signer:
'Either speak slowly in order for the patient to lip read or request a signer themselves or ask patient to do so'
- 1 surgery said that they did not have a specific method

The surgeries were also asked if they provided general health information in the form of BSL videos and/or display websites such as SignHealth, Diabetes UK, Macmillan Cancer support (who have BSL videos).

- 6 surgeries said that they did display this type of information on a television screen
- 3 surgeries reported they currently did not do this, but would see if this could be added:
'No although we do have electronic media where this could be added'
'We have TV screens but no specific BSL videos - I will be looking for these now though!'
- 3 surgeries said they did not do this.

All of the findings suggest more work could be done to ensure that Deaf patients receive an equitable service whenever they come into contact with service providers. Although, some good practice has been evidenced in this report there are some inconsistencies and opportunities for improvement that would make a big difference to the experience of Deaf patients and in the long run the health outcomes.



Recommendations

From the evidence we have collated from the two surveys, we would suggest the following recommendations:

- GP and Hospital Services to offer SMS text messaging service for Deaf patients to book appointments, receive reminders of their appointments & receive test results.
- Service providers should ensure that Deaf patients have an equitable service by one or more of the following:
A member of staff who is BSL Trained.
Service providers include Deaf Awareness training as part of their induction programme. This should be in conjunction with a recognised organisation (such as Cumbria Deaf Vision).
Deaf Awareness Training for staff member(s) should be reviewed annually.
- Deaf patients to be treated with the same respect & dignity as hearing patients. This needs to be done to meet the CQC Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 10
- A need for visual aids, number systems or vibrating pens/pads in waiting areas to inform patients when it is their turn.
- Waiting areas to have Deaf appropriate information/ literature in waiting areas.
- Reception staff to be trained or have written instructions of how to book recognised Qualified and Insured Interpreters. In cases where an interpreter is not available to attend, then the use of recognised online interpreter services should be prioritised. Interpreter names, addresses and contact number should be clearly visible in waiting areas.
- Service providers should still book an interpreter when a Deaf patient refuses the services of a recognised interpreter to safeguard themselves from any misunderstandings by either party.
- All service providers need to have a policy on how to support Deaf patients. A copy of guidelines on supporting Deaf patients can be accessed from Cumbria DeafVision.

Useful links:

- Cumbria DeafVision, The Civic Centre, ground Floor, Carlisle, CA3 8QG
Tel: 01228 210205 Email: csu@deafvision.co.uk
- SignHealth- Best Practice for Deaf Patients
<http://www.signhealth.org.uk/for-healthprofessionals/good-practice-for-deaf-patients>
- SignHealth - Sick Of It Report
<http://www.signhealth.org.uk/health-information/sick-of-it-report/sick-of-it-english/>
- NHS England - Accessible Information Standard 1605
<https://www.england.NHS.uk/ourwork/patients/accessibleinfo-2/>

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Kenneth Lippet - Barrow Group
Debbie Halliwell - Kendal Group
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- The NHS Area Team for their support in promoting this research to the GP surgeries in Cumbria.
- The GP Surgeries who took part in this research.

HWC December 2015

your voice counts

*'Doctor comes out and shouts name,
but we don't know what name gets shouted.*

*We only know if nobody else stands
up then it must be us.'*





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