

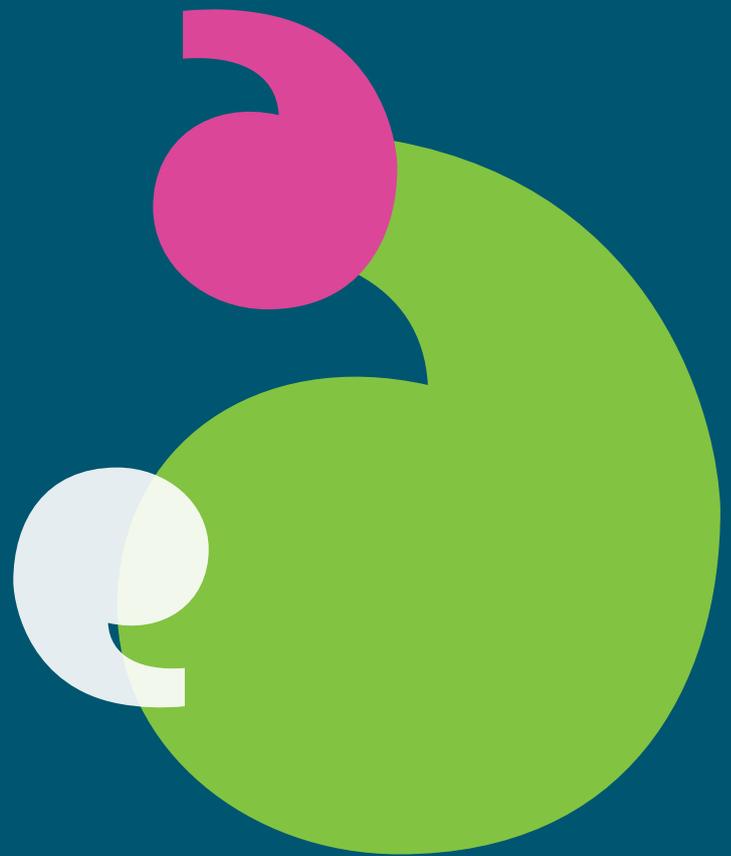


Deaf Community

Speaks Up On Local
Health Services



November 2014





Foreword

Healthwatch Leicester has welcomed the opportunity to undertake this research and to work in partnership with the Deaf and hard of hearing community and organisations on this exciting project.

This research has revealed that there are a number of barriers faced by the Deaf and hard of hearing people in accessing local health provision. It demonstrates the need to break down the communication and access barriers that exist for many people who are Deaf or hard of hearing.

Therefore, the study highlights the need for greater deaf awareness among health services, and the necessity for professionals to embrace diverse ways of communicating with Deaf users and to recognise the different needs of their patients.

The Equality Act 2010, outlines responsibility for health providers to make reasonable adjustments for the way they provide services to Deaf and hard of hearing people. This is to ensure that Deaf patients are being given equitable provision to non-deaf users in accessing services. Achieving this in health services locally is crucial, as people often seek access to health provision in times of need.

Looking forward, we hope this report will assist health partners to identify opportunities to engage more effectively with Deaf and hard of hearing people, and to build on already existing community resources and strengths to improve their health and wellbeing. We hope, this research will provide insight to local health agencies to commit and to plan for improved service provision to people with hearing impairments.

We would like to see local partners adopt the recommendations and to seek greater involvement of the community in decision making, meaning that local provision is accessible to the Deaf and hard of hearing community. If such adjustments can be made, this should improve the experience and access of people with hearing loss.

We believe that implementation of the British Sign Language Charter will provide the framework for taking forward many of the recommendations.

This project has been a starting point for local Healthwatch as a newly established consumer champion for health and social care to engage and explore the needs of the local deaf community.

We plan to continue to work with our partners to facilitate the collective voice of the Deaf community and to improve their health outcomes.

Acknowledgement

Healthwatch Leicester would like to thank the Leicester Deaf Forum and British Deaf Association for providing support and assistance on the project design and implementation. Thanks goes to all volunteers for helping to recruit Deaf and hard of hearing participants, and many thanks to all the participants who without, we would not have been able to complete this project.



Summary

This report outlines the issues surrounding access to local health services for Deaf and hard of hearing residents in Leicester and Leicestershire by examining access to the services within the last 12 months. A number of local deaf projects took part in this study and shared their insight on the accessibility of local health services.

The report explains the purpose of this study and the methodology used. It also sought to set out recommendations on how local health services could be improved to meet the needs of the Deaf and hard of hearing community.

53 participants who are Deaf sign language users or hard of hearing took part in the research.

To summarise, the study highlights that some Deaf people have a positive experience of local health provision, however many Deaf users face significant challenges. The report examines a wide range of experiences within health settings, which has resulted in a number of themes emerging.

The key issues identified were:

1. Emergency and Urgent Care Access

- Access and pathways
- Patient experience

2. Communication Support

- Provision of Interpreting Services: access, choice, quality
- Difficulty in communication with health professionals

3. Information Accessibility

- Limited understanding and use of healthcare information

4. Health education and prevention

designed to help the Deaf and hard of hearing communities improve their health and wellbeing

5. Deaf awareness among

health professionals to improve patients experience and quality of care



Some quotes used in this report were shared with Healthwatch Leicester by Leicester City CCG during their interaction with the Open House Meeting.



Background

Understanding Deaf and Hard of Hearing Terminology

Deaf is a term applied to those people with a serious hearing loss. Deaf with a capital D refers to those members of the community who are considered culturally Deaf and use British Sign Language (BSL) as their primary method of communication.

Hard of Hearing are comprised of people who have a measurable hearing loss, representing two main categories: people who have lost their hearing ability over a period of time, usually in their adulthood; and those who have had hearing loss from early childhood but have not learnt to sign or do not use sign language. Hard of hearing individuals use English as a preferred method of communication and typically have higher level of literacy than sign language users.

Local Deaf community

According to the NHS Information Centre¹, there are 2,325 people registered as Deaf and hard of hearing in Leicester and 5,150 people registered in Leicestershire.



2,325

people registered as deaf and hard of hearing in Leicester



5,150

people registered as deaf and hard of hearing in Leicestershire

The tables below illustrate further breakdown of these statistics:

A number of people registered as Deaf by age:

Locality	0-17	18-64	65-74	75 or over
Leicester	20	280	25	75
Leicestershire	30	400	65	150

A number of people registered as hard of hearing by age:

Locality	0-17	18-64	65-74	75 or over
Leicester	5	235	140	1,535
Leicestershire	10	470	425	3,600

¹ Health and Social Care information Centre (HSCIC), People Registered as Deaf or Hard of Hearing - England, Year Ending 31 March 2010 <http://www.hscic.gov.uk/pubs/regdeaf10>



There are a number of various Deaf community groups within Leicester City who use BSL (British Sign Language) to communicate every day, but meet and work in “isolation” in the hearing world. These groups are Leicester Deaf Club, Leicester Deaf Forum, Leicester Deaf Action Group, Over 50's Deaf Club, BME Coffee Morning HearNow Project and Leicestershire Deaf Children's Society.

Why we decided to undertake this project

The implication of deafness on access to health provision is variable and associated with a number of factors. One of the key issues is related to barriers in communication with professionals resulting in much poorer health outcomes for this particular community of interest. Many studies have illustrated that Deaf people find it difficult to access mainstream physical and mental health care. ('Sick Of It' Report, Signhealth, March 2014)

According to the national GP Survey (2009)², the percentage of the Deaf Community who reported that their health is 'Poor' was 10% compared to 6% of the national population. And 30% of Deaf people who thought that they needed to see their GP were not able to, compared to 11% of the general population.



10%

Deaf Community reported their health is 'Poor'



30%

Deaf people who thought that they needed to see their GP were not able to,

Local anecdotal evidence has been identified by the varied Deaf community groups that include access to physical entry to health related buildings such as audio buzzers, lack of access to health website through BSL, lack of trained front line staff in Deaf Awareness, last minute booking of interpreters, booking of untrained and unqualified BSL English Interpreters, limited mobile numbers to go alongside telephone numbers to access range of health services, issues with access to their GPs, dentists, community health services and inaccessible information about health.

In light of the above, Healthwatch Leicester in partnership with the Leicester Deaf Forum and the British Deaf Association decided to work together and to find out more about these problems areas.

The project also aimed to build effective local engagement mechanisms and relationships with the varied Deaf community groups in Leicester City so their voice can be heard and help create an visible impact through the varied health networks.

² As referred by SignHealth charity following publication of the results from the national GP Survey 2009, <http://www.signhealth.org.uk/v3/wp-content/uploads/2014/10/Why-Are-You-Still-Missing-Me.pdf>



Methodology

A small steering group³ was formed, involving Heathwatch Leicester, Leicester Deaf Forum members and representatives from the British Deaf Association (BDA). The aim was to focus on the recent experience of contact with health services.

In order to examine a broader range of services this study not only focuses on Primary Care provision but also looks at emergency and hospital care.

The steering group deliberated on the questions to be asked, because many Deaf people do not feel comfortable with filling in forms and writing. Therefore a simple questionnaire was developed by the steering group to ask about the experience of accessing local health provision.

The following eight sections were included in the questionnaire:

- 1. About Me: Gender, Age, Home Area**
- 2. My Hearing Needs**
- 3. Access to local Deaf and hard of hearing networks**
- 4. Interactions with local health outlets and professionals**
- 5. Communication methods with health professionals**
- 6. Access to Interpreting Provision**
- 7. My experience**
- 8. Information accessibility**

The steering group made sure that the questionnaire was accessible by including a picture glossary to help the Deaf people understand the questions. This is because many Deaf people have lower literacy levels which results in difficulties to process complex text and information.

A copy of the questionnaire is in Annex 2.

Participants were approached through community networks and one to one interviews. The majority of the feedback was captured via face-to-face interactions with the groups using Deaf volunteers, as we found that was the preferred methods of contact and communication. They also wanted to ensure that individuals fully understood the questions and were able to give as much information as possible about their experiences.

The study also includes an insight from a number of engagement activities conducted by Heathwatch Leicester prior to the survey, including visits to HearNow Project BME Coffee Morning and Open House Meetings.



³ Annex 1 details of the steering group



Questionnaire results

We collected information from fifty-three people living in Leicester and around the county of Leicestershire⁴. This is what we have learnt from them:

Participants' profile:

Gender



42%
Female



55%
Male



4%
Transgender

Age:



Are you Deaf or Hard of Hearing?

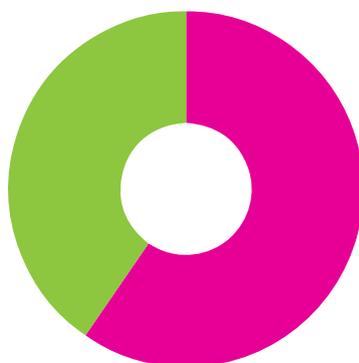


85%
Deaf



15%
Hard of Hearing

Home area: Where do you live?



60%
Lived in Leicester

40%
Lived in Leicestershire

⁴ The scope of the study aimed at the City residents as this project was undertaken by Healthwatch Leicester however the collected information has indicated that many of the participants who took part in the study are residents of the county, leading us to believe that Deaf groups serve not just the needs of the City Deaf community but also to facilitate the needs of county residents.



Interaction with health services in the local area

The following responses to the question:

Have you visited or had contact with any of these services within the last twelve months?



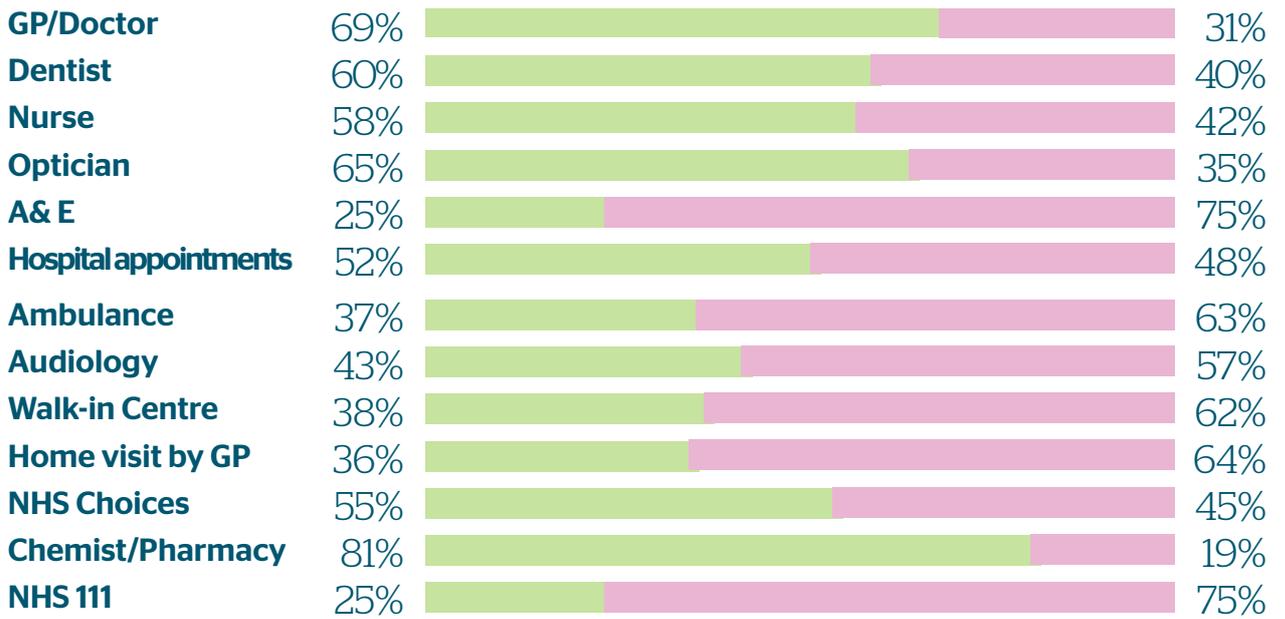


Are you happy with these health services listed below?

KEY:

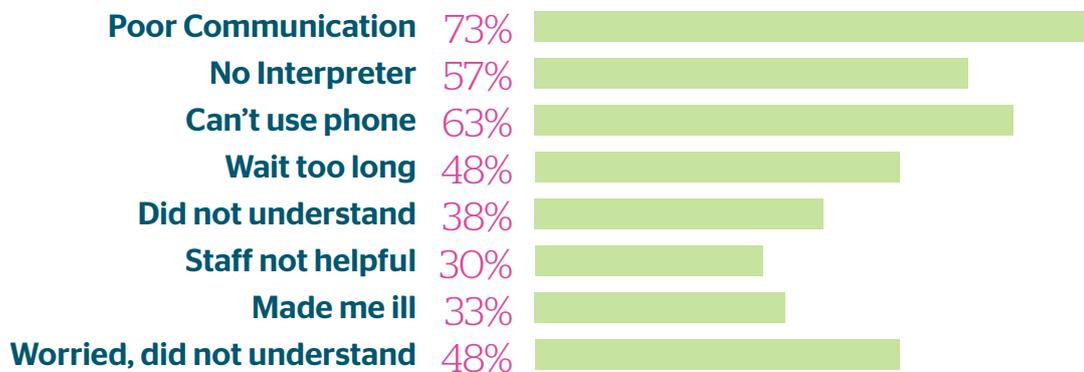
Yes 

No 



Participants that were dissatisfied with the health services they received gave the following reasons:

If you are not happy with local health services, tell us why?





Findings and themes

A number of themes emerged which describes the experience of Deaf and hard of hearing people when in contact with local health settings. The collected qualitative data presents number of interesting patients stories and provides even greater insight into their experience.

Here are the five overarching themes in the responses collected from our participants;

- 1. Emergency and Urgent Care Access**
- 2. Communication Support**
- 3. Information Accessibility**
- 4. Health education and prevention**
- 5. Deaf awareness among health professionals**





1. Emergency and Urgent Care Access

One of the emerging issues we identified is that very often Deaf people do not fully understand the access pathways and will use the most 'convenient' provision to them to seek help. Nearly 96% of responders used Emergency and Urgent Care setting as primary care pathways. Whilst this pattern can also be common amongst non-deaf users, Deaf people may be particularly prone to exercise a wrong choice due to a communication barrier. The responders generally had simplistic views of how the health system operates and they assumed that they are using the right access route.

'My son was poorly and in pain so we went to the LRI. We were signed in and we waited until to see someone to be told that we should go to our GP. He said we just needed pills from an over the counter pharmacist.'

It should also be noted that while presenting themselves at the Urgent Care setting, Deaf people found the interaction with frontline staff problematic.

A disturbing picture emerges from the following accounts of experiences reported to us by Deaf people:

"I was in A&E with a heart problem. I requested an interpreter at 3am in the morning. All I knew was that I had a problem with my heart but I couldn't understand anyone. I was frightened and stressful, because I didn't know what was going on. Luckily it wasn't serious I was sent home after an hour. No interpreter came."

"I had a blackout at home. I sent a text to the A&E service and the police came instead, they broke down my door to get in and had to pay for a new one."

"Can a BSL be booked for deaf patients on arrival at A&E? If not we need a full time interpreter at the triage reception point."

"When I was taken by ambulance I just assumed that they would take me to the LRI. The ambulance crew couldn't tell me where I was going because they didn't know BSL. So, it was a shock when I was taken out of the ambulance at Glenfield Hospital. I got very confused and the experience was very stressful especially as I went with heart problems."

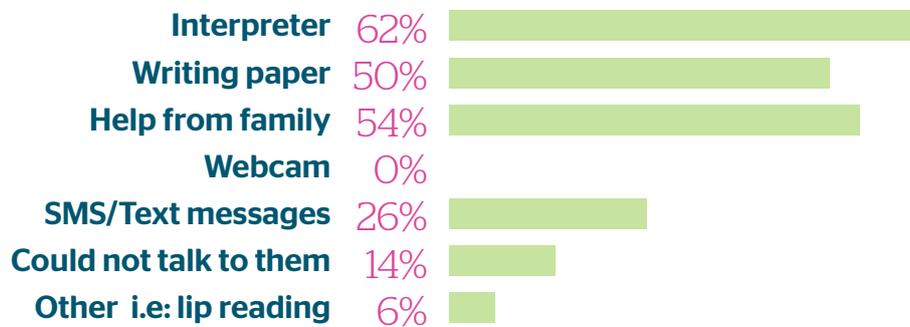


2. Communication Support

It was no surprise to find the most critical issue was communication between local health services and Deaf people.

They told us that they use many different methods of communications with health professionals. The methods of communication cited by the participants in this survey were:

How do you communicate with local NHS & health professionals, e.g. reception or doctor?



For Deaf people, the single key issue was the provision of interpreting services. Many told us that interpreters were not supplied by the health agencies even when they requested it.

“I have a new GP - I go with my sister who interprets for me. The hospital always provides interpreters but not the GP’s. If the GP sends me to the hospital they phone my sister. Why do they phone her and not write to me!”

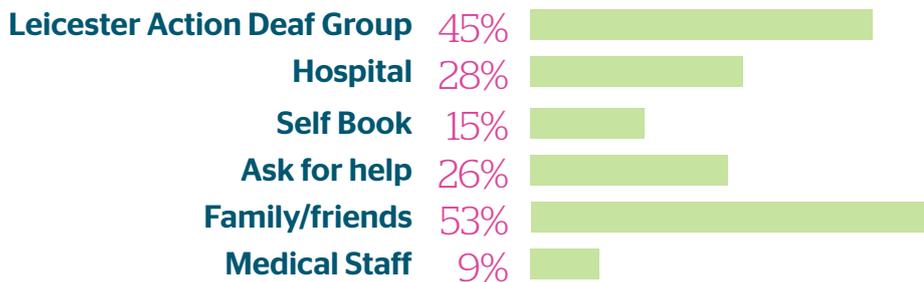
“If the hospital and GP records showed that the patient is Deaf and needs support, then an interpreter can be arranged in advance of the appointment.”

“I went to the LRI at 2am in the morning because my wife was unwell. We were waiting hours for her to get a check-up with little information as there was no interpreter and after our long wait the check only took 10mins and she was discharged.”



More than half of the responders stated that they used a family member who can hear and sign to communicate with health professionals. Responders said that having family members act as an interpreter is not recommended because it might create mis-communication and does not respect their confidentiality, privacy and dignity. The Deaf people we spoke expressed their concerns and unease at continually having to rely on their family members and friends in order to communicate and liaise with health services.

How do you ask to book an interpreter for your appointments?



Here are two examples of the need for an interpreter to be available to Deaf people within health settings.

A 15 year-old girl had to be the interpreter for her Deaf grandfather when he became ill and was taken by ambulance to hospital. On several occasions the young girl asked hospital staff if they could provide an interpreter. Her auntie told us what happened:

“At the hospital my dad had to have tests and go to different departments and my niece asked hospital staff if they could get an interpreter. The staff kept asking her to ‘wait a minute’ and then told my niece that there was no interpreter available, so she had to wait with my father until 5am. My niece was very upset and when she got home she burst into tears. She is not an interpreter, she is still at school and it’s not fair to put her in that position.”

Here a Deaf person describes how they became frustrated with ambulance staff when they spoke to a neighbour about his father, rather than speak to him.

“My father fell at home and because he has Care Call⁵ an ambulance was called. As his carer I received a text from Care Call to say that an ambulance had been called. I went to his house and was trying to explain that I am Deaf and that my dad was Deaf too.

A lady from across the road came over so the ambulance crew talked to her and not to me. I felt annoyed as I am the son and it’s my father you are talking about. Then my daughter arrived and so they spoke to her and not to me, again this upset me”

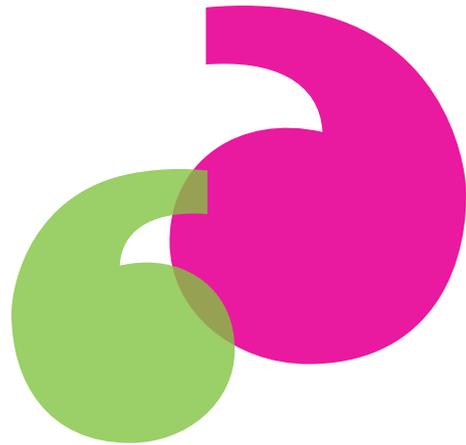
⁵ Care Call refers to Single Point of Access, a unit which coordinates all urgent and non-urgent referrals for community nursing, intermediate care, therapy services and admission to community hospitals across Leicester, Leicestershire and Rutland.



There were number of complaints about the quality of interpreting provided.

We found that the opportunity for choice was limited. People we spoke to claimed that there is little attempt to facilitate patient choice, and they did not feel they were given the opportunities to express their wishes.

“At my GP you can request an interpreter at the time you arrive for your appointment but you cannot pre-book. There is about a two-week wait for a GP appointment with an interpreter present. When you feel unwell you can’t wait two weeks”





3. Information accessibility

The majority (77%) of people said they do not understand and use the healthcare information provided.

Do you understand NHS information from leaflets, website and papers?

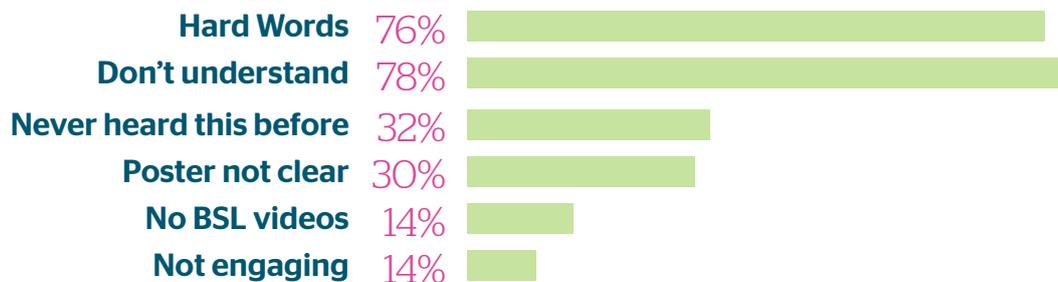
Yes

No



Further breakdown of the issue suggests that 79% people said that they found the language too complicated and full of jargon. They did not understand much of the text information in letters, posters and health promotion materials. Deaf sign users whose literacy levels are often limited, require a family member or a third party (including local support groups) to explain the information and the medical jargon used in written documents.

Those who did not understand NHS information gave the following reasons:



Below are just few examples of the participants feedback:

“Information produced by health services should be more accessible, too many ‘big’ words”

“I wish we could have BSL videos facilities”

“Sometimes I do understand but many times I struggle”

“We receive letters from the hospital, which we cannot understand so we have to come here to Frog Island to get the documents interpreted...”

“Medical jargon needs to be explained well so people need to be trained to at least Level 6 in BSL. There is a lot of terminology and complicated words.”



4. Health Education and Prevention

All participants expressed concerns about limited resources available to help them take responsibility for their own health and wellbeing. They would like more information on services in the local area on health related issues. We found that Deaf people need information in accessible formats to include, face-to-face interactions and health promotions talks.

5. Deaf awareness among health professionals

In addition to communication issues, one of the most prominent concerns among the responders was the extent to which health professionals have deaf awareness. A number of accounts suggest there is a need, in particular for front line staff to recognise the issue and make adjustment when required.

“Any GP, nurses and consultants in any health setting need basic sign language training”

“Ambulance people need to have BSL training. There is an emergency text number to alert the ambulance service, and then we get a text message back to acknowledge us with an appointment time or that the ambulance is on its way, but after that we can't reply with specific information”

“My father had a fall. The paramedic came on his bike. Me and my father are both deaf. The next-door neighbour came round and the paramedic was relaying all the information to him about my father. Eventually my daughter arrived who can sign, which meant it took about four people's time when the paramedic could be equipped with basic sign language. It should be part of their training to become a paramedic.”



Recommendations

Improving health services for Deaf and hard of hearing individuals can only be implemented if all parties involved understand each other's needs and have willingness to work together.

Deaf people stated that they would like to see the following improvements made to local health services:

1. **Deaf awareness training** for all frontline health care professionals, so that they have clear guidance of booking an interpreter. An interpreter should be offered to all Deaf patients that request one.

2. **Deaf friendly appointment system** via email and text messages to health services.

“A video phone at the reception point of A&E and in GP surgeries so that the patient can access a translator as and when they need one.”

3. **Mobile communication App** to improve access to health services at relevant contact points.

4. **Access to preferred communication** - Deaf and hard of hearing people should be given access to communicate in their preferred methods e.g. BSL interpreter, lip reading.

5. **Better commissioning arrangement of BLS interpreters** a single fund to provide a shared pool of BSL interpreters with up to date list of fully qualified interpreters

6. **Deaf people registration** - improved identification and registration of Deaf people within health settings. The following practical solutions were given by the responders:

“All patient records should state if someone requires BSL. There is no current system in place that stores this information.”

“NHS cards are perhaps a good place to display whether someone is deaf and needs the support of BSL.”

7. **Better health education** - a greater provision of information on local health services, particularly health awareness campaigns preferably via group talks or using BSL support

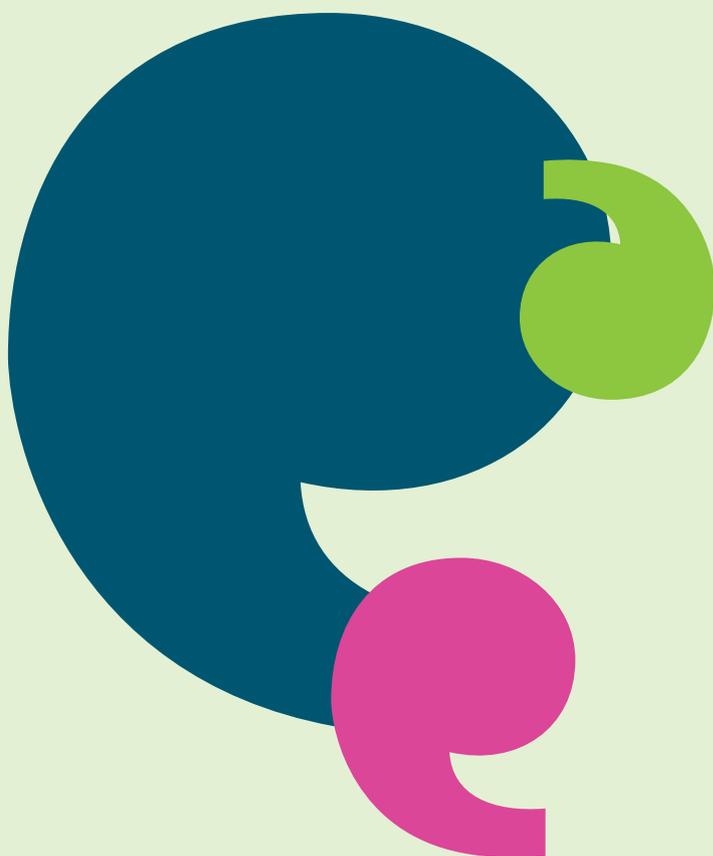
8. **Working together** - establish a working group representing local Deaf Community, British Deaf Association and partners to meaningfully engage and involve the community in decision making. To meet with the strategic partners to follow up on the recommendations and to see what actions have been taken.

9. **BSL Charter** - Implementation of BDA's British Sign Language Charter to encourage health agencies and authorities to improve access and provision of local services.

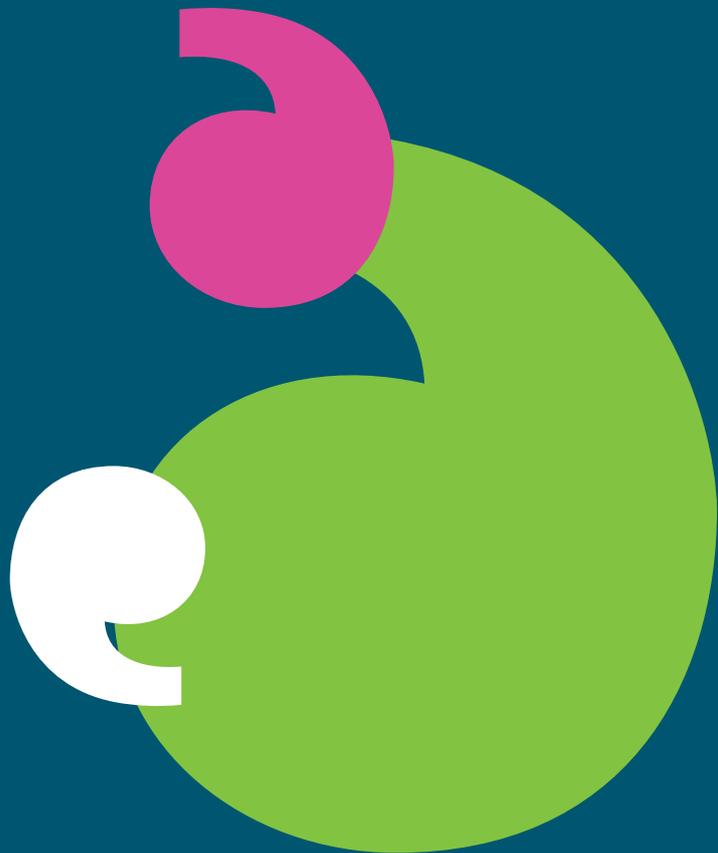
Conclusion

We believe that implementation of the BDA's British Sign Language Charter will provide the framework for taking forward many of the recommendations. This report has highlighted the importance of the Deaf community involvement in decision making to make sure they are to be fully informed about their care and services provided to them.

We hope that the government's vision of an NHS that puts patients and the public first, where 'no decision about me without me' becomes the key driver for local commissioners, providers and health authorities in any ongoing or future engagement with the Deaf and hard of hearing community.



Annex





Annex 1: Steering Group Members

Leicester Deaf Forum

Leicester Deaf Forum is a user network bringing together a range of Deaf groups to discuss matters and issues important to the Deaf community. The Forum meets monthly at the Leicester Deaf Action Group. If you would like more information about the forum please visit www.ldag.btck.co.uk

British Deaf Association

British Deaf Association (BDA), a member-led organisation founded in 1890, with a primary purpose has been the status and recognition of the Deaf Community and British Sign Language (BSL) in the United Kingdom. The cornerstones of the BDA are:

- Language
- Community
- Identity
- Heritage of Deaf people
- Representation of Deaf peoples needs, aspirations, rights and responsibilities

It focuses on achieving equality for Deaf people through community empowerment, membership and campaigning. Working with local Deaf and BSL Communities is crucial to the success of BDA campaigns and creates opportunities for Deaf people to develop, participate and contribute in wider society.

The BDA is a high profile national "Deaf People's Organisation" with a strong presence throughout England, Scotland, Wales and Northern Ireland. We operate in a fast-paced, politicised environment, dealing with complex and often controversial social issues and with multiple stakeholders. www.bda.org.uk

Healthwatch Leicester

Healthwatch Leicester is an independent community watchdog to help the people of Leicester get the best out of their local health and social care services.

How do we do this?

- We reach out to all communities within Leicester and listen to their views and experiences of the health and social care services they receive.
- We then meet with the people who run and plan local health and social care services. It is here that we voice the concerns of local people to the decision makers.
- We monitor the standard of health and social care services in Leicester and we can enter these premises to observe the quality of care being provided.

For more information on Healthwatch Leicester visit www.healthwatchleicester.co.uk



Annex 2: Leicester Deaf Forum Health Survey 2014



LEICESTER DEAF FORUM HEALTH SURVEY 2014

Introduction
Leicester Deaf Forum is carrying out this survey in partnership with Healthwatch Leicester and British Deaf Association (BDA) to find out your experience in accessing health services in Leicester City.

MAN WOMAN TRANSGENDER
 GAY, LESBIAN, BISEXUAL STRAIGHT
 DEAF HARD OF HEARING

Where do you live? Home area:
 City County:
 Leicester City
 Leicestershire




AGE
 OVER 50 18 - 50 UNDER 18

Where do you go?
 LEICESTER DEAF SOCIAL CLUB OVER 50'S
 OPEN HOUSE (FROG ISLAND) NONE
 OTHERS

Have you visited these?

Dentist	<input type="checkbox"/>	A & E	<input type="checkbox"/>
Optician (for eye test/glasses)	<input type="checkbox"/>	Nurse	<input type="checkbox"/>
Hospital (for appointments)	<input type="checkbox"/>	Ambulance	<input type="checkbox"/>
Audiology (for hearing aids)	<input type="checkbox"/>	Walk-in centre	<input type="checkbox"/>
Home visit by Doctor	<input type="checkbox"/>	NHS Choice	<input type="checkbox"/>
Chemist/Pharmacy	<input type="checkbox"/>	NHS 111	<input type="checkbox"/>
		GP/doctor	<input type="checkbox"/>

How do you communicate with NHS e.g reception or doctor?

Interpreter	<input type="checkbox"/>	Writing paper	<input type="checkbox"/>
Webcam (VRS)	<input type="checkbox"/>	Could not talk to them	<input type="checkbox"/>
SMS/Text messages	<input type="checkbox"/>	Help from family	<input type="checkbox"/>

How do you ask to book an interpreter for your appointments?
 LDAG (Frog Island) Hospital Self book

Ask for help Family/friends Medical Staff

Do you understand NHS information from leaflet, website and papers?
 Yes No

Why?

Hard words	<input type="checkbox"/>	Don't understand	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	Never heard	<input type="checkbox"/>
Poster not clear	<input type="checkbox"/>	Not interested	<input type="checkbox"/>
		No BSL videos	<input type="checkbox"/>

Survey carried out by

- Leicester Deaf Forum
- Leicester Deaf Club
- Leicester over 50+ Deaf Club
- Leicester Deaf Action Group
- Other; e.g Healthwatch Leicester

With support from Healthwatch Leicester and British Deaf Association

July 2014

Are you happy with these Health services below in Leicester?

	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Please tick:		
GP/doctor	<input type="checkbox"/>	<input type="checkbox"/>
Dentist	<input type="checkbox"/>	<input type="checkbox"/>
Nurse	<input type="checkbox"/>	<input type="checkbox"/>
Optician (for eye test/glasses)	<input type="checkbox"/>	<input type="checkbox"/>
A & E	<input type="checkbox"/>	<input type="checkbox"/>
Hospital (for appointments)	<input type="checkbox"/>	<input type="checkbox"/>
Ambulance	<input type="checkbox"/>	<input type="checkbox"/>
Audiology (for hearing aids)	<input type="checkbox"/>	<input type="checkbox"/>
Walk-in centre	<input type="checkbox"/>	<input type="checkbox"/>
Home visit by Doctor	<input type="checkbox"/>	<input type="checkbox"/>
NHS Choice	<input type="checkbox"/>	<input type="checkbox"/>
Chemist/Pharmacy	<input type="checkbox"/>	<input type="checkbox"/>
NHS 111	<input type="checkbox"/>	<input type="checkbox"/>

If you are not happy with the health service, tell us why:

Poor communication with reception	<input type="checkbox"/>	No interpreter	<input type="checkbox"/>
Can't use phone	<input type="checkbox"/>	Wait too long for appointments	<input type="checkbox"/>
Asking for help	<input type="checkbox"/>	Did not understand and gave up	<input type="checkbox"/>
Made me ill	<input type="checkbox"/>	Staff not helpful	<input type="checkbox"/>
Worried, not understand what is happening	<input type="checkbox"/>		

Additional information:



Glossary for the Health Services:



GP Doctor



Dentist



Optician



Nurse



A&E



Hospital booked appointments



Audiology



Walk-in Centre



GP Doctor home visit



NHS Choices



Chemist/pharmacy



NHS 111



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