

Seen and Heard

A Strong Voice for Local People

Project Report December 2021



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Introduction

Access to Healthcare is a right afforded to all citizens in the United Kingdom via the NHS. The first principle of the NHS Constitution for England is that:

‘The NHS provides a comprehensive service, available to all.’

Whilst no one would question this right, it is sometimes the case that people have difficulty accessing healthcare in a way that meets their individual needs¹.

Legislation has worked toward equality for all for many years and in 2016 the Accessible Information Standard (AIS)² was fully implemented in law through the Health and Social Care Act.






The AIS aims to ensure that people who have a ‘*disability, impairment or sensory loss*’ get the information they need in a way they can understand, and applies to all publicly funded health and social care services.



NHS commissioned video for the Accessible Information Standard
<https://www.youtube.com/watch?v=ZJngMo37WvA&feature=youtu.be>

Providers of health and adult social care services have duties to support those who access their services who have information or communication needs because of a disability or sensory impairment.

Providers must adhere to the five key principles, as follows:

-  1. **Identify** the communication and information needs of those who use their service
-  2. **Record** the communication and information needs they have identified so that they are easy to understand
-  3. Have a consistent **flagging** system so that if a member of staff opens the individual's record it is immediately brought to their attention if the person has a communication or information need
-  4. **Share** the identified information and communication needs of the individual when appropriate
-  5. **Meet** the communication and information needs identified

¹. <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>

². <https://www.england.nhs.uk/publication/accessible-information-standard-specification/>



Since the introduction of the AIS a post-implementation review was conducted by the NHS, which worked to assess the impact of the Standard. The review also highlighted the inconsistent application of the principles and variable quality of support available for those who need it.

Full details of the Accessible Information Standard are provided in Appendix A.

Healthwatch works in partnership with the Care Quality Commission (CQC), the regulator that monitors and inspects all organisations providing care to ensure standards are being met. All NHS and social care providers must be registered with the CQC and must conform to standards set by them.

During the Summer of 2021, the Care Quality Commission (CQC) commissioned four local Healthwatch; Central Bedfordshire, Luton, Bedford Borough and Milton Keynes, to work with two identified seldom heard communities whose members face barriers when trying to access health and care services, in particular the 'Deaf community' and the 'homeless community'. The main aim of the project was to help improve systemic behaviours by highlighting health and social care challenges, issues and concerns, specifically raised by local residents who are seldom heard.

Healthwatch is an independent statutory body that has powers to ensure that NHS leaders and other decision makers listen to people's feedback and improve standards of care. All local Healthwatch work to understand the experience of users and carers through a range of engagement activity and have a role in empowering people to get the most from the services they access, which can be a challenge for people from traditionally marginalised groups, who may have additional needs, to ensure equality of access.

Staff from Healthwatch Milton Keynes (HWMK) and Luton (HWL) worked in partnership with the homeless community, and staff from Healthwatch Bedford Borough (HWBB) and Healthwatch Central Bedfordshire (HWCB) engaged with the Deaf community. The term 'D/deaf' has been adopted culturally to represent a shared identity for people with serious hearing loss, often from birth, who use communication methods including lip reading and British Sign Language (BSL). This report focuses on feedback received from the D/deaf community.

The intended outcomes of this project were as follows:

- ◇ To publish a comprehensive report of findings to key stakeholders.
- ◇ Raise confidence within the D/deaf community that their involvement has had an impact.
- ◇ Improve understanding of the challenges, issues and concerns for D/deaf people accessing health and social care services.
- ◇ Improve health and social care staff understanding of the needs of D/deaf people accessing health and care services.
- ◇ Promote quality in healthcare for D/deaf people through our networks.
- ◇ Feedback information gathered to the CQC to empower individuals from the D/deaf community to engage with them.
- ◇ Highlight issues and inform the Integrated Care System (ICS) for BLMK of the need to commission services that the D/deaf community can easily access.

What we did

Local Healthwatch, from two areas of BLMK (Central Bedfordshire and Bedford Borough), worked together to organise and promote a focus group for members of the Deaf community to attend, and give feedback, on their experience of accessing health and care services.

The focus group was held on 20th November 2021 at a local community venue in Bedford that had suitable communication tools, for example, hearing loop systems. The focus group was set up and co-produced by staff from HWCB and HWBB, together with a local support group 'Access Bedford'. Access Bedford is a registered charity that works with the D/deaf and hard of hearing community in Bedford Borough, and coordinates a range of local events and activities across Bedford Borough to improve access for the D/deaf community. They also work with other services and providers to look at how to improve accessibility issues so that the D/deaf community can get the information they need.

In total, 10 members of the D/deaf community were in attendance: five men and five women in the age bracket of 30-70 years. This included a married couple. Attendees included members of the Deaf community, many of whom don't have English as their first language and others who are hard of hearing. Mixed communication methods ranged from those needing BSL interpretation, lip reading, participants with cochlea ear implants and those requiring a hearing loop.

To promote the focus group to the D/deaf community, Healthwatch posted adverts on Facebook, via their websites and regular e-bulletins as well as via Access Bedford. Direct contact was made with local charities as well as the 'Deaf and Hearing Impairment Team' at Bedford Borough Council working in partnership with Central Bedfordshire Council.

A structured questionnaire was developed, appropriate for focus group attendees, and in line with ICS and CQC priorities. In total, 13 questions were proposed, and initially reviewed by Access Bedford for suitability. During the focus group session each question was clearly displayed via a PowerPoint presentation to gather qualitative and quantitative feedback about user experiences of health and social care services accessed and provided during the pandemic. In addition, attendees were asked about their knowledge of the 'Care Quality Commission (CQC)' and the health and social care champion 'Healthwatch (HW)'.

The full list of 13 questions can be found in Appendix B. Unfortunately, due to time constraints Questions 10 and 11 were not addressed.

Two BSL Interpreters were in attendance at all times; alternately, they communicated each question to the attendees, and, in turn, communicated answers and comments back to HWCB/HWBB staff. Notes were taken and an audio recording was made and subsequently transcribed, with written consent from each attendee.

From within the focus group, two individuals expressed an interest in providing a case study, or more in-depth study, of the challenges and barriers they face as individuals when attempting to access health and care services. Follow-up appointments were arranged with both individuals.





Summary of feedback

Challenges of current and future provision

The challenges experienced by participants of the focus group when accessing health and social care services have been themed under individual headings. Relevant quotes from participants have also been included to highlight or illustrate an issue or concern.

General


Focus group participants were asked how they would like to be defined during the session, and for the purposes of the final report to the CQC. All agreed they preferred to be referred to as the 'Deaf community'.

When asked what type of services participants had accessed prior to and during the pandemic, answers included the following:

- | | |
|---|--|
| ◇ GP services | ◇ Access Bedford |
| ◇ Hospital services
(Addenbrookes/Bedford/Milton Keynes) | ◇ Child & Adolescent Mental Health Services
(CAMHS) |
| ◇ Interpreters | ◇ NHS111 |
| ◇ NHS Smoking Cessation Service | ◇ Dentist |
| ◇ NHS Track and Trace | ◇ Audiology Services |
| ◇ Vaccination centres | ◇ Circle Integrated Care |
| ◇ Putnoe walk-in centre | |

When asked how frequently they had used these services during the pandemic, one person said they had used them '*more*' than they would have pre-pandemic, four people said they had used them '*less*', and five people said '*about the same*' during the pandemic.

Focus group participants were keen to explain that they felt there were massive delays in obtaining a health care appointment and added that it is more difficult to access services at the weekend. There were concerns, not just for the current generation of Deaf people accessing health and care services, but also for the future of Deaf children. Participants felt very strongly that healthcare service providers should be more proactive in providing better access for the Deaf community including keeping up to date, easily accessible and improved records of a patient who is Deaf, so each person can be easily identified as being Deaf before an appointment/treatment is considered.



“Nothing ever changes or happens; they have the funds but don’t do it; it’s rubbish”

“We need to do better in the 21st century”

“D/deaf people are treated as bottom class, 3rd class, bottom of the pile. It’s old fashioned, not good enough”

Health and Care Services

Of all the services that participants of the focus group had attended, the more frequently mentioned services included the following:



General Practitioner (GP)

Accessing a GP appointment was a key challenge for most participants of the focus group. Feedback suggested that all staff, especially receptionists and General Practitioners (GPs), lack Deaf awareness. They felt very strongly that receptionists were not reading a patient’s notes accurately, prior to offering an appointment, to determine what needs the patient may have and/or if a patient is Deaf. The consensus was they all felt more training was required for all healthcare staff in this respect.

“I have to constantly repeat to the receptionist that I am Deaf and have to explain how to book an Interpreter”

Participants of the focus group also said that they would use the GP service (and all healthcare services) more, if Deaf awareness was improved. In addition, if GPs were committed to change it would vastly improve their experience of the service.

When asked what improvements could be made to GP Practices for Deaf people, suggestions included the following:

- ◇ Text message appointments and reply service via text.
- ◇ Interpreters clearly seen on a screen in the surgery.
- ◇ GPs to be qualified in BSL.
- ◇ Increased use of email.
- ◇ For a person’s Deaf status to be displayed more prominently on the screen with instructions for the receptionist on what to do (instead of a footnote at the bottom of the patient records which is easily overlooked).



One participant explained they had been at a particular GP surgery for seven years and they did not have him registered as a Deaf patient on their records.

“Add something to the screen as an alert that it is a Deaf person. The responsibility seems to be on the Deaf person”

Another participant, who had undergone a biopsy for cancer at Addenbrookes Hospital said:

“The GP tried to give me my biopsy results over the telephone! I have to drive to the GP every time”



Hospitals

Heightened concerns were expressed about the lack of provision of suitable services for Deaf people by the local hospital in Bedford compared to hospital services in Peterborough and Cambridgeshire. Participants said staff at Bedford Hospital rarely booked Interpreters, did not make provision for Deaf patients, and added that there are *‘no regular meetings’*, *‘no staff training’*, *‘no actions taking place’* and *‘no equality for Deaf people’* who visit there.

“Peterborough and Cambridgeshire seem to have good Deaf awareness, lots of actions, more awareness. They have ‘Signlive’. It’s not just for me, it’s for the Deaf community”



Covid Vaccination Centres

At vaccination centres, because staff were wearing masks, this made it incredibly difficult for a Deaf person to lip read and participants were very clear that many staff had refused to remove their masks even if a Deaf person wore a badge to show they were Deaf.

For a Deaf person to obtain a vaccination at a vaccination centre they had to be accompanied by a friend or family member to assist them with communication. One Deaf participant explained that the vaccination letter sent was not clear to him, but he could not contact them by telephone, so he had to ask Access Bedford to explain what to do.

“They come out and call my name - I’m Deaf! - they waste my time, it’s frustrating”

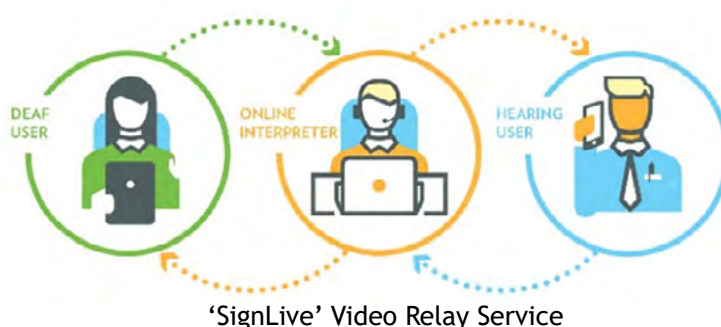


Communication

It was very clear from the focus group that communication is a major challenge and a huge barrier for the Deaf community when trying to access and use health and social care services.

‘SignLive’ is a service provider of online video interpreting services through its Video Relay Service (VRS) and Video Remote Interpreting (VRI), however not everyone is able to access the service. One participant explained he had made a formal complaint to Bedford Hospital a few years ago about the lack of ‘SignLive’ availability in the hospital, but that years later nothing had changed although other hospitals had made changes.

The whole group felt that health and social care providers rely too much on using the telephone, and since they are now using more digital technology, such as Zoom, health and social care provision has gone backwards, and this causes concern and anxiety for the future. The Deaf community need face to face communication, or digital communication, such as ‘SignLive’, that meets their specific needs.



It was also highlighted by participants that not everyone’s first language is English. Written English is a completely different language and, therefore, not readily understood by those who have British Sign Language (BSL) as their first language.

Participants also felt that if Receptionists and Interpreters could have a better relationship then things would improve. Some participants explained that, on occasion, they had been refused access to Interpreters and/or felt that they had to justify access to an Interpreter.

In addition, participants stated that when Deaf patients receive a ‘do not reply’ text message from the GP surgery they often have to drive to the surgery, as they have no other way of responding, therefore further disabling their ability to communicate with the healthcare provider.

There were also concerns expressed about the potential for ineffective or mis-communication leading to delays in diagnosis or inappropriate treatment or care for the Deaf person.

“I don’t have good English. It’s difficult, I’m under stress and panicked”



Interpreters

Feedback from the focus group suggested that a lack of provision of Interpreters was an issue for them when accessing most health services. Healthcare staff were not aware how to book an Interpreter, or in some cases why they should, and it was very clear that access to an Interpreter was very 'hit and miss'.

Participants felt that the lack of access to Level 6 NRCPD registered BSL Interpreters, a requirement by law for clinical appointments, made them feel more anxious, adding to their anxiety about their health needs in situations that were already stressful for them. Consequently, they would like to be notified if an Interpreter had been booked. One participant suggested that each Primary Care Network (PCN) have an in-house Interpreter that could be shared across the practices within the network.

There was also concern that many Interpreters were not available locally and there was clearly a lack of strategic thinking with regard to the provision of Interpreters.

Participants felt that even when they were provided with an Interpreter, they were unable to stay for the duration of the appointment, as they had to leave to attend another appointment.

"There are so many stories about GP's and Bedford Hospital booking Interpreters, they have the cheapest contract with no quality"

"We get Interpreters from 'Language is everything' in Hull - why Hull? It's my right to choose an Interpreter. I have constantly requested to book via my own agency"

"Lack of Interpreters is worrying"



Autonomy & Privacy

There was concern from all participants about the reliance on a Deaf persons' family and friends to support them when accessing services, however families do not always live nearby to support. This also denies a Deaf person their privacy and confidentiality whilst having a consultation or treatment. Many patients do not want to share their medical history or symptoms with their family.

One participant of the focus group, as a parent of a young, ill child, wanted to communicate with their GP. The GP wanted to talk to the daughter on the telephone which the parent felt was inappropriate and added to their levels of anxiety.





CQC / Healthwatch

Participants were given information about the Care Quality Commission and when asked if they were aware of the CQC, three people said ‘yes’ they were aware of them, two people said ‘no’ and two were ‘not sure’. One person had contacted the CQC previously for work purposes but did not elaborate further, and two people chose not to comment.

One participant asked if the CQC would know what a ‘good service’ was for the Deaf community and also if they were aware of their needs in accordance with the Accessible Information Standards?

Issues were also raised about whether the CQC worked solely using ‘English’, as for many BSL users, English is not their first language. Many participants wondered how a Deaf person would be able to contact them, for example, writing or via telephone? One participant commented:

“CQC is about writing reports - not hopeful”

When asked about their knowledge of Healthwatch, eight people said they knew of Healthwatch and two people were not sure. Of the three people that had contacted Healthwatch previously, two had found it very useful. However, one person said that HWBB insisted on using English and this set up a barrier.

One participant said that they hoped ‘*Healthwatch, the CQC and the Patient Liaison Services (PALS) worked together more in the future to improve services*’ whilst adding that they would contact these organisations in the future should they want to take an issue forward.

“HWBB booked the Interpreters”

“Healthwatch - there was not an Interpreter and English is not my first language”



User stories

During the focus group many participants shared their experiences of accessing health and care services as a member of the Deaf community, explaining more about the barriers and challenges faced. Some of their stories are detailed below:



A service user went to the GP for a doctor's letter to start a new job. It was busy on the telephone, so he went to the doctor's surgery as he was anxious about getting the letter on time. He was able to speak but the receptionist refused to remove her mask to enable him to lip read. He added:

"I'm avoiding going now"

Prior to the Covid pandemic a male participant went to the hospital about an ankle issue. He was accompanied by his mum. An Interpreter came but had to leave before the end of his consultation to attend another appointment. He said that this was a regular occurrence and that he wants a more private conversation and should not have to rely on family members as Interpreters.



Image: National Deaf Children's Society



A male participant was referred to the smoking cessation service for six weeks after which he was required to get repeat prescriptions from his GP to continue with his course of treatment. The GP failed to respond to his repeated requests for the supplies needed to continue the programme and he began to smoke again. He said:

"It's money wasted. I got support from other agencies, but the GP let me down. It has just destroyed me"



One participant had a shoulder issue and received a letter from Circle Integrated Care. A telephone call was required so the participant sent an e-mail but no reply was received.

Shortly after, a second letter arrived from MSK regarding a face-to-face appointment however there was a massive delay in securing a suitable date.

During the pandemic one participant had to call an ambulance because of an emergency. He went to Bedford Hospital Accident & Emergency with his son, and they communicated with the Deaf father via 'SignLive'. He asked the hospital to book an Interpreter and waited four hours for one to arrive. He needed to understand what they were saying to him about his son as he was a concerned parent. He felt patronised, angry and frustrated and felt that they were lying to him. He subsequently contacted the Child and Adolescent Mental Health Service (CAMHS) who were very good and booked an appointment for him and his son with Interpreters. He added:



“I needed information about my son. The information was sent to the GP however I received no feedback”



A male participant received a letter about the Covid-19 vaccination that was unclear to him. He required a vaccination as he is vulnerable and has a medical issue; he also required explanations about allergies. He had a face-to-face appointment with his GP and showed him the letter. The GP confirmed he would contact the NHS on his behalf but failed to do so. After two months with no contact, he visited Addenbrookes Hospital for a follow-up appointment and mentioned the letter to his consultant. He explained that the consultant was very informative, provided an Interpreter for him and clarified the information contained in the letter. He is now worried about the Booster vaccination and asked how he could access a booster without an Interpreter? He added:

“I’m scared, worried, I don’t want to go out and use public transport”



Conclusion

The participants of the focus group stated that they had used the following services during the pandemic: GP services, Hospitals (Addenbrookes / Bedford / Milton Keynes), Interpreters, NHS Smoking Cessation Service, NHS Track and Trace, Covid-19 vaccination centres, Putnoe walk-in centre, Healthwatch, Access Bedford, CAMHS, NHS111, Dentists, Audiology Services and Circle Integrated Care.

Most experiences concerned local GP services, vaccination centres and hospitals, mainly Bedford, Addenbrookes and Milton Keynes Hospitals.

From feedback received from all participants of the focus group, the Deaf community clearly felt that prior to the pandemic in March 2020, services were slowly starting to improve, however during the pandemic, all participants felt that access to services had severely deteriorated. When asked how frequently they had used health and care services during the pandemic, one person said they had used them '*more*', four people said '*less*' and five people said '*the same*'. However, when asked about using these services in the future, participants very clearly said that they would only use services, and have more confidence in all services, if they improved, if Interpreters were provided, and if Deaf awareness for professionals was increased.



They felt that professionals do not understand the concerns and needs of the Deaf community and the detrimental effect that it has on them. There is general anxiety in the Deaf community about how to access services, who will accompany them to an appointment, whether they will have access to an Interpreter, and who will be paying for the Interpreter.

The Deaf community feel that health and care services have '*gone back in time*' and with all of the technology currently available to support marginalised people there should not be such difficulty when communicating with health and social care professionals. The participants want to see tools like 'SignLive' being used more widely and frequently. However, they confirmed that their overall preferred choice remained 'face-to-face' consultation.



Although participants were given clear information during the focus group about the CQC and Healthwatch, not all participants were aware of these organisations or how best to contact them. There was a lack of knowledge as to how aware the CQC are of the needs of the Deaf community in accordance with AIS, what a good service looks like, and how to resolve problems. There was also concern as to whether the CQC worked solely using 'English', as for many people in the Deaf community 'English' is not their first language.

Generally, feedback from the focus group highlighted that the requirements of the Accessible Information Standards are not being met by health and social care services, predominantly from GP practices and Bedford Hospital.

For many Deaf patients their needs were not identified when registering at a GP practice, or if they were, they were not prominently displayed on their records, so were not flagged up when the patient contacted the practice, (Ref: AIS 7.1, 7.3 and 8.1).

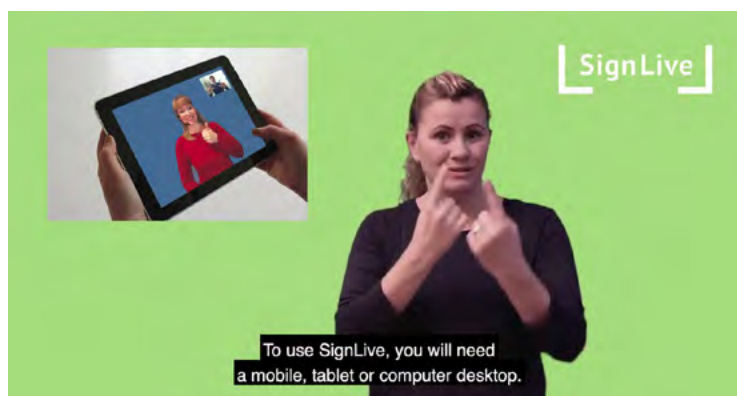


Recommendations



Following analysis of all feedback received from participants at the focus group, Healthwatch Central Bedfordshire and Healthwatch Bedford Borough would recommend the following to help improve access to health and social care services for the Deaf community:

- ◇ Increased Deaf awareness training is recommended for all health and social care professionals (especially Receptionists as first point of contact) and that a basic BSL Level 1 qualification to be incorporated into Equality & Diversity training modules for medical students.
- ◇ All service providers to comply with the AIS to ensure that Interpreters are readily available, to be more proactive in ensuring that they are available when and where required, for as long as is required. Better access to Interpreters would increase a Deaf person's confidentiality and privacy, and reduce their levels of anxiety before and during an appointment with a health and/or social care service.
- ◇ All service providers and commissioners to consider the commissioning of local, quality interpretation agencies to provide a personalised service, allowing greater continuity and reliability for the service user and service providers.



- ◇ Each Primary Care Network (PCN), and local hospital, to seriously consider employing an 'in-house' qualified Interpreter, and for each PCN to appoint an AIS dedicated individual to support and enforce AIS within the Network. This would ensure better identification, recording, flagging up and sharing of a Deaf person's needs when using services.
- ◇ Best practice should be shared between hospitals to improve their services for the Deaf community.
- ◇ GP practices to make a private space is available (where applicable) to be used to enable patients from the Deaf community to communicate their needs in confidence.
- ◇ Ensure that 'SignLive' and other digital solutions are more accessible and readily used. Explore the potential for use of other technological solutions to improve two-way communication, for example, use of video interpreting. It was noted specifically that Bedford Hospital needs a stronger Wi-Fi signal to enable this.



Finally, Healthwatch Central Bedfordshire and Healthwatch Bedford Borough will directly feedback any concerns and issues raised during the focus group meeting to the newly created BLMK Integrated Care System (ICS) to help inform future commissioning decisions.

Healthwatch will continue to support and engage with the Deaf community and will be undertaking follow-up in-depth interviews with some participants of the focus group. In addition, Healthwatch intend to highlight any issues and concerns raised from the focus groups to the BLMK ICS when fully launched, to ensure that access to services for the Deaf community are improved and sustained.





Follow up actions

The final report will be shared directly with the Care Quality Commission to include a formal request to help increase awareness of communicating successfully with the Deaf community to identify their needs, and to raise a query on how they intend to comply with the AIS requirements, and how they will help to resolve the issues highlighted in the report.

At the conclusion of the focus group meeting, it was agreed that any reports resulting from the focus group and service user interviews would also be provided in a summarised BSL format.

It was strongly felt that, by improving services now, accessibility for future generations of the Deaf community will be much improved.



Appendix A

Accessible Information Implementation Guidance – Excerpts of the actions which relevant organisations **MUST** take.

Identification of Needs - (*Accessible Information Implementation Guidance sections 7.1 and 7.3*)

Communication and/or information needs must be identified at registration/upon first contact with the service or as soon as is practicable thereafter. This initial question may be asked over the telephone, face-to-face at a reception desk, as part of a registration or admission form or through an alternative process.

In addition, communication and/or information needs **MUST** be identified proactively and opportunistically - the next time an existing patient/service user makes contact with/ is seen by the service - but not retrospectively. There is no requirement for a retrospective search or 'trawl' of records to identify patients with needs, although this would be considered good practice, particularly for some groups of patients (**see section 7.3**).

Following identification of the existence of a communication or information need, the specific nature of the support and/or format required **MUST** be identified. (**Accessible Information Implementation Guidance 7.1**).

Individuals must be asked about any information or communication support needs by a member of staff upon their first or next interaction with the service. This could, for example, be over the telephone when calling for an appointment, results or repeat prescription, or face-to-face. Where the conversation is held face-to-face a private room or area should be offered and made available as appropriate. (**Accessible Information Implementation Guidance 7.3**).



Recording of Needs - (Accessible Information Implementation Guidance 8.1)

Such Information must be recorded.

Systems and documentation **MUST** be formatted so as to make any record of information or communication needs 'highly visible'.

Organisations **MUST** ensure that information recorded about individuals' information and communication support needs is accurate:

- ◇ **MUST** enable an individual to review the data recorded about their communication and information needs and request changes if necessary; and, where necessary functionality exists
- ◇ **SHOULD** enable an individual to record their own communication and information needs

Flagging of Needs - (Accessible Information Implementation Guidance 9.1)

A record of communication and/or information needs **MUST** be flagged or otherwise highlighted/made 'highly visible' to relevant staff when the individual has subsequent interaction or contact with the service (to enable appropriate actions to be taken to meet those needs).

Where electronic record or administration systems are used, a record of information or communication support needs **MUST** be flagged (or linked to an alert) to ensure that, once recorded, staff are prompted to respond to individuals' information and/or communication support needs and/or automatic processes are triggered in order that needs can be met, for example auto-generation of correspondence in an alternative format.

Guidance for Reviewing and Updating Needs - (Accessible Information Implementation Guidance 9.3)

As made clear in the Specification, once data is recorded about individuals' information or communication support needs, systems **MUST** prompt for, and staff **MUST** ensure that, such data is regularly reviewed and if necessary updated. Services should set up appropriate prompts and include review of this information alongside reviewing and updating data held in other fields, for example demographics, and as part of longer appointments, such as for a health check.

Sharing of Needs - (*Accessible Information Implementation Guidance 10.1*)

Organisations must ensure that information about individuals' information and/or communication support needs is included as part of existing data-sharing processes, and as a routine part of referral, discharge and handover. Note that this data-sharing is to support direct patient/service user care and is not for reporting or analysis.

Meeting of Needs - (*Accessible Information Implementation Guidance 11.1 and 11.2*)

Services **MUST** provide one or more communication or contact methods which are accessible to and useable by the patient, service user, carer or parent. The method(s) **MUST** enable the individual to contact the service, and staff **MUST** use this method to contact the individual. Examples of accessible communication/contact methods include email, text message, telephone and text relay. (*Accessible Information Implementation Guidance 11.1*).

Information, including correspondence and advice, must be provided in one or more accessible formats appropriate for the individual - in line with records made in this regard. Where systems are used to auto-generate correspondence, systems **MUST** identify a recorded need for an alternative format and either automatically generate correspondence in an appropriate format (preferred) or prompt staff to make alternative arrangements. Systems **MUST** prevent correspondence from being sent to a patient in a standard format where this is not suitable/not in line with their recorded needs. (*Accessible Information Implementation Guidance 11.1*).

Where needed, appropriate, professional communication support **MUST** be arranged or provided to enable individuals to effectively access / receive health or adult social care, to facilitate effective / accurate dialogue, and to enable participation in decisions about their health, care or treatment. (*Accessible Information Implementation Guidance 11.1*).

Appropriate action must be taken to enable patients, service users, carers and parents to communicate, including through staff modifying their behaviour and/or supporting the use of aids or tools. This includes provision of communication support for individuals accessing both outpatient and inpatient services, including long-term care, and those in receipt of publicly - funded social and/or NHS care whilst resident in a nursing or care home. (*Accessible Information Implementation Guidance 11.1*).

As stated in the Specification, "Organisations must take steps to ensure that communication support, professional communication support and information in alternative formats can be provided promptly and without unreasonable delay. This includes making use of remote, virtual, digital and telecommunications solutions." (*Accessible Information Implementation Guidance 11.2*).

Meeting of Needs - Specific Contact Method (*Accessible Information Implementation Guidance 11.4.2*)

Organisations **MUST** ensure that an individual's need to use or be contacted by an alternative communication method is flagged and/or highly visible to staff to enable appropriate action to be taken.

Meeting of Needs - Specific Information Format (*Accessible Information Implementation Guidance 11.4.3.1*)

Organisations must ensure that an individual's recorded need for information in an alternative format is flagged and either triggers the automatic generation of correspondence/communication in an alternative format (preferred) or prompts staff to make alternative arrangements. A standard print letter must not be sent to an individual who is unable to read or understand it.

Organisations **MUST** also ensure that they have effective processes in place to ensure and assure the accuracy and quality of translated or transcribed information.

Organisations are advised (although not required) to consider the accessibility and usability of their website, where this offers information or advice for patients, service users, carers and parents. Individuals may be signposted to online information by way of meeting their needs, however, the service provider **MUST** ensure that this is accessible to the individual, including where they have a disability, impairment or sensory loss.

Meeting of Needs - Interpreters (*Accessible Information Implementation Guidance 11.4.4.1*)

Must be suitably qualified.

Meeting of Needs - Use family and friends as Interpreters (*Accessible Information Implementation Guidance 11.4.4.3*)

In all instances, the individual patient, service user, carer or parent **MUST** be offered professional communication support where they have an identified need for communication using British Sign Language, Deafblind manual or other alternative communication system.

Where an individual has sensory loss (hearing loss and / or visual loss) and no other impairment, a professional Interpreter/communication professional must be used (see section 11.4.4.1) unless there is documented, supported evidence of the individual's explicit preference for the use of a family member/friend/carer. The parameters in which the individual's family member/friend/carer is to be used must be agreed with the individual and recorded as part of their record or notes. This preference **MUST** also be regularly reviewed and **MUST** be reviewed whenever a new course of treatment/episode of care is started or proposed, or significant decision or choice is to be made.

Where an individual has sensory loss (hearing loss and/or visual loss) and one or more other impairments which impact upon their ability to communicate, for example, a learning disability, and especially where individuals have multiple or complex needs, it may be appropriate for one or more family members, friends or carers to support communication and/or act as an Interpreter or communicator instead of or alongside one or more communication professionals.



Discussion about how an individual communicates and the support needed to enable effective communication with a health or social care professional must take place with the individual and/or with their parent or carer as appropriate. Whatever decision is taken must be clearly documented and, where the individual may lack capacity, must be demonstrably in their 'best interests'. Use of family members, friends or carers to support communication/act as Interpreters is most likely to be appropriate where an individual has multiple/complex needs (for example a moderate to severe learning disability and sensory loss) and/or a personal method of communication (i.e., not 'standard' BSL or Deafblind manual).

In all instances, consideration must be given to the most effective way of enabling effective, accurate dialogue between a health or care professional and the service user to take place. Communication support must enable individuals (as much as possible) to provide or withhold consent, and to make informed choices about care or treatment. Services must also recognise that communication support and interpretation supports both the health or care professional as well as the service user - and clinicians reliant upon family members, friends or carers do so 'at risk' with regards to associated lack of assurance about not only their skill and ability to communicate/interpret effectively, but also how their lack of objectivity may affect accuracy and completeness of the messages conveyed.

Appendix B

Focus Group Questions

Question 1

What defining term would you like us to use in our final report, for example, gender-represented, Deaf community, seldom heard, marginalised, disadvantaged, other?

Question 2

What health and social care services have you used in the pandemic?

Question 3

How frequently did you use those services during the pandemic?

Question 4

What challenges did you experience or face when accessing services?

Question 5

What services do you think you will use in the future?

Question 6

What do you know about these organisations?

Question 7

Have you had any previous experience of these organisations?

Question 8

Did you find them helpful?

Question 9

Would you use either of them in the future?

Question 10

What would you use the CQC for?

Question 11

What would you use Healthwatch for?

Question 12

What do you feel the future looks like for health and social care services?

Question 13

What changes would you like to see to enable you to better access the services you need?



About Healthwatch Central Bedfordshire and Healthwatch Bedford Borough

Healthwatch Central Bedfordshire (HWCB) and Healthwatch Bedford Borough (HWBB) are consumer champions, promoting choice and influencing the provision of high quality health, social care and wellbeing services for all across Bedfordshire.

HWCB and HWBB have significant statutory powers to ensure that the voice of the consumer is strengthened and heard by those who commission, deliver and regulate health and care services. HWCB and HWBB engages and consults with all sections of the local population so that a wide cross-section of views are heard, understood and acted upon. Everything we say and do is informed by our connections to local people and our expertise is grounded in their experience.

HWCB and HWBB are two of three local Healthwatch in the County of Bedfordshire and belong to a network of local Healthwatch. Healthwatch England leads, supports and guides the Healthwatch network which is made up of the national body and local Healthwatch across each of the 152 local authority areas in England.

Healthwatch is the only body looking solely at people's experience across all health and social care. As a statutory watchdog our role is to ensure that local health and social care services, and the local decision-makers put the experiences of people at the heart of their care.



healthwatch Bedford Borough

Healthwatch Bedford Borough
21-23 Gadsby Street
Bedford
MK40 3HP

www.healthwatchbedfordborough.co.uk

tel: 01234 718018

e: enquiries@healthwatchbedfordborough.co.uk



@HealthwatchBB



[Facebook.com/HealthwatchBB](https://www.facebook.com/HealthwatchBB)



[healthwatchbedfordborough](https://www.instagram.com/healthwatchbedfordborough)

Registered Address: 21-23 Gadsby Street,
Bedford MK40 3HP
Community Interest Company No.
8385413

Healthwatch Bedford Borough

healthwatch Central Bedfordshire

Healthwatch Central Bedfordshire
Capability House
Wrest Park
Silsoe
Bedfordshire
MK45 4HR

www.healthwatch-centralbedfordshire.org.uk

tel: 0300 303 8554

e: info@healthwatch-centralbedfordshire.org.uk



@Healthwatch_cb



[Facebook.com/Healthwatch Central Bedfordshire](https://www.facebook.com/Healthwatch Central Bedfordshire)



[hw_centralbeds](https://www.instagram.com/hw_centralbeds)

Registered Address: Capability House,
Wrest Park, Silsoe, MK45 4HR
Registered Company No: 08399922
Registered Charity No: 1154627



Healthwatch Central Bedfordshire