

Accessible Information Standard

Do people get the information they need in the way they need it.

Report of findings.

A partnership report – Healthwatch Hampshire, Healthwatch Isle of Wight, Healthwatch Southampton & Healthwatch Portsmouth

April 2024

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Summary

The Accessible Information Standard is designed to ensure everyone, no matter what their needs and preferences, has access to information that they understand, and communication support they may need.

All organisations that provide NHS or adult social care must follow the Accessible Information Standard by law and in full. However, this has never been fully or widely implemented and this report aims to provide evidence from local people across Hampshire (including Southampton and Portsmouth) and the Isle of Wight of how this affects people in their daily lives. It also aims to provide recommendations to be taken forward into actions and change.

Through a co-production approach, over a 3-month period, we engaged with 118 people (as well as parents, families and care givers) who have a disability, impairment, or sensory loss, to gather their stories and experiences to understand whether they are aware of their rights under the AIS. Our findings included:

- Most people were unaware of the AIS or even that they have the right to ask for information and communication support in a way which suits them, and that they should only have to ask for this once.
- The majority have never been asked about their preferred communication methods.
- Many people told us that not getting information and support in a way that's right for them leads to a loss of independence, privacy and dignity.

Some quotes we received from people included:

“If feels like – if you are blind, confidentiality is an afterthought”.
(Southampton).

“I have had many bad experiences with several services, that I now have low expectations. When a service does something really simple such as electronic forms I can edit, this makes me very happy that my needs are being met”.
(Southampton).

Our recommendations for improvement have been grouped into the following key themes:

- The need to improve awareness of the Accessible Information Standard for patients and staff across the Integrated Care System.
- The need to improve identification and recording of preferred communication formats.
- The need to improve staff skills for recording and arranging communication support for people.
- The need to ensure the role of support networks, support workers and advocates is recognised.
- The need to diversify communication formats and styles.
- The need to ensure effective use of the NHS annual health review/check.
- The need to develop the oversight role of the Integrated Care Board.

We will now be working closely with the Integrated Care System to take forward these recommendations.

This report is also available in Easy Read, as a British Sign Language video and an audio file.

Acknowledgements

We want to thank all the people who shared their experiences of using health and care services with us, and the organisations who helped coproduce this project. In particular we wish to thank:

- [Dynamite Portsmouth](#)
- [Hampshire & IoW Integrated Care Board](#)
- [Hampshire Parent Carer Network](#)
- [MAKE \(Aldingbourne Trust\)](#)
- [Mencap Isle of Wight](#)
- [People Matter Isle of Wight](#) (facilitated the Isle of Wight Learning Disability Partnership group).
- [Portsmouth Association for the Blind](#)
- [Portsmouth City Council](#)
- [Portsmouth Hospitals University NHS Trust](#)
- [Sight for Wight](#)
- [Solent NHS Trust](#)
- [Southampton Sight](#)
- [The Portsmouth Deaf Association Club](#)
- [Winchester Go LD](#)
- We have also drawn on information and support provided by [Healthwatch England](#) as well as [NHS England](#).

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Background

From 1 August 2016 onwards, all organisations that provide NHS care and/or publicly funded adult social care are legally required to follow the Accessible Information Standard.

The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, care givers and parents with a disability, impairment or sensory loss.

Health and social care providers should share those needs with other providers to ensure people are asked once, then everyone they are in contact with should provide information and communicate with them as they have asked.

This animated video, produced by the charity Sense provides a step-by-step overview of the Standard. The video includes subtitles and BSL interpretation.

[Accessible Information Standard Video](#)

Previous Reviews

Since the Accessible Information Standard was implemented there have been various reviews of its effectiveness by Healthwatch England, local Healthwatch across the country, voluntary organisations and charities. Findings would appear to suggest that the Standard has not had the desired impact for many of the people it set out to help and support. For example:

In late 2021, a [coalition of charities](#) surveyed NHS and social care professionals in England, as well as disabled people who have accessible information and communication needs, about the NHS Accessible Information Standard (AIS). More than 900 people gave responses.

- Only 11% of patients covered by the AIS had equitable access to the NHS.
- 35% of professionals reported that their organisation provides regular training linked to the AIS. 37% reported training had never occurred.
- 67% of Deaf people reported that no accessible method of contacting their GP has been made available to them.
- 81% of patients reported having an appointment when their communication needs were unmet.
- 77% of people with accessible information needs reported rarely or never receiving information in alternative formats.

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- Only 41% of complaints procedures were reported to be accessible by the professionals who filled in the survey.
 - 1 in 3 health and social care providers were unaware or unsure of the existence of the AIS.

In 2022 [Healthwatch England](#), as part of a wider project, looked specifically at 605 people who said that they need support communicating with healthcare staff. The high-level findings were:

Understanding information and asking for support

- One in five (20%) said they struggle to understand most of the information given by services.
- Over half (51%) had asked for support to understand information.
- Five in ten (53%) had asked for support to contact services.
- Four in ten (44%) had asked for support to communicate with staff.

Getting support

- Three in ten (30%) said they rarely or never get the support they need.
- Two in ten (22%) had been refused information in a format they need.
- Over one in four (28%) had been refused support to understand healthcare information.

Other issues

- Over a third (38%) said not being provided with accessible information affected their mental health and wellbeing.
- Nearly half (48%) feel uncomfortable asking for accessible information.
- Over half (53%) said staff attitudes affected their ability to ask for support.
- Nearly half (47%) think how services communicate has got worse since the start of the COVID-19 pandemic.

In early 2023 a coalition of national charities, who had been campaigning collectively over the past year to make health and social care information accessible for everyone, wrote an [open letter](#) to Dr Neil Churchill, Director for Experience, Participation and Equalities at NHS England, expressing huge concern that millions of people continue to experience barriers to accessing health and social care because they do not receive the communication support they need.

The above is only a small selection of the reviews undertaken.

This Review

We know from the feedback described previously that the Accessible Information Standard has never been fully implemented. Many people are not aware of their rights under the AIS and their information and communications support needs are not provided in the way that best suits them. Information about people's needs is not always identified, recorded, flagged, shared and met – the key requirements of the AIS.

After a successful bid to the National Institute for Health and Care Research Small Grant Scheme, targeting under-served communities, Healthwatch Hampshire, Healthwatch Portsmouth, Healthwatch Southampton and Healthwatch Isle of Wight came together to work alongside people with a need for accessible information and communications support to ascertain how the AIS is working for local people. Feedback gathered will be taken forward into further work with the Integrated Care Board to ensure the AIS is implemented in a way that truly benefits those for whom it was developed.

Through a co-production approach, over a 3-month period, the 4 Healthwatch engaged with people (as well as parents, families and care givers) who have a disability, impairment, or sensory loss, to gather their stories and experiences to understand whether they are aware of their rights under the AIS. We wanted to know whether information and communications are provided in the way that best suits people and how things could be done better.

The project aimed to raise awareness of the AIS to those who should be accessing information and communications support and hear the voices of those who should be benefiting from it.

This report summarises what we have learned. Those organisations and people who were involved will be asked to help develop the recommendations which will be shared with the Integrated Care System, to support their implementation of the AIS, currently being reviewed, more consistently and comprehensively. Our final report will be in various formats such as Easy Read, video and voice files.

The Integrated Care Board have already expressed their wish to work collaboratively with us on ensuring the AIS is fully met. We aim to have in place a "user group" to continue the work beyond this phase of the project.

Methodology

During the summer of 2023 the 4 Healthwatch engaged with local communities and groups who consist of and represent the interests of our target groups (learning disabilities, visual impairment, hearing loss, blind, deaf), reaching out to people who should be benefitting from the AIS.

In the first stage of this coproduced work, it was important to understand and determine the mechanisms that these groups felt would be the most effective to hear from people about how / whether their information and support needs are met when engaging with health and social care services. Co-production requires flexibility, understanding the broad outcome from the outset, but the ability to adapt the focus and methodology with our co-production partners.

The organisations we worked with designed posters advertising the project, easy read agendas and provided help and guidance on the right methods to communicate with people (including use of British Sign Language dialects and written British Sign Language), and either facilitated engagement or jointly facilitated (with Healthwatch) events/focus groups and one-to-one sessions. Examples of materials used are available on request.

Having agreed our methodology and subject matter we then embarked on engagement, finding out the levels of awareness and use of the AIS.

A set of focus group questions and prompts was developed as below:

- Explain what the Accessible Information Standard (AIS) is.
- Have you heard about the AIS / ever been asked what your communication or information needs are?
- If yes.....
- What works well for you in terms of your communication/information needs being met?
- Can you give us some examples?
- If no.....
- What doesn't work for you in terms of your communication/information needs being met?
- Can you give us some examples?
- What could be done better in terms of your communication/information needs being met? (What would you like to change?)

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- Are your experiences the same with all the organisations you are in touch with?

Questions were also circulated (with a briefing) to partners where requested, to enable more people to have their say.

All participants were provided with a GDPR Information Briefing about the project and their data protection. This information was available in Easy Read format (designed by People First Forum and a poster designed for IOW by Mencap). Ethical considerations, quality controls and Data Protection Impact Assessments were also undertaken.

Advice and guidance on methodology received from partner organisations:

- Print the questions and information sheet in large font. Font size 16 - 18 (or even 20-22 if possible) and use font style Calibri or Verdana.
- Create an Easy Read version of the information sheet and the AIS itself.
- Face to Face is often preferred but if using online systems Zoom is preferable to Microsoft Teams (there can be issues with Teams for visually impaired people as it's not always fully compatible with technology programmes used).
- Consider contrast on documents - (standard is black writing on white) – ivory/pale, yellow/beige background can be better or white writing on black background.
- Braille format needs to be considered (however fewer people with visual impairments are using this now).
- If images are used, ensure description text is included.
- Create a short, simple to understand presentation to guide the sessions, however PowerPoint and .pdf files can be difficult to access/use and are not fully compactable with some screen reader software. Most compatible is Word.
- If using a website, consider text to speech facility.
- Offer the opportunity for a 1 to 1 discussion or phone call if preferred.
- Post the opportunity to be involved on social media.
- Create visual cue cards to guide the sessions (our thanks to Winchester Go LD who checked our information with a group of adults with learning disabilities. Based on this feedback, we created the cue cards and made some small changes to language).

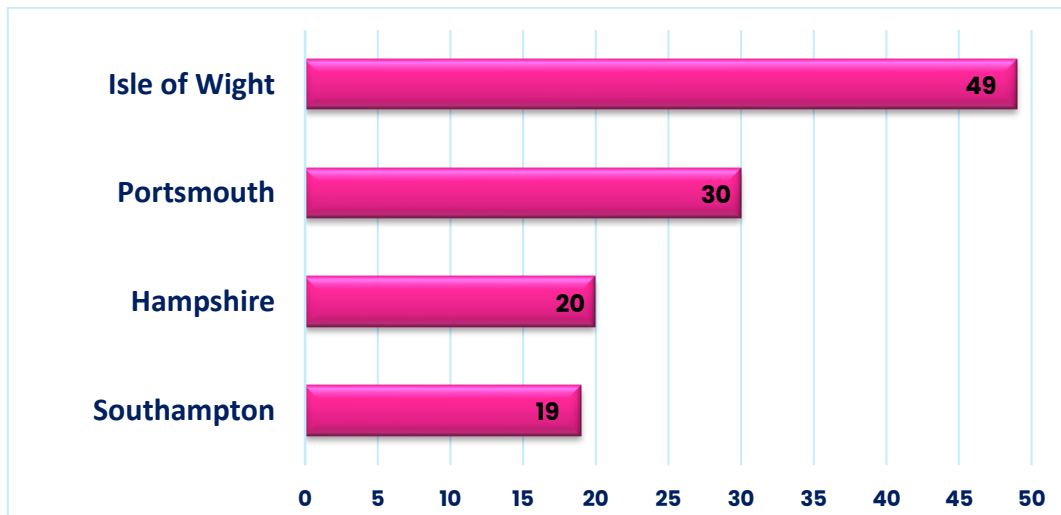
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- Give people the opportunity to draw, write, speak or record their feedback.
 - Hold focus groups where people feel comfortable (community settings), on days, and at times of day convenient for participants.
 - Hold informal group discussions.
 - Provide refreshments.
 - Use the services of British Sign Language interpreters where necessary.
 - Let the support organisation help facilitate sessions to help engagement and focus, and at venues that participants are familiar with.
 - Written posters and information sheets would not be suitable for many people with sight issues. (Information was sent to partner organisations, where requested, via email which was then shared with people using communication methods they were comfortable and familiar with).

Note – although this report primarily relates to feedback about health and social care services, we also received general feedback concerning banking, housing and travel issues. We have included this feedback as it helps to give an overview of the challenges people face in their day to day lives (and can affect health and well-being).

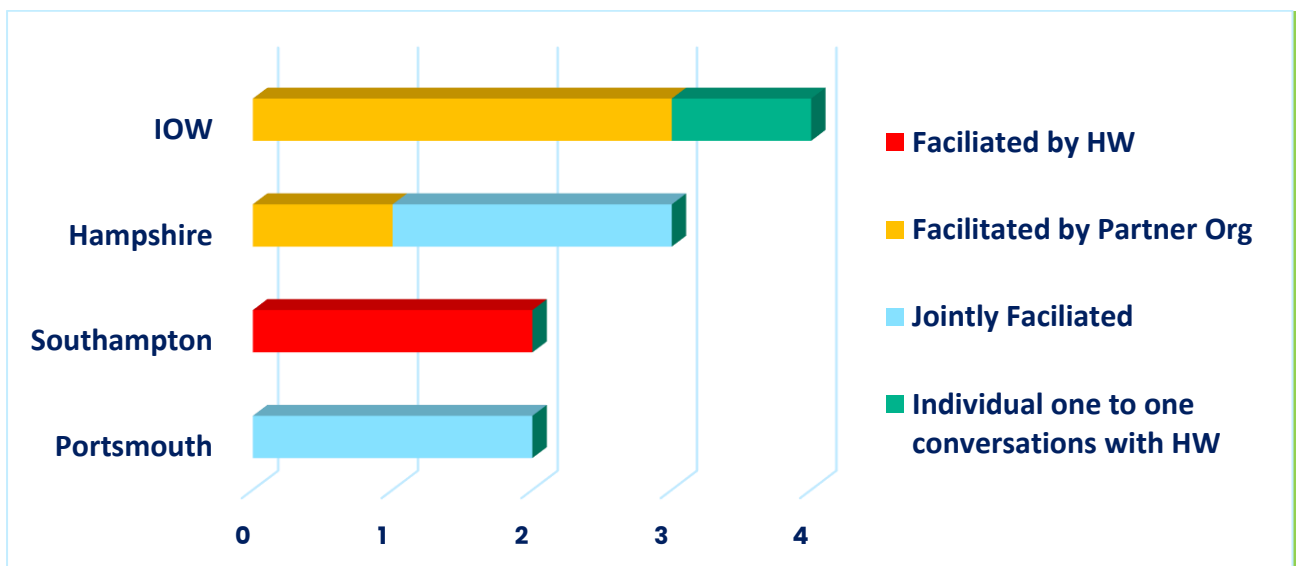
Findings

TOTAL NUMBER OF PEOPLE ENGAGED WITH: 118

Number of people engaged with for each Healthwatch area:



Number of sessions undertaken:



Feedback

Comments about communication methods:

EMAIL
POSITIVE
Many people who lose their sight in later life (many with macular degeneration) find it very difficult to learn braille or to read large print, but emails can be adjusted on screen.
NEGATIVE
Some said they receive too many emails; they can get missed and misinterpreted.
Not everyone has access to a printer for emails etc.
Emails can carry too much complex information for deaf people or those with a learning disability who's first written and spoken language is British Sign Language.
Written in English (works for some people but not all).
Easy read needed.

TEXT/WHATSAPP/APPS
POSITIVE
Some people received text communication from their dentist, particularly for appointments and reminders, which they found helpful.
Some, but not all dentists, ask the patient's preference about whether they'd like a text or a written appointment card.
Many like using WhatsApp and prefer it to text as its free, people use it regularly and it uses Wi-Fi so doesn't depend on reception.
Text can be a useful reminder, some participants had "talk back" phone calendars.
2-way texts are good for communication.

NEGATIVE
Can often get too many, to the point of feeling “harassed”.
Text reminders are sometimes incorrect (e.g. reminder for appointment that’s just been cancelled).
It’s sometimes unclear what they are for and where they are from.
Some people with sight issues use phone Apps to read back text, useful for letters, but not for information such as leaflets.
Post appointment text feedback surveys from eye clinics (for example) are not always accessible to people with sight issues.
Appointment text messages are sent from 'no response' sources but deaf people who are able to use texts would like to be able to respond if they need a different time.

TEAMS/ZOOM/ONLINE
POSITIVE
Face to face or video makes it easier to communicate as people can interpret body language/use signs.
Use of video / Facetime supports people who lip read when consultations are planned.
NEGATIVE
Meetings online should be followed up in writing as it can be hard to digest what you are being told.
Many people prefer Zoom to Microsoft Teams, but Teams seems to be more widely used by services.
Not everyone has the ability to complete online forms.
Many GP surgeries are only accepting online appointment bookings with an emphasis on e-consult. This can take up to an hour with a screen reader. E-consult can be hard to use for people with complex needs. If you need help the teams are far away and hard to contact.

There was general feedback about the NHS App:

- It isn't user friendly but hard to navigate and use.
- People are being pointed towards the App to make appointments, but there are no appointments available.
- Not everyone has a smartphone.
- More people would use the App for things like making appointments if it was easier to use.

Many people with a learning disability are having to learn how to use online banking and this places them in a vulnerable position. (many don't have contactless cards, and some can find it difficult to understand the concept of money when it is 'virtual'). However, some people did advise that online banking is reasonably straightforward once it has been set up.

LETTERS/WRITTEN COMMUNICATIONS

POSITIVE

Can be good because information won't be forgotten or misunderstood.

People can share the information with their support network if they need help to understand it (this also relates to texts and emails).

It avoids language barriers and can be absorbed at the person's own pace.

It's good to have written documents as sometimes additional copies of documents are required – e.g. diagnosis/condition to share with school.

For people who travel with medication etc, there can be a need for evidence at border control, which often needs to be a paper copy or where you can't always rely on signal etc.

NEGATIVE

Letters could be more concise and avoid using jargon. They should be in simple, straightforward language.

Many people would prefer Easy Read versions.

One person advised they received a leaflet about aftercare (e.g. after wisdom tooth removal) but could only just understand it and felt an Easy Read version or even a video would have been better.

Appointment letters from the ADHD team and St Mary's (IOW) are not in an accessible format (and reminders are not always sent). However, Covid and flu jab letters WERE sent in accessible format.

Hospital discharge letters are not written in accessible formats.

Letters from the Department of Work and Pensions and financial contribution council letters are not accessible or easy to understand, with people having to get help from family members to understand them.

Council tax letters can be very complicated for people with a learning disability.

Letters often arrive too late for patients/service users to communicate a changed time requirement leading to missed/wasted appointment slots.

PHONE

NEGATIVE

Although many people use phones, many do not access Apps or other communications methods such as WhatsApp.

Some expressed frustration about being called by the GP repeatedly (for example, health checks) when they don't like to be called.

Many people find telephone calls difficult, especially telephone queuing systems (where you have to select an option and press different buttons). There are lots of options and numbers, sometimes none of the numbers relate to what the person needs and by the time they get to "reception" they forget why they have called or don't understand the process.

Many phone systems have menu options (e.g. press 1 for, press 2 for). There is not always the option to say the number instead and when using modern technology, it is usually a flat screen so many people (especially those with a visual impairment) can't feel the numbers either.

For people with sensory impairments, the hold music can be annoying and overwhelming.

Languages and dialects can be tricky to understand when on the phone.

Doctors (and others) often speak too quickly, and it can be hard to keep up.

Many medical professionals call from an unknown number, many people do not answer calls from unknown numbers.

Most GP appointments need to be booked by 8.30am. For people who need a care giver or some support to make an appointment and receive this support at certain times, it can be a disadvantage and many people reported missing same day appointments or not being able to book appointments.

Phone calls are of little/no use for deaf people. Deaf patients/service users have received phone calls which they can't respond to even though their patient notes state 'deaf'.

Even though a number of people told us they had requested only to be contacted by phone (especially those with sight loss), this doesn't always happen.

Additional feedback for NHS 111:

- Many people said it was easier to call 999 or go to A&E due to communications difficulties with NHS 111. The script used has lots of questions which people found confusing. Many of the questions were not relevant and left them feeling worried, confused and exhausted.
- 111 phone line as currently provided does not work for deaf people without text solutions. However, video relay with an interpreter does work for deaf people. This option should be more publicised when 111 offer ways to communicate with people who have additional needs.

It can be difficult to find phone numbers for banks and housing associations and they are not easy to find on websites. Phone menus can be long winded and confusing (one individual had to go through 6 menu options on the website to report a repair request to their housing association).

It is clear from the feedback that one size does not fit all, and people have a diverse range of preferences and needs. Some of the comments received:

“I like communication by phone but not by text”. (Hampshire)

“I prefer text or phone – not email. The dentist emails me my appointments and I don't like that”. (Hampshire)

“I find text quicker than email”. (Hampshire)

“I prefer speaking”. (Hampshire)

“I like to get a letter in the post and to show it to mum and dad”. (Hampshire)

“I have the patient access App to order my meds and it tells me when my next appointment is. I find this easy”. (Hampshire)

“My GP has just started using Easy Read, but it is only in black and white”.
(Hampshire)

“They call me, but I prefer being contacted by text”. (Hampshire)

“I find communicating hard because I don’t like meeting new staff”.
(Hampshire).

“I booked a blood test with Newport Health Centre last week and they texted me the appointment”. (IOW)

“Our only option is to sit in a telephone queue for 10 minutes or go into the surgery and share our problems with the world”. (IOW)

“The appointment could be personal; I don’t want my kids or my Mum to know if it’s personal. You don’t have privacy”. (IOW)

“The good thing about an email is that you can go back to it, make it larger. If a telephone number is in the text of a letter, it’s very difficult to locate it whereas if it’s in an email, you can use the arrow across to it.” (IOW)

Comments about health services:

Positive

- Annual health check forms at some surgeries (e.g. Tower House IOW) produced for learning disabled are useful.

Negative

- GP services and hospital services often do not communicate with each other. For example, a GP will email about a referral, but the patient has already had the appointment or been re-referred somewhere else. This is very confusing.
- The Living Well Partnership (includes several GP surgeries in Southampton) often offers appointments at sites other than the one a patient is registered with. This can be difficult for people, especially those with visual impairments and those who are physically unable to attend.
- People often have to navigate their way round “the system” (parents, care givers etc) as there is no other option. If you have the knowledge and experience you may be able to find your way around and hopefully work out the miscommunications or errors.
- Many people are in contact with a huge number of different organisations/parts of organisations, all often communicating in different ways, even when they are both from the same umbrella organisation, like the NHS. For example, one clinic may send emails, but then others within the same hospital communicate via Teams or letters. GPs often leave voicemails which can get missed or lost if a voicemail “box” gets full.
- Audiology services at Royal South Hants Hospital (University Hospital Southampton NHSFT) preferred method of contact is via the phone.

Patients have had to research extensively to find an email address – this is not forthcoming from staff, the website or letters received.

- Few, if any, had heard of the special needs dental service.
- For those that have used the special care dental service (Southampton), the service sends letters with pictures. Patients have asked several times for letters to be sent in large print or sent electronically but requests have not been addressed.
- The emergency dental system is complicated. One person with a learning disability had to take their support worker with them to the emergency appointment as it's quite daunting and they had to fill in a complicated form prior to the appointment.
- Although some people were very happy with their dental practice not all find communication easy (unable to answer questions about dental health changes).
- Some people have been refused communication in their preferred way (e.g. asking a Trust to email appointments but being refused).
- Pharmacists don't always explain how to take medications and the instruction forms in the packets can be very difficult to understand. (Boots, for example, do not provide verbal explanations), although some pharmacies will provide large font medication labels if asked.
- Some GP websites are confusing and not intuitive – some people would not be able to use eConsult without the support of a relative or a support group. Others would use 111 instead.
- Specific feedback on hospital car parking (note, the following feedback was received from Portsmouth engagement but will likely also be relevant for other sites):
 - There is no access to on-screen instructions if the patient/service user (deaf) has a problem. Calling via the help button is no use for deaf

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- people. One patient was being told he had to pay £x but he could not hear!!!
- Location of disabled parking bays in both Queen Alexandra Hospital car parks is very difficult and far from the front door/s, thereby requiring long walks (which disabled people find difficult).
 - Car Parking fines have been issued to patients who park in disabled bays AND display a Blue Badge AND inform Reception.
 - Patients waiting for interpreters to arrive incur consequentially increased car parking charges.
 - Blue badge parking is not free at Queen Alexandra Hospital.
 - Blue Badge car parking information is often incorrect, not up-to-date and not in accessible formats.
 - Ticket machine links to card payment facilities when out of order require payment in cash. If patient does not have cash or has to return to car to find cash – personal safety issues as well as major inconvenience for people with disabilities – by which time the transaction is cancelled and fines are issued.
 - Automatic Number Plate Systems need to link to Reasonable Adjustment flags in order to ensure Blue Badge holders are not discriminated against through unfair car parking fines.
 - Training and awareness is needed for car parking/facilities staff.
 - Additional feedback re Southampton - Booking hospital transport has changed and can now only be booked via an online system by the patient rather than the service/ward. This is not possible for many people, especially those with visual impairments.
- Specific feedback relating to Southampton Eye Clinic:
 - Patient was told bad news at a face-to-face appointment and then given poor quality/grainy document to take away regarding follow on treatment/operation. Patient asked for the information in different formats (larger font, Grade 1 braille or electronically). The clinic was unable to accommodate with all requests and instead offered to find a CD with the information but advised it would probably be outdated. Patient declined CD as did not have a device to play it on. Patient felt that the service made it hard for them to understand their forthcoming treatment and make an informed decision about their care.

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- People feel the staff can be insensitive to patient needs/conditions – for example, one participant advised they are always asked if they have driven themselves to the appointment, despite clearly having a guide dog and a white stick.
 - A patient who is totally blind is routinely asked to look at the eye chart on the wall. Patient finds this traumatic every time and the issue has been raised with Southampton Eye Clinic.
 - A patient whose pupils stay the same size due to a particular condition is routinely given dilating eye drops at appointments. Patient has questioned this several times but is told “everyone has them administered”.
 - A patient had a traumatic experience when a technician inserted the wrong lens in the field vision machine resulting in readings of high loss of vision. This resulted in patient being admitted as an inpatient and given IV medication which could have been fatal, before the false results were detected. This incident has caused the patient PTSD and resulted in their care being transferred to another provider.

General comments:

Positive

- IOW council annual reviews are focussed on the person and their strengths. They are useful and people feel able to contribute with time given to express needs and views, with the focus on the aspirations of the person rather than the available funding.

Negative

- Some people wear a Hidden Disabilities Sunflower lanyard (a discreet sign that the wearer has a hidden disability and may need additional support, or who are excused from wearing face masks) when attending appointments, although not all. Some did not wish to use it or did not like using a lanyard. Some advised the scheme had been abused by people wearing them who are not entitled to do so. Some people had received abuse for not wearing face masks whilst using the lanyard.
- Many people like using messenger, Facebook, voice notes and facetime but understand these might not always be suitable for medical issues.

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- Even when services have been asked to send information in different formats (such as large print or via audio), people still receive standard texts or have been told that their preferred method (especially audio) is not an option.
 - Verbal announcements and display screens on buses and trains are very useful (especially for people who get disorientated, at night or during bad weather when windows are steamed up and locations are harder to recognise). However not all companies across the area do this and not all the functions are always apparent.
 - General feeling of a lack of privacy due to needing to include family and support network in communications with services because “that’s the only way”.
 - People expressed concern that the adult services personal independence plan can take up to 6 months to receive back once agreed and is never in an accessible format. (IOW)
 - The concessionary bus pass form (IOW) is very confusing and the wording on the ‘category section’ has been seen as upsetting and offensive.
 - Some people expressed concern that the police do not have the right awareness of learning disabilities and autism, and this can lead to misunderstandings. They often look only at physical disabilities and there is a lack of understanding of hidden disabilities.
 - More and more services are moving towards sole online access (especially to make appointments). This method does not support many people with additional needs.
 - There can be an assumption by many professionals/staff that people with additional support needs have someone (family member/friend) to assist (whether at face-to-face appointments, to gain online access or read letters aloud). There can also be assumptions that people have high level

of confidence and/or independence and are therefore not asked if they require support.

- Specific comments relating to Interpreters:
 - St Mary's Hospital Portsmouth and Queen Alexandra Hospital Portsmouth use different systems to book interpreters and different contract providers which leads to confusion. (Note Queen Alexandra Hospital advise that they are looking into producing letters in larger font as they recognise their duty under the AIS).
 - Where available, Family Liaison Officer Teams could help setting up video calls.
 - Use of interpreters is essential for deaf people in situations involving complex health information and conversations with professionals.
 - It is important that interpreters are always pre-arranged for appointments.
 - If an interpreter arrives late, some clinicians start the appointment without the interpreter being present. This does not lead to meaningful communication and can make people feel marginalized.
 - Interpreters must be able to sign in British Sign Language.
 - The patient/service user should be asked if they prefer male/female interpreter, particularly when undergoing intimate examinations/conversations.
 - Even when a patient/service user has a yellow folder (used in Queen Alexandra and other hospitals to signify deaf client), there have been times when no interpreter has been booked.

Further examples of individual experiences/cases studies:

- Individual had a letter from the ADHD clinic (IOW) not in an accessible format, inviting them to an online appointment. Individual's preference was a face-to-face appointment (due to learning disability and ADHD), but this was refused due to consultants being on the mainland.
- IOW participant had to attend surgery (name available) for blood pressure readings and was advised they could not have someone with them (this raised anxiety levels, which raised blood pressure and meant a return visit

for more readings). On another occasion, “they spoke to my parents not me. I think they need to be more understanding of people with special needs”.

- The hepatology department at the Queen Alexandra Hospital in Portsmouth advised a participant that they were unable to send out appointment letters in large print and could only send them in the standard size 10 font (inaccessible for participant with sight loss).
- One person (with Learning Disabilities) had been told by their GP about the AIS but it hadn't been explained to the patient, so they didn't know what to do with the information (Portsmouth).
- Participant (Southampton) received many letters regarding review of housing benefits, all of which they were unable to read. Participant was also unable to use the online services they were directed to. (Participant had previously notified service of their visual impairment). Housing benefit was stopped without notification and participant was sent a bill for unpaid rent. Participant did not want to involve family. They eventually spoke to a member of staff in the service who listened and supported them by making a new benefits claim whilst on the phone and backdated the housing benefit. Participant felt this was down to luck that they managed to speak to this person who supported her to resolve the issue. This help is not the norm.
- When participant (Southampton) attends their GP surgery, the staff always state their name and tell them to go on through without offering any assistance. Participant finds this frustrating as staff assume they have brought someone to help them. Participant has been visually impaired since birth and therefore this must be stated on their medical notes.
- Visually impaired participant was attending a Guide Dog Fundraising Event and met a nurse who shared that they recently had a guide dog assisting a patient on a ward and proceeded to name the dog. The guide dog community is quite small in Southampton and a dog's name can mean a patient is easily identified (it's like using the actual patient's name) and

thus patient confidentiality was broken. Although unintentional, this reiterates the need for staff to have appropriate training and awareness.

- Participant (Southampton) is a guide dog owner and attended an appointment at the fracture clinic. When she entered the consultation room, the locum consultant made a yelping noise and left the room and refused to treat the patient because of the presence of the dog. This issue was taken up with PALS.
- Participant attended the orthopaedic clinic at Royal South Hants Hospital (part of Practice Plus). They were asked to complete paper copy forms before attending. When participant arrived for the appointment, they informed staff they were unable to complete forms due to visual impairment. Staff told them to take a seat in the waiting area and someone would support them to complete the form. Staff then proceeded to try and complete the form with participant in the waiting room, in a public area amongst other patients. Participant voiced that they were uncomfortable completing the form in a public area and was told a clinician would complete the form with them instead but then proceeded to ask if participant was HIV positive or had Hepatitis. Participant felt the situation could easily have been avoided had the service sent the form electronically to complete before appointment and staff should have taken them to a private area to complete the form.

Some of the comments received:

“I never see my own Doctor as they are busy and it’s hard to explain to other Doctors what’s wrong because they don’t understand me”. (Hampshire)

“I don’t like my appointment on NHS link. I find it hard to put my number and date of birth and I keep missing my appointments”. (Hampshire)

For appointment.....” A word document on an email would be best”. (IOW)

“Over the years my kids have had to read my cervical screening results to me”.
(IOW)

“People with visual impairments are always expected to rely on someone else for communication or mobility support (family & friends). This leads to a lack of control over our own care. We already share enough about ourselves when people see our white stick – we are already highlighting our disability”.
(Southampton).

“It feels like – if you are blind, confidentiality is an afterthought”.
(Southampton).

“I have had many bad experiences with several services, that I now have low expectations. When a service does something really simple such as electronic forms I can edit, this makes me very happy that my needs are being met”.
(Southampton).

People told us about organisations and support groups providing good practice examples of communication:

- Avalon House (Winchester Community Hub).
- Smokefree Hampshire.
- Eye clinic at IOW NHS Trust.
- Living Well Partnership Surgery (Southampton), automated phone message asks those that are able to use other methods (e-consult/face to face) to secure an appointment should do so, freeing the line for those that cannot.
- Solent NHS sexual health services (supportive and make reasonable adjustments and have a direct line for people with learning disabilities and videos of how to access the service).
- Amazon – easy to use website and memory function.
- Southampton Autism Assessment Service (Southern Health), ask about preferred communication methods.

Conclusions

- Most people we engaged with were unaware of the AIS or even that they have the right to ask for information and communication support in a way which suits them, and that they should only have to ask for this once.
- The majority have never been asked about their preferred communication methods.
- Many people did not know who should be asking them and when.
- People find it frustrating that they must explain about their needs every time they engage with services (unless it is someone they know well or have seen multiple times) as it makes accessing services stressful.
- Many people told us that not getting information and support in a way that's right for them leads to a loss of independence, privacy and dignity.
- People are still being given information and communicated with in ways that are not the preference of that person, family member or care giver. Communication support needs should be identified and documented with better use of the Reasonable Adjustment alert system.
- Many people rely on parents, family members, care givers and support organisations for information (for example – talks on scams) and communication. This means it is this support network who are communicated with rather than the person with the additional need. This can also be a potential issue when some services aren't always happy to share confidential information with someone other than the patient/service user.
- Where appointment letters and information leaflets are not available in accessible formats, this can have implications for future treatment, with people potentially being turned away if they have not followed advice given prior to appointments.

In summary, one size does not fit all. Individually personalised communication plans are essential to ensure all patients and service users have accessible communications.

Recommendations

The following Recommendations (kindly themed by EDI Project Manager (NHS Hampshire & Isle of Wight Integrated Care Board), have been generated by the feedback and from our own learning. These Recommendations will be confirmed and prioritised with partners and shared with the Integrated Care Board and other stakeholders to be actioned (where possible and appropriate).

1) Improve Awareness of AIS for patients and staff across the Integrated Care System:

- Run an awareness campaign about the AIS, using large print, Easy Read, Braille, BSL/signed, subtitles, and audio versions of information.
- All services should know that people should be asked about their communication and support needs. (People with health conditions, or caring for people with extra needs, don't always have the time or energy to ask for communication in a way they can understand or even realise that they can request this). If you are only supposed to say it once (as per the AIS), who do you say it to first, where is this logged and how do all the services know where to look? Proactive conversations about communication and support needs should be ongoing and happen at different "touchpoints" in the system to ensure needs and preference are current and effective.
- Some areas/departments/staff are not aware of care choices and wishes documents that should be available, accessible and known about. These should include guidance on specific communication requirements for patients/service users.
- Services and providers need to engage with community groups to ensure that letters/leaflets and information is user friendly and AIS compliant.

2) Improve identification and recording of preferred formats:

- It would be helpful if communication needs were linked to NHS numbers.
- It would be useful to have standard, easily identifiable medical cards for emergency services to help identify that the patient has a sensory loss or additional communication need.
- Information about a patient's condition, diagnosis, disability, communication preferences, etc should be at the start of a patient's records for all services/departments - instead of being buried within history of notes as and when they are shared. This should always be the first thing healthcare staff see.
- No one had heard of a "hospital passport", although there was interest that using it could help (a document about a person and their health needs. It also has other useful information, such as interests, likes, dislikes, communication needs and any reasonable adjustments that someone might need). Services should raise awareness of this to people.
- Better use of the Reasonable Adjustment alert system (and yellow folders).
- Use of a medical ID bracelet, password protected and QR coded, which could be presented at all medical appointments. This would save patients having to tell their stories time after time. (Many European countries provide patients with a debit size card which contains information including diagnosis, disability and communication needs. The card can be swiped at various medical settings including GP, hospital, dentist, opticians, etc.).
- Few people had heard of the "[The National Disabled Identification Card](#)". This could be helpful if people knew about it.
- Patient/service user notes and records should clearly state when an interpreter is required. (GP notes should state if an interpreter is needed when making referrals to secondary care. Otherwise, hospital appointments are wasted.)

3) Improve Staff skills for recording and arranging communication support:

- Staff need to have ongoing training and awareness on how to communicate with people who have additional needs, how to book interpreters, where to go for help and support etc. This will help identify and break down barriers experienced by people. For example, autism is often categorised under learning disability instead of neurodiversity. People told us that they have experienced healthcare staff talking slower and emphasising words and asking, “do you understand what I am saying to you” and “are you able to make health decisions for yourself”. This is insensitive and rude and shows a lack of awareness.
- Some people with additional communication and support needs find waiting in clinics for long periods of time / delays very stressful and it can cause distress. It’s important for staff to provide reassurance and support at these times.

4) Ensure the role of support networks, support workers and advocates are recognised:

- Services need to recognise people in the support network (parents, family members, care givers, support organisations) and ensure information and communication needs support that network as well as the patient/service user. Most of the people we spoke to relied heavily on the support of family/friends to help with communications from NHS services and Adult Social Care Services. Support networks are also crucial when it comes to accompanying people to appointments. (One person advised they rely on their daughter who lives an hour’s drive away and only visits once each week. This has meant that short notice appointments received via post have been missed).
- It should be noted that not everyone has family/care giver/support networks (leading to increased isolation and vulnerability to poor health care) making it even more important that each service provider they engage with acts in accordance with the AIS and utilises the Reasonable Adjustment alerts/red flag alerts/yellow folders. When a patient does not have a support network and attends appointments independently, staff could (particularly at hospital receptions) physically escort patients to the

correct department and support them with navigating around the hospital (could this be a role for volunteers?).

- Some support workers were unsure if people with a learning disability are flagged on the GP system. They feel uncomfortable announcing their job role at the reception (and in front of other people), to justify the reason they are accompanying the individual to the appointment. If systems can be updated to show a person's additional support needs this would negate this issue.

5) Diversify communication formats and style:

- Suggestions for improved communications include (see also Appendix for further guidance received from Sight for Wight):
 - More widely available Easy read materials.
 - Use of Large (16 font) and very large font (16+++). Adequate font size varies with individual needs but many requested a size of 20.
 - Text colour and background colour alternatives.
 - Messages in audio formats.
 - Raised letters (printed materials).
 - Provide email addresses as standard practice.
 - Phone calls and reminders by real human beings. (This was a top priority for many).
 - Ensure people with additional communication and support needs receive the same information as people who do not have these needs, not a “watered down” or summarised version.
 - British Sign Language has dialect variations with differences between a Northern dialect and a Southern dialect. Local service providers need to ensure that the appropriate dialect is used.
 - Long words, accents and use of jargon are all issues that cause frustration and services should check information for this.
 - GP surgeries should allow people who rely on others to book appointments the ability to access booking systems at times other than 8.30am or have a separate line which is learning disability friendly.
 - A suggestion for phone menus for GP surgeries: an easier to understand list for people with a learning disability. When you call

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- the GP the first thing said is “if you have a learning disability press ‘x’”. This will need to be developed in partnership with practices and IT providers to ensure a fair and effective system.
- More use of screens, subtitles and British Sign Language translation for deaf people and lipreaders to access information (in surgeries, clinics and offices).
 - Lip readers (and many people with hearing issues) are unable to communicate with staff wearing masks. Some staff have refused to temporarily lower masks to enable lip reading. Transparent face shields or window masks could be worn if staff in clinics need to continue to wear masks. Staff could be reminded to lower masks where safe to do so.
- Providers need to have a better understanding of patient/service user needs in terms of utilising interpreters. Again, one size does not fit all.
 - Where available, Family Liaison Officer Teams could help setting up video calls.
 - It is important that interpreters are always pre-arranged for appointments.
 - Appointments should not be started until the interpreter has arrived.
 - Interpreters must be able to sign in British Sign Language.
 - The patient/service user should be asked if they prefer male/female interpreter, particularly when undergoing intimate examinations/conversations.
 - Consider making access to NHS 111 more learning disability friendly, maybe with a different script? Or ensure people are advised they can use video with an interpreter.
 - Appointments (in all settings) need to be longer, to accommodate certain communication needs. This should be recognised if the Red Flag alert system is properly used.
 - Open days, where people can try out new gadgets (and possibly new communication methods or talk about communication and information support needs) have proved useful and could be extended to other areas such as GPs, Trusts and local authority.

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- Patients (especially those with hearing loss) should be given a pager that vibrates when medication is ready to collect from the pharmacy.
 - Medicine labels and instructions on how to take medication and other important information should be available in easy read and large font/text.
 - Reintroduce requests for repeat prescriptions via phone as standard. Many surgeries have removed this option and only offer requests via email/app or face to face.
 - Food menus in all hospitals should include pictures of food (not all hospitals do this).
 - All hospital TVs should have the capability to show subtitles.
 - Personal Independent Plans would benefit from the addition of a QR code which could refer to a website which could read out the plan, or the plan could be available in audio form or easy read.
 - Participant mentioned use of signing robots at Norwich Hospital that assist patients navigating the hospital building to get to the right place at the right time. More research may be required here.
 - A review of how hospital car parking facilities are made more accessible/equitable for patients/service users should be undertaken at all sites.

6) Make more effective use of the NHS annual health review/check:

- People should be asked about their information and communication needs at annual health reviews, and services need to recognise that communication needs can change over time.
- Some GP practices send out annual health check forms in easy read format, which is somewhat accessible, but could be improved by changing the accompanying letter to easy read as well. The annual health check

forms could be bolder and in larger print, some of the pictures don't relate to the meaning of the words (using photographs would be better). An audio version of the form would also be helpful so people can listen back to it. (Note – participants at the Mencap Hayland's Farm focus group (IOW) advised they would be happy to support GP practices to improve the form to make it more user friendly.)

- The first page on the health check form asks people what their main spoken language is, which infers that the person can communicate verbally. This could say 'preferred method of communication'.
- In the 'reasonable adjustments' section, it would be helpful if there were examples to support people's understanding. E.g. the persons preferred method of contact, or whether they have a sensitivity to bright lights.
- There is a box covering substance abuse which is illustrated by a picture of a syringe. This could potentially give people a negative impression of positive use of syringes, such as vaccines. Other images would be more useful.
- There needs to be consistency with the annual health check forms across surgeries.

7) Develop the oversight role of the Integrated Care Board

- The Hampshire & IOW Integrated Care Board website does not contain any information on the AIS, other than an Accessibility Statement and information about Equality, diversity and inclusion.
 - [Equality, diversity and inclusion: Hampshire and Isle of Wight ICS](https://hantsiowhealthandcare.org.uk) (hantsiowhealthandcare.org.uk)
- This is the same with the IOW Council and the IOW NHS Trust. Local authority and NHS Trusts should have full information about the Standard (including the legislation and people's rights).
 - Example of good practice can be found on <https://www.healthwatchisleofwight.co.uk/advice-and-information/2022-03-15/accessible-information-standard-what-you-can-expect-services>

Additional suggestions from Ed Walton, EDI Project Manager at NHS Hampshire & Isle of Wight Integrated Care Board:

- Hold an ICP event on accessible communication?
- Nominate an AIS lead, and co-ordinate a working group across the system with input from staff and patients.
- Explore the Leeds model?

Learning Points for this project methodology

- Some of the partner organisations held drop-in (turn up on the day) sessions for their members. It was not possible to know beforehand how many people would attend, or the nature of their communication needs. In one instance only 1 person attended a session (however that 1 person wore so many hats and had so many different experiences that it was almost like having 10 people in the room). More communication and discussion with partners would help to alleviate these issues.
- Group discussions worked well but good facilitation skills are required to ensure individuals also have a chance to express themselves in a group environment. Dividing bigger groups into “break out” groups may be more comfortable.
- The tools we used worked well (e.g. easy read information and cue cards).
- It was good practice to have an easy read version of documentation readily available.
- We sometimes underestimated the severity of the learning disabilities of attendees and some attendees found it confusing. In hindsight, [Makaton](#) (signs and symbols) would have helped.
- Providing people with easy read documents to take away and read at their convenience, with an open invitation to contact us later, was helpful.

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- Several younger people advised that their parents either help them or deal with communication on their behalf, so they were unsure if their parents had specified communication needs or had been asked. It would have been useful to talk with parents and care givers for their input.
 - If the project was undertaken again it would be good to run some further sessions, specifically for the project rather than attending already established partner organisation groups such as drop-in sessions. It was often only possible to run one session in the project timeframe, due to scheduling of partner organisation meetings.
 - In one session (IOW), a participant with a learning disability helped facilitate the group, this worked very well.
 - Posters and information sheets were not appropriate for people with sight issues but working with partners a more suitable method of communication was achieved.
 - Partner organisations were essential in terms of facilitation and support for participants. Co-production takes time and while communications meant a need for more time, different resources etc, partners were incredibly helpful and able to not only advise, but also offer to help.

Next Steps

- Some Care Quality Commission Inspection Reports have identified that services have issues in terms of implementing the AIS (for example [Portsmouth Hospitals University NHS Trust CQC Inspection Report May 2022](#) – pages 4 and 15 specifically). These reports could be followed up with relevant Trusts/services to ascertain actions taken.
- When updated AIS guidance is issued (date unknown) each service could be asked how their accessible information and communications policy/policies align with the refreshed guidance, whether changes are needed and how these will be implemented.
- To support the Integrated Care Board as they implement new AIS guidance, the next stage of this review will be to establish a working group (with partners and the Board) to take forward the ideas and suggestions for improvement documented in this report.

Appendix

The following additional feedback from Sight for Wight provides suggestions on using large print:

- People living with AMD (age related macular degeneration) cope best with size 24 font with 1.5 lines spacing.
- What does large print mean:
 - Large print size eighteen
 - Extra-large print size twenty-six
 - Super-large print size sixty-four
- What is an accessible font: Ariel
- Use of colours. Asking for the perfect colour combination is impossible as there are so many forms of sight loss, but a few good pointers include:
 - Always avoid: Red and Green. This is the most common form of colour blindness - This means people cannot distinguish between red and green where the tone of the colours is similar - this combination is therefore always best avoided.
 - Generally speaking, solid bright colours are the easiest to see and pastel colours are harder to see.
 - Light reflection on a surface has a significant impact so matt surfaces reduce this impact.
 - Contrast is especially important. Always choose two contrasting colours. One dark one and one light one. Below is a list showing colours in groups and choosing one for the background and from a different group for the text provides this essential contrast:
 - navy blue, brown, and black – DARK
 - blue, green, and purple – MEDIUM
 - pink, yellow, pale blue and pale green – LIGHT

Sight for Wight also provided feedback regarding designing online surveys for those that use screen readers (feedback received via Wessex Cancer Alliance).

- Put tick boxes on the left of questions (as screen readers won't necessarily find the boxes on the right if there is white space on the page between the choice to select and the box to tick)
- If using a scale (e.g. one to 10) put these vertically (otherwise the question is read to the person each time they hover over the next point on the scale).
- Make it explicit in the introduction how many questions will be asked. Repeat how many are left as the person clicks through the survey. This is better than stating "it will take you 10 mins to complete" as it could potentially take a visually impaired person much longer.

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