

Accessible Information Standard

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

Report of findings.

EXECUTIVE SUMMARY

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 the full 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:

“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).

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.

The full 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.

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). A more in-depth breakdown of the Recommendations can be found in the full report.

- 1) Improve Awareness of AIS for patients and staff across the Integrated Care System.**
- 2) Improve identification and recording of preferred formats.**
- 3) Improve Staff skills for recording and arranging communication support.**
- 4) Ensure the role of support networks, support workers and advocates are recognised.**
- 5) Diversify communication formats and style.**
- 6) Make more effective use of the NHS annual health review/check.**
- 7) Develop the oversight role of the Integrated Care Board.**

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.

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