

Experiences of the Accessible Information Standards in Health and Care

Stockton-on-Tees Report

May - August 2022

WEBSITE: WWW.HEALTHWATCHSTOCKTONONTEES.CO.UK

TELEPHONE: 01642 688312

EMAIL: HEALTHWATCHSTOCKTON@PCP.UK.NET

| Contents | Page |
|---------------------------------|-------------|
| Summary..... | 3 |
| Background and Methodology..... | 4 - 5 |
| Findings..... | 6 - 9 |
| Main Findings..... | 10 |
| Recommendations..... | 11-12 |
| Appendix..... | 13 - 14 |

Summary:

[Healthwatch Stockton-on-Tees](#) (HWS) supported the Healthwatch England (HWE) 'Your Care, Your Way' campaign during March - May 2022. Due to unforeseen circumstances, HWS were not able to receive feedback from the paper copy surveys in time to share with HWE in May 2022. However, HWS have been able to use people's feedback to understand how the Accessible Information Standard (AIS) is working on a local level to find out how people experience receiving health information from health and care services. We heard from twenty-four people. Fifteen people told us that they require communication support to understand their health and care and would therefore be covered by the AIS. Nine people told us that they don't require support to understand their health and care.

The overall findings of this engagement, based on what people have told us, show that:

- Receiving an appropriate level of support from family, carers, and support staff to access and understand information, and to communicate with health and care services is important for those people that are covered by the AIS.
- People who are covered by the AIS experience disadvantage in accessing health and care information when needed, and this has had an impact on the quality of care that they received.
- People who are covered by the AIS have been refused a request for support to understand health care information when they have asked, and at times they've not been provided with health care information that they could understand or access.
- Those who are covered by the AIS are more likely to experience difficulties in accessing health and care services - particularly GP services and dentists, because of communication problems.
- People who are covered by the AIS reported that the quality of communication from health and care services has got slightly worse since the start of the COVID-19 pandemic. People who aren't covered by the AIS have reported that communication has stayed the same.

Based on the findings, the following recommendations have been made:

1. Health and care services to be accountable for delivering the Accessible Information Standard.
2. Every health and care service to have an accessibility champion so that health and social care staff know who is responsible for leading local accessible information policy and delivery, and to support staff awareness of their compliance with the standard.
3. To involve people with communication needs in designing better services.
4. To provide mandatory training on accessible information for all health and care staff - to enable staff to understand the standard and regularly provide information in the formats patients need, and to proactively ask patients about their communication needs.

Background and methodology

In March - May 2022, Healthwatch England launched the 'Your Care, Your Way' campaign. The campaign calls for improved accountability and implementation of the Accessible Information Standard (AIS) in health and care.

The AIS gives disabled people and people with sensory loss the legal right to get health and social care information they can understand, and the communication support they need. By law, all publicly funded health and social care providers must fully comply with the AIS and ensure people are given information about their health and care in accessible formats (Healthwatch England, 2022). Please see the appendix for AIS summary, and [YouTube Video](#) for the NHS England animated video - providing a step-by-step overview of the standard, with subtitles and BSL interpretation.

As part of 'Your Care, Your Way', HWE wanted to know about people's experiences of getting accessible health and care information, whether the standard is being delivered by services, and if it goes far enough? The campaign has been supported by Healthwatch organisations across the country. In March - May 2022, Healthwatch Stockton-on-Tees supported the HWE 'Your Care, Your Way' campaign by promoting and sharing the information and the link to the national survey on the HWS website, social media platforms and the newsletter. The findings from the national survey can be found at: <https://www.healthwatch.co.uk/news/2022-07-25/disabled-people-report-being-blocked-nhs-care-due-poor-communications>

In February-June 2022, HWS collaborated with Stockton-on-Tees Borough Council Community Based Learning Disability Day Services to find out about the views and experiences of people with a learning disability in relation to their health and wellbeing over the past year. For further information please access the Healthwatch Stockton, Bee Happy: Our Health and Wellbeing since COVID-19 Learning Disability Report (February - June 2022): www.healthwatchstocktonontees.co.uk/report/2022-11-17/bee-happy-our-health-and-wellbeing-covid-19-learning-disability-report-2022. This contact enabled us to extend the feedback to focus primarily on people experiences of accessing health care information.

To enable people to access the national survey more readily, we provided paper copies of the online survey, along with easy read versions. However, due to unforeseen circumstances, HWS were not able to receive the feedback from the paper copies in time to share with HWE in May 2022.

However, HWS have been able to use people's feedback to understand how the AIS is working on a local level, specifically, how people with a learning disability and their family, carers and support staff, experience receiving health information from health and care services. This has enabled us to identify the disadvantage that those covered by the AIS experience (in comparison to those who aren't covered by the AIS) in accessing health and care services/information. The importance of family members, carers, and support staff in helping people to access and understand

information, and to communicate with health and care services, has been highlighted.

We heard from twenty-four people. Fifteen people told us that they require communication support to understand their health and care and would therefore be covered by the AIS. Nine people told us that they don't require support to understand their health and care, and would therefore not be covered by the AIS, at the time.

The specific conditions impacting on people's ability to understand health and care information include a learning disability (14 people), hearing loss (4 people), a mental health condition (1 person), and other health conditions not specified (1 person).

SURVEY FINDINGS

Q1. How would you describe your ability to understand any information about your healthcare you are given by services? Examples of healthcare information could include appointment letters, face-to-face consultation, leaflets, or information on a website.

Six people told us that they can understand it all with support from family members, carers, and support staff. Six people told us that they can understand some of it with support from family, carers, and support staff. Three people told us that they don't understand any of it. Nine people not covered by the AIS told us that they can understand all of it.

Q2. When using health and care services, have you ever asked for support to help you understand health or care information that you've received?

Six people have asked for support. Five people haven't asked for help and support; in addition to the support they receive from family, carers, and support staff. Four people don't know if they've asked for help and support.

Q3. When using health and care services, have you ever asked for support to help you contact health or care services?

Seven people told us that they have asked for support. Four people told us that they haven't asked for support, however they receive support from family, carers, and support staff. Four people don't know if they've asked for help.

Q4. When using health and care services, have you ever asked for support to help you communicate with healthcare staff/services?

Eight people have said that they have asked for support to help communicate with health care staff/services. Four people haven't asked for support to communicate; however, they already receive support from family, carers, and support staff. Three people don't know if they've asked for support.

Q5. How would you describe your attempts to get support from health and care services with understanding information, contacting services, or communicating with staff?

Ten people said that they don't need any additional support, in addition to the support that they're already receiving, as they feel that they already get the support that they need.

One person said that they sometimes get the support they need, and three people told us that they didn't know.

Q6. Have you ever been refused health care information in a format and/or language you needed, even though you asked for it?

Eight people said that they have not been refused health care information when they have asked for it, and six people said that they didn't know.

Q7. Have you ever been refused a request for support to understand health care information that you have been given, even though you asked for it?

Two people have told us that they have been refused a request for support to understand information, when they have asked. Seven people have told us that they haven't been refused, and five people have told us that they don't know if they've been refused.

Q8. What was the impact of not being provided with health care information you could understand or access?

Five people were unsure if they had any previous difficulties in access health care information that they could understand due to receiving support from parents/carers/support staff and were therefore unsure of any impact that this may have had on them, if any.

Three people have told us that not being provided with health care information that they could understand or access, has led to missed appointments, not being able to contact the service that was needed, not being able to understand how to take their medication/taking the wrong dose of medication, missing out on important information about their health, and that this had affected their mental health and wellbeing.

With reference to the HWS Bee Happy: Our Health and Wellbeing Report, an additional person told us that they found waiting for their appointment *'stressful'* and that they *'don't understand what's been talked about'* when they are at the appointment.

Q9. Which, if any, health, or care services have you struggled to access as a result of communication problems?

As a result of communication problems, people have told us that they have had difficulties in access GP services (5 people), Dentists (4 people), Hospital appointments and treatment (2 people), NHS 111 (2 people), COVID -19 vaccinations (2 people), social care (1 person), A&E (1 person).

Q10. How do you feel about asking health or care services to provide information in a way that you can easily understand?

Four people have told us that with help from parents, carers, and support staff, they feel very comfortable in asking. Four people have said that they feel somewhat comfortable in asking, and one person said that they feel a bit uncomfortable in asking. Five people have said they don't know if they would feel comfortable.

Four people who aren't covered by the AIS have stated that they don't know if they would feel comfortable, or they would feel somewhat, or a bit uncomfortable in asking for information in a way that can be easily understood.

Q11. Which of the following affect your ability to ask health services to provide information or communicate with you in a way that you can easily understand?

The most stated reasons include:

- The amount of support received from family, carers, and support staff (7 people)
- My level of confidence (4 people)
- Whether the information is readily available in the right format for my needs (4 people)
- The attitude of staff (1 people)
- My ability to communicate (4 people)
- My previous experience (1 people)

Four people who aren't covered by AIS told us that the attitude of staff and the level of confidence would affect their ability to ask for information if they needed to.

Q12. Do you know how to complain if you are not given information in the format or language you need or support to understand information?

Five people have told us that they would receive support from their parents/carers to make a complaint. Eleven people have stated they would, either, not know how to make a complaint, or they are unsure if they would know how to make a complaint. Four of these people aren't covered by the AIS.

Q13. What changes have you noticed about the way in which health and care services communicate with you since the COVID-19 pandemic started?

Six people have told us that they have either noticed a big improvement, or some improvement in the way health and care services communicate with them - two of these people aren't covered by the AIS. Five people have said that there have been no changes in the way health and care services communicate with them - three people aren't covered by the AIS. Seven people have said that they've noticed that the way health and social care services communicate with them has either got slightly worse or a lot worse - two of these people aren't covered by the AIS. Four people answered that they didn't know.

Main Findings

The importance of receiving help from family members, carers, and support staff to access and understand health information.

The findings highlight the importance, for those covered by the AIS, of receiving some level of support from family, carers, and support staff to access and understand information, and to communicate with health and care services. The amount of support that people receive from family, carers and support staff has been stated as the main factor that could affect people's ability to ask health services to provide information or communicate with them in a way that can be easily understood, when needed.

Inequalities in accessing health and care for those who are covered by the Accessible Information Standard.

Those who are covered by the AIS are between two-three times more likely to have been refused a request for support to understand health care information when they have asked, and to have not been provided with health care information that they could understand or access. It's important to those who require communication support, that they are made to feel comfortable in asking for information from health and care services in a way that can be easily understood.

The findings show that people who are covered by the AIS experience disadvantage in accessing health and care information when needed, and that this has an impact on the quality of care that they've received. This includes missing appointments, not being able to contact the service that was needed, not being able to understand how to take medication, taking the wrong dose of medication, missing out on important information about their health, and that their mental health and wellbeing has been affected because of this.

Those who are covered by the AIS are more likely than those who aren't, to experience difficulties in being able to access health and care services - particularly GP services and dentists, because of communication problems.

Overall, people who aren't covered by the AIS have reported to have experienced no changes in the way health and care services have communicated with them since the pandemic. However, those who are covered by the AIS, have reported to have experienced it as slightly worse. This concurs with Healthwatch England (2022) 'Your Care, Your Way' campaign and national survey findings, whereby HWE respondents covered by the AIS, reported that the quality of communication from NHS and social care services had worsened over the last two years. Healthwatch England (2022) have stated that health and care services are failing in their legal duty to provide

accessible information for people with physical and learning disabilities, and for people who are affected by communications challenges and require support.

Recommendations:

For full responses from service providers and commissioners, please see links below.

Stockton-on-Tees Borough Council - no response

NHS North East & North Cumbria Integrated Care Board -

<https://www.healthwatchstocktontees.co.uk/response-nhs-nenc-icb-hws-accessible-information-standards-health-and-care-report-2022>

Tees Esk and Wear Valleys NHS Trust -

<https://www.healthwatchstocktontees.co.uk/response-tewv-hws-accessible-information-standards-health-and-care-report-2022>

North Tees and Hartlepool NHS Foundation Trust -

<https://www.healthwatchstocktontees.co.uk/response-north-tees-hartlepool-nhs-foundation-trust-hws-accessible-information-standards-health-and>

| Recommendation number: | Recommendation | Responsible Body | Comments |
|------------------------|---|--|----------|
| 1. | Health and care services to be accountable for delivering the Accessible Information Standard. | Stockton-on Tees Borough Council NHS North East and North Cumbria Integrated Care Board Tees Esk and Wear Valleys NHS Trust North Tees and Hartlepool NHS Foundation Trust. | |
| 2. | Every health and care service to have an accessibility champion so that health and social care staff know who is responsible for leading local accessible | Stockton-on Tees Borough Council NHS North East and North Cumbria Integrated Care Board | |

| | | | |
|----|---|---|--|
| | information policy and delivery, and to support staff awareness of their compliance with the standard. | <p>Tees Esk and Wear Valleys NHS Trust</p> <p>North Tees and Hartlepool NHS Foundation Trust.</p> | |
| 3. | To involve people with communication needs in designing better services. | <p>Stockton-on Tees Borough Council</p> <p>NHS North East and North Cumbria Integrated Care Board</p> <p>Tees Esk and Wear Valleys NHS Trust</p> <p>North Tees and Hartlepool NHS Foundation Trust.</p> | |
| 4. | To provide mandatory training on accessible information for all health and care staff - to enable staff to understand the standard and regularly provide information in the formats patients need, and to proactively ask patients about their communication needs. | <p>Stockton-on Tees Borough Council</p> <p>NHS North East and North Cumbria Integrated Care Board</p> <p>Tees Esk and Wear Valleys NHS Trust</p> <p>North Tees and Hartlepool NHS Foundation Trust.</p> | |

Appendix:

NHS England. Accessible Information Standard - Summary.

The Accessible Information Standard aims to make sure that people who have a disability, impairment or sensory loss get information that they can access and understand, and any communication support that they need from health and care services.

The Standard tells organisations how they should make sure that patients and service users, and their carers and parents, can access and understand the information they are given. This includes making sure that people get information in accessible formats.

The Standard also tells organisations how they should make sure that people get support from a communication professional if they need it, and about changing working practices to support effective communication.

By law ([section 250 of the Health and Social Care Act 2012](#)), all organisations that provide NHS care or adult social care must follow the Standard in full from 1st August 2016 onwards.

Organisations that commission NHS care and / or adult social care, for example Clinical Commissioning Groups (CCGs), must also support implementation of the Standard by provider organisations.

What does the Standard tell organisations to do?

As part of the Accessible Information Standard, organisations that provide NHS care or adult social care must do five things. They must:

1. Ask people if they have any information or communication needs and find out how to meet their needs.
2. Record those needs clearly and in a set way.
3. Highlight or flag the person's file or notes so it is clear that they have information or communication needs and how to meet those needs.

4. Share information about people's information and communication needs with other providers of NHS and adult social care, when they have consent or permission to do so.
5. Take steps to ensure that people receive information which they can access and understand and receive communication support if they need it.

What does the Standard include?

The Standard says that patients, service users, carers and parents with a disability, impairment or sensory loss should:

- Be able to contact, and be contacted by, services in accessible ways, for example via email or text message.
- Receive information and correspondence in formats they can read and understand, for example in audio, braille, easy read or large print.
- Be supported by a communication professional at appointments if this is needed to support conversation, for example a British Sign Language interpreter.
- Get support from health and care staff and organisations to communicate, for example to lip-read or use a hearing aid.

More information

There is more information about the Accessible Information Standard [on the NHS England website](https://www.england.nhs.uk/accessibleinfo) at www.england.nhs.uk/accessibleinfo

For more information, please email NHS England at england.nhs.participation@nhs.net or telephone 0300 311 22 33.

Or you can write to:

Accessible Information Standard
NHS England
7E56
Quarry House
Quarry Hill
Leeds
LS2 7UE