

Accessible Information

May 2024



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Background and Scope

Healthwatch Bracknell Forest, whilst attending a local sensory needs support group, heard about some individuals not receiving the communication needs they had from health providers and the impact on them.

Everyone should be able to make informed decisions about their health and care. All communications, information and digital tools should be accessible with the option to personalise. Under the [Equality Act 2010](#) it is illegal to discriminate on the basis of disability

In 2016 the [Accessible Information Standard](#) was introduced to give disabled people and people with sensory loss the legal right to receive information from the NHS and local adult social care in a format they choose, so they can understand information and can access communications support if needed.

Healthwatch in East Berkshire (Healthwatch Windsor, Ascot and Maidenhead, Healthwatch Slough and Healthwatch Bracknell Forest) undertook a piece of work to find out if the standard is being delivered as it should be to those residents in East Berkshire who need accessible information.

This report was originally published in 2023. However we received additional substantive information from a deaf resident about failings in the provision of accessible information. We therefore decided not to circulate the report until we had worked with the resident to understand and record their experiences. This can be found at the end of the report in the form of a Patient Story.

This report details the results of this work, providing evidence for continuing investigation around this topic.

Summary

Primarily we spoke to people in Bracknell Forest, although we did speak to a handful of people in Slough and Windsor, Ascot, Maidenhead, generally it was more difficult to find support groups in those two areas. Although our work did not return high numbers, the general aim was to speak to concentrated group of people, at support groups, with similar sensory or learning disability needs. In doing this we sought to get a feel for the delivery of the Accessible Information Standard. The results do appear to provide evidence of inconsistencies within some services and across services.

Highlights from the results:

- Many people said face-to-face interaction helps to make information accessible/helps with communication.
- Some people said no services asked them what their information needs were.
- Some people said they had not told services about their information needs, primarily because they don't know what they are entitled to or have a difficulty asking.
- Even if information was provided, many people still said they did not get what they needed.
- The impact of not getting accessible information affects physical and mental well-being as well as prevents people from accessing services and clearly understanding and communicating with them.
- Many people rely on family and friends to communicate with services on their behalf.
- Many people are unsure what they are entitled to in terms of accessible information.
- There is little information in health settings about the Accessible Information Standard and peoples right under the standard.
- Many people do not know how to complain if they are not given the accessible information they need.

Recommendations

- Frimley ICB to run an awareness campaign about the accessible information standard. To include visible posters in all health settings explaining the Accessible Information Standard and what patients rights are under the standard. Posters should also be provided in large print, easy read. Digital information should include BSL signed, include subtitles and audio versions of information should be included.
- We could not find any information about the accessible information standard on the Frimley Health Foundation Trust website. If it is on the website it is not easy to find. Accessible Information standard to be included on the website which is prominent and easy to find.
- To ensure everyone who has a communication need is identified, every time NHS and social care staff have contact with a service user, they should always ask the service user “do you have any communication needs that requires us to make adjustments for you”. If adjustments are required, record these on the reasonable adjustments digital flag.
- A clear complaints procedure relating to accessible information needs to be communicated to all those who require accessible information. This could be included on the posters that explain the accessible information standard and patients rights.

Methodology

We developed a survey, which we presented and discussed with, individuals found during our engagement work and also in some focus groups of people across the region which identified with the below characteristics.

- People with Learning disabilities.
- People with sight impairment.
- People with hearing impairment.

Our discussions took place primarily in support group sessions or with individuals, based on people's communications needs.

Findings

Number of completed responses received:

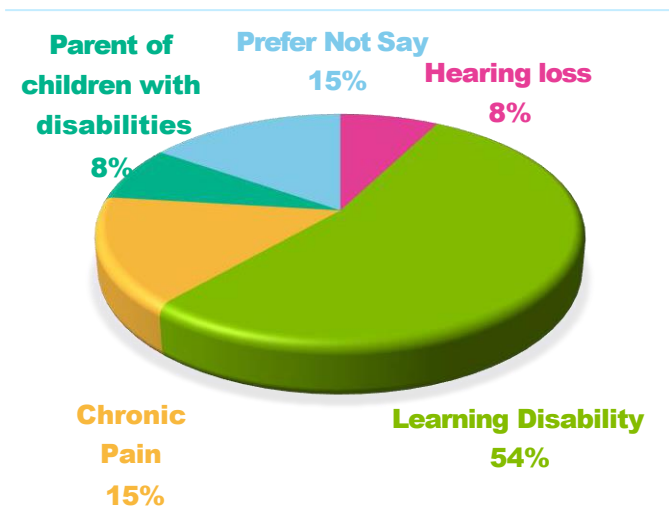
Healthwatch Slough = 8

Healthwatch Windsor, Ascot & Maidenhead = 13

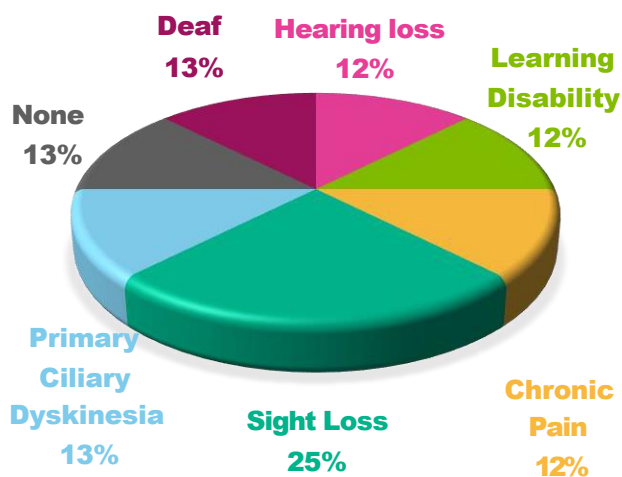
Healthwatch Bracknell Forest = 31

1) Which of the following applies to you:

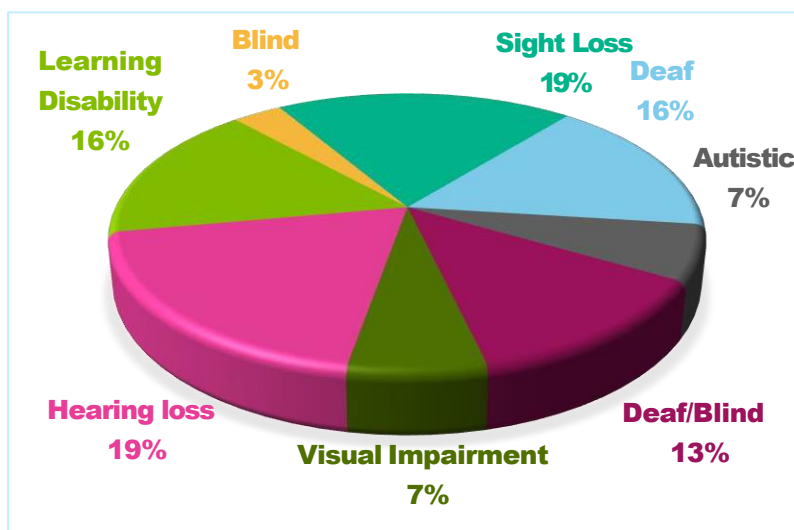
Healthwatch Windsor, Ascot & Maidenhead



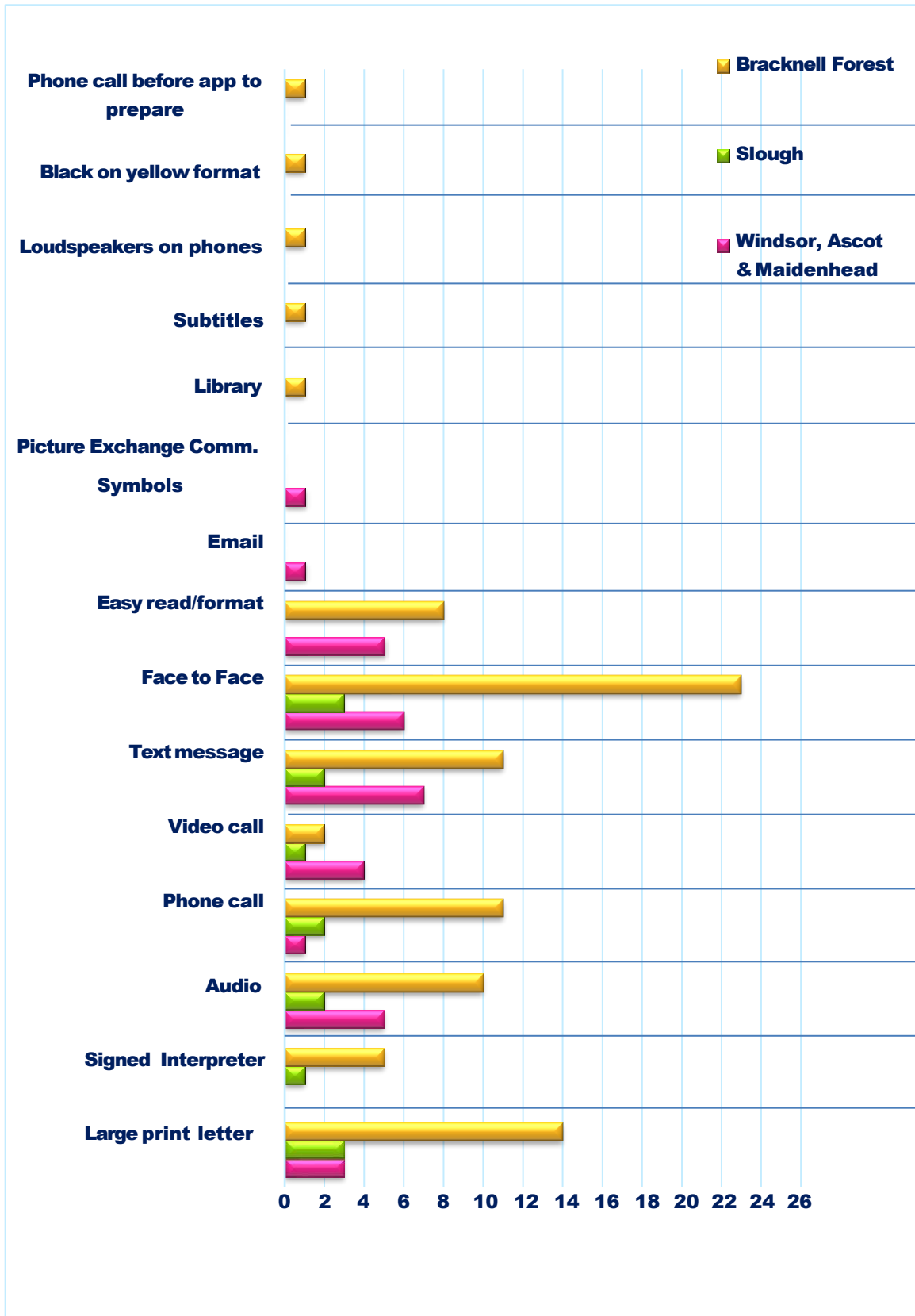
Healthwatch Slough



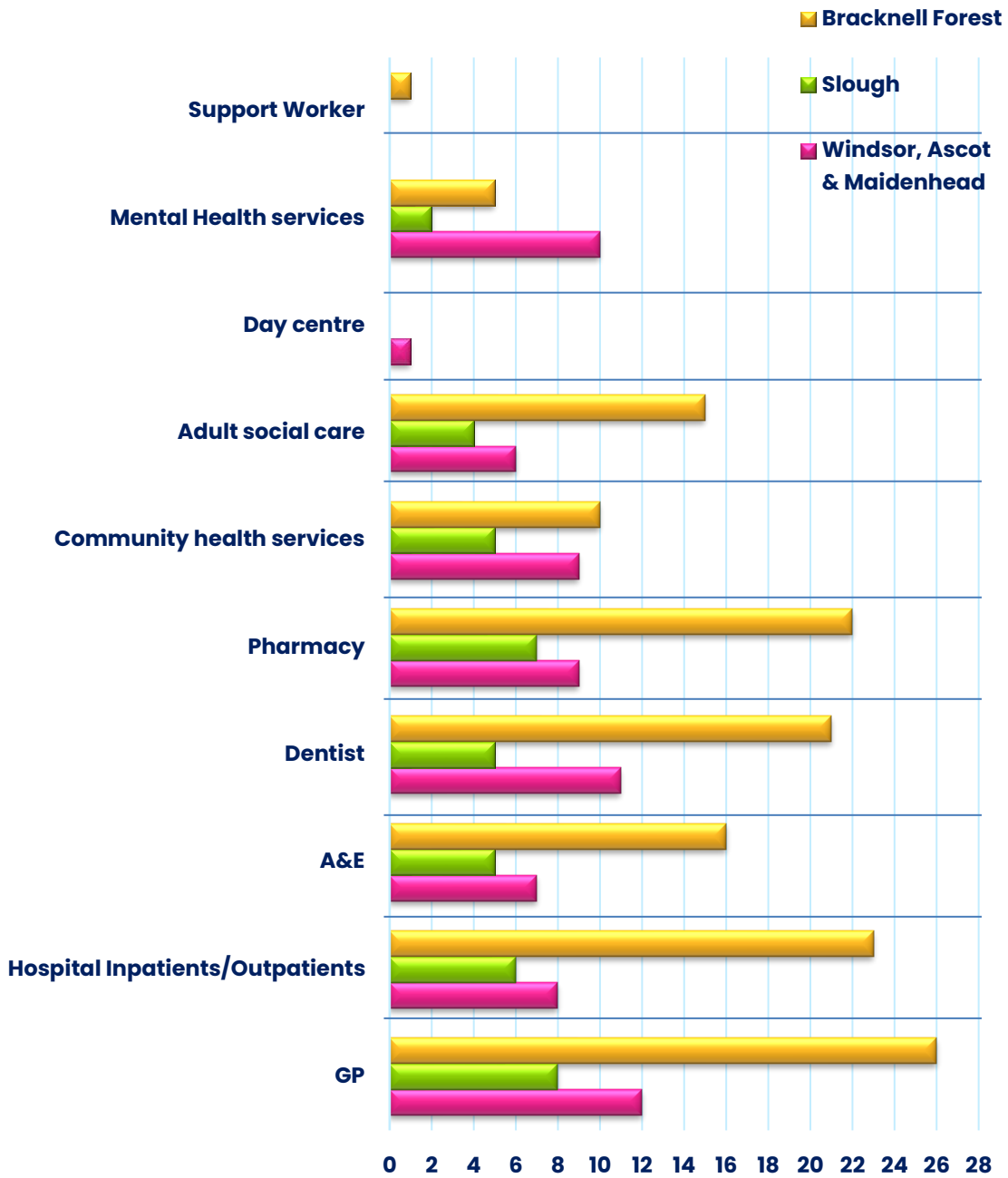
Healthwatch Bracknell Forest



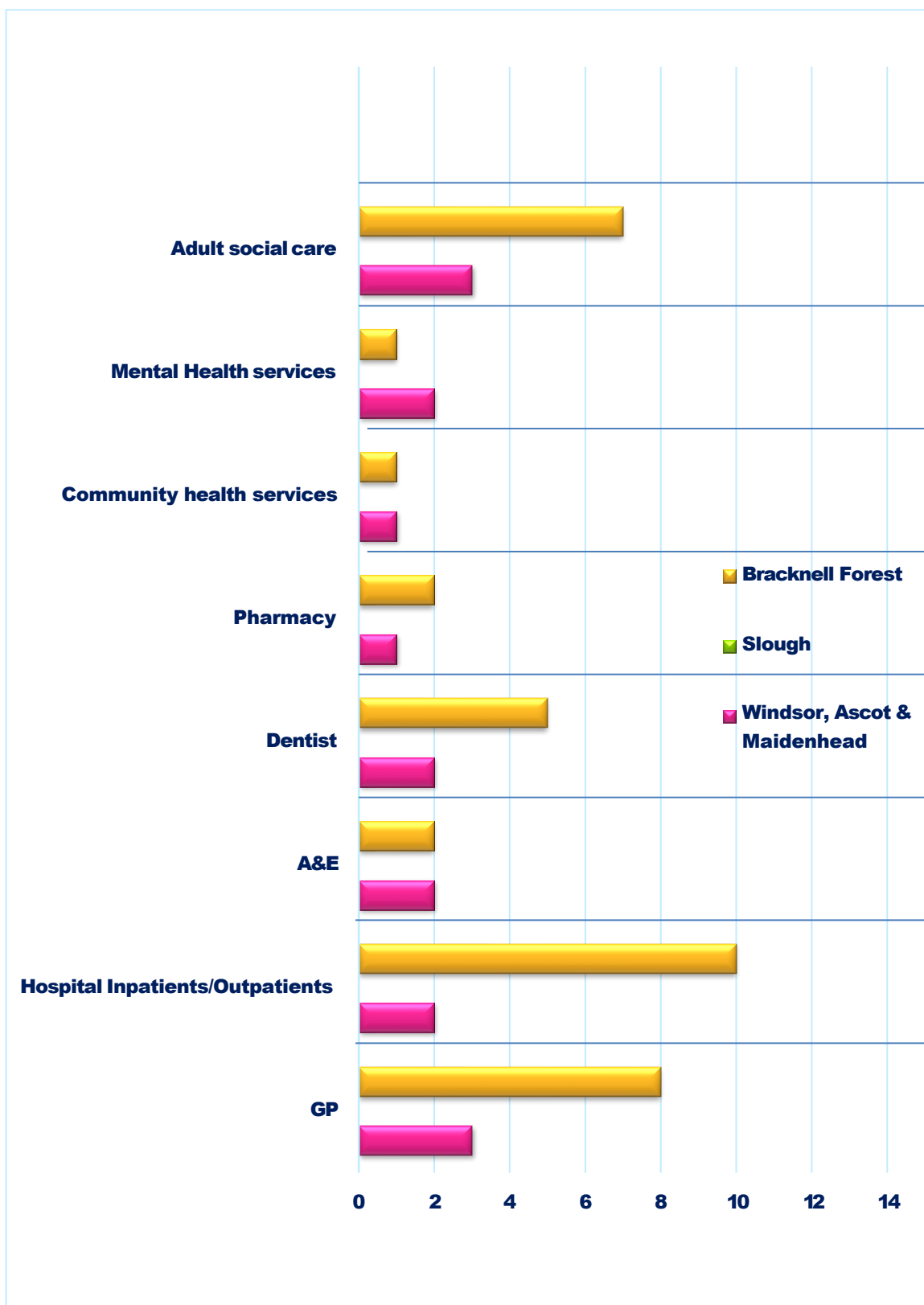
2) Which of the following helps to make information accessible to you and/or helps with communication (choose all that apply).



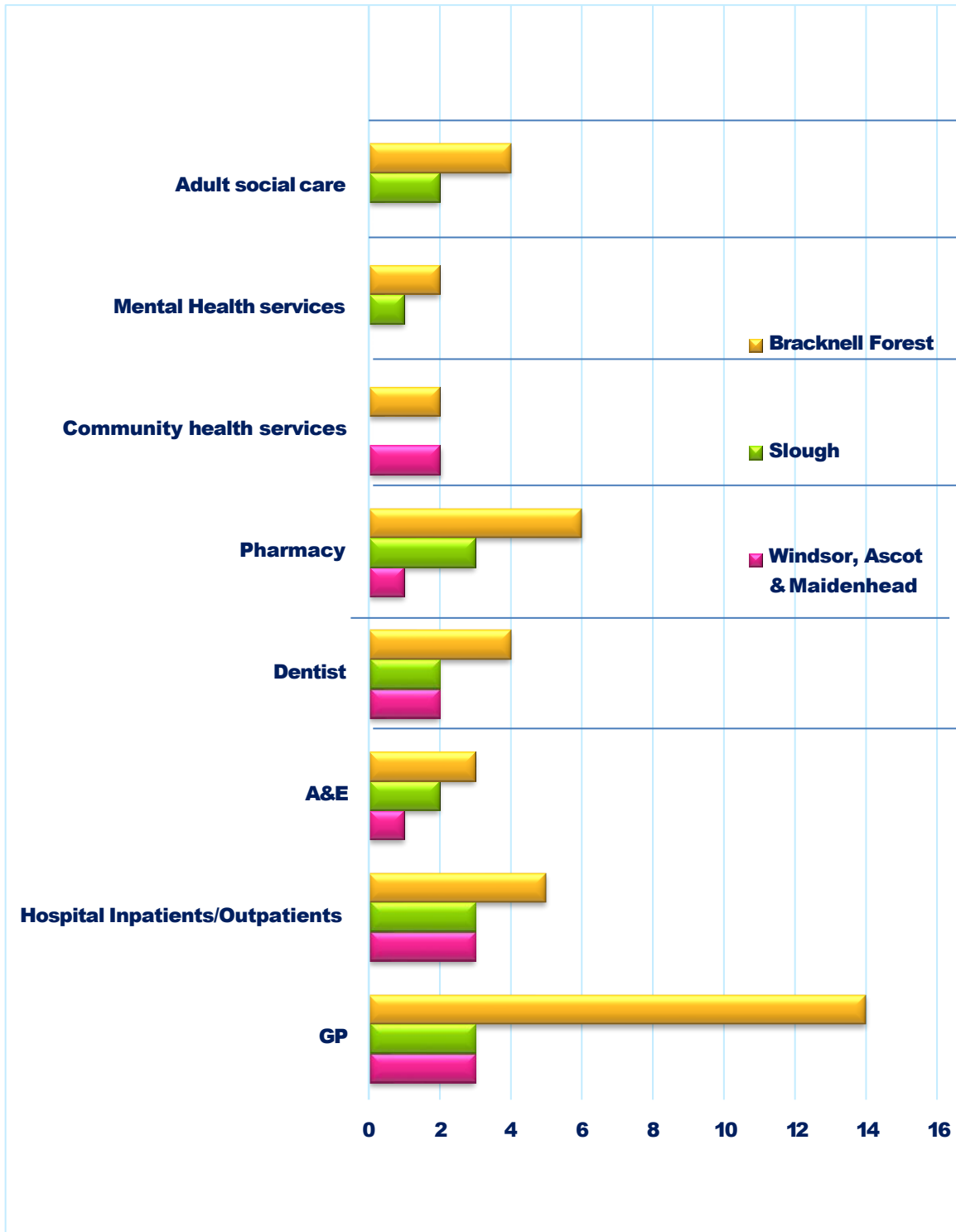
3) Which of these services have you used? (choose all that apply).



4) Have any of these services asked you what your accessible information needs are? (Choose all that apply).



5) If services haven't asked you what you need, have you told any of them what your accessible information/communication needs are? (Choose all that apply).



Comments received for Question 5:

"There is great resistance to provide signed services interpreters due to associated costs."

75-84 Male with hearing loss (HW Bracknell Forest).

"I haven't so much been refused as much as they just don't seem to bother."

55-64 deaf male (HW Bracknell Forest).

"Hospital outpatient regarding masks, very difficult as I lip read."

75-84 female with hearing loss (HW Bracknell Forest).

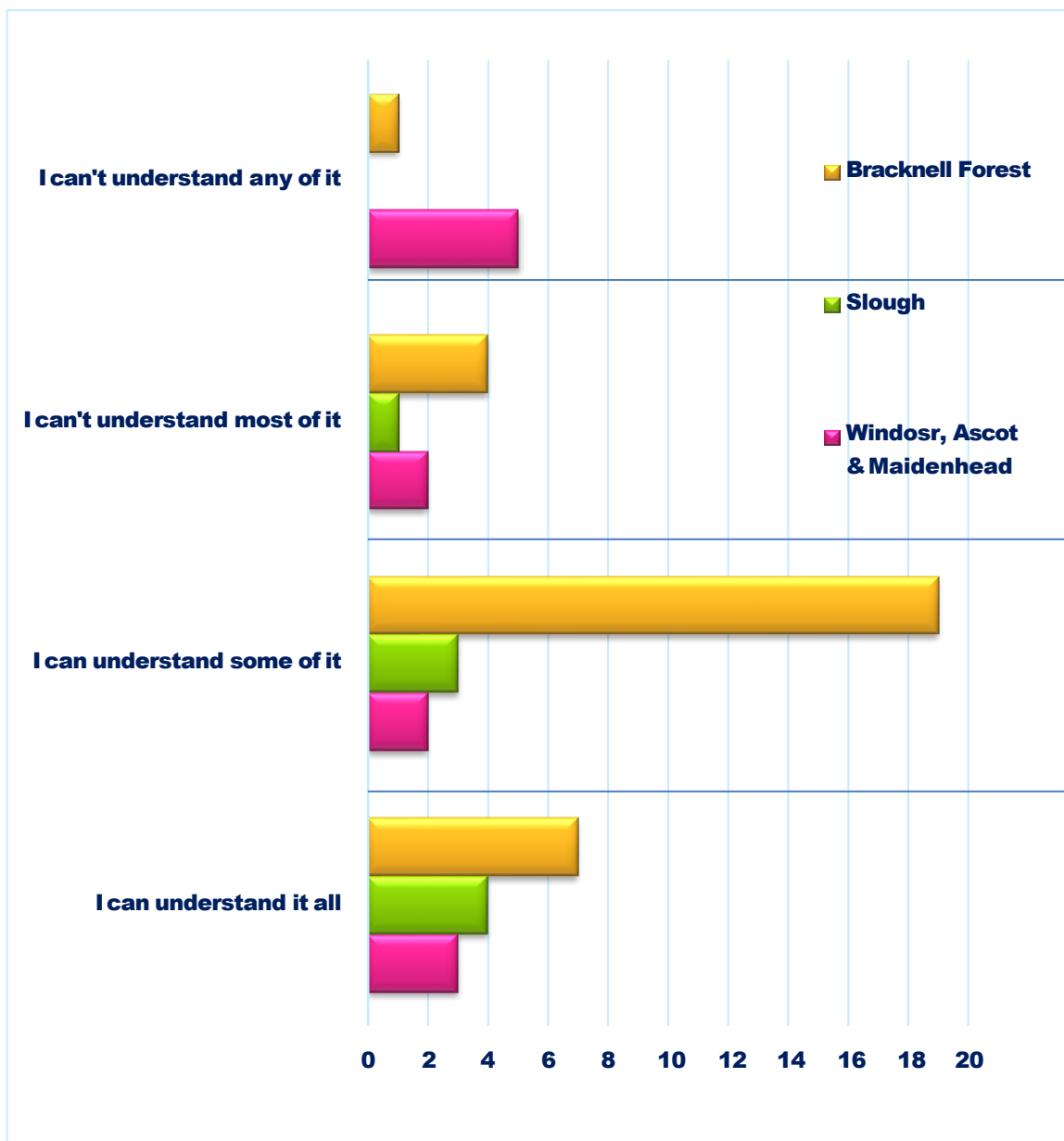
"Adult Social Services would not help me."

Over 80 deaf/blind female (HW Bracknell Forest).

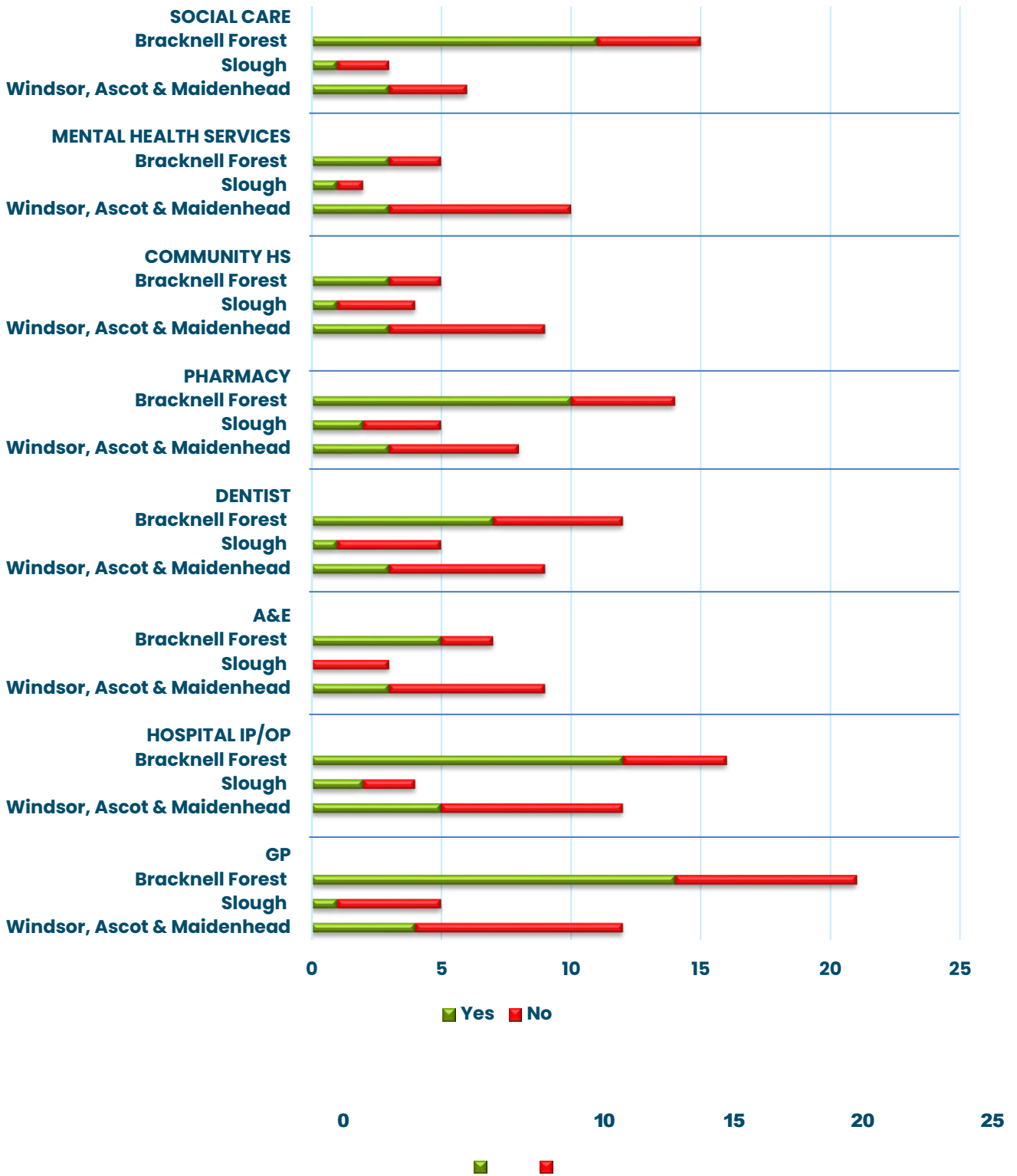
"Pharmacy, they could not enlarge print and made it very hard to read medication, so my daughter has to do this for me."

Over 80 female with sight loss (HW Bracknell Forest).

6) How would you describe your ability to understand information given to you by NHS services or local social care if it isn't given to you in an accessible format.



7) If services asked you what your accessible information needs are, or, if you told services what your needs were, did you get what you needed? (Choose all that apply).



Comments:

"All face-to-face communication is difficult, as are telephone conversations."
Over 80 male with hearing loss (HW Bracknell Forest).

"Unable to make appointment on phone also difficult in person."
75-84 female with hearing loss (HW Bracknell Forest).

"Can never get through or have a face-to-face appointment."
55-64 male with sight loss (HW Bracknell Forest).

"My family has to help me if I get information in a way I can't understand myself".

Comment received from 2 people with Learning Disabilities, one male and one female, both 25-34 (HW Bracknell Forest).

8) What was the impact on you when services didn't provide you with your accessible information and/or communication needs? (Choose all that apply).

Response	No. of Responses		
	Windsor, Ascot & Maidenhead	Slough	Bracknell Forest
Didn't affect me at all	3	3	5
I had to get a family member or friend to speak to the service provider	6	2	12
It affected my mental health	2	1	6
It affected my physical wellbeing	0	1	1
I couldn't understand important information I received about my health	1	1	4
I missed health or social care appointments	1	0	2
I couldn't contact the service that I needed	1	3	14
I couldn't clearly understand or clearly communicate with health or social care staff	5	1	7
I couldn't understand important information about my medication	1	1	1
I took the wrong dose of my medication	0	0	2

Comments Received for Question 8:

"I ended up having a severe infection which had a knock-on effect and caused other health problems. My mother had to constantly call and try to get the medical support I needed."

18-24 female with hearing loss (Healthwatch Windsor, Ascot & Maidenhead).

Like many of us it's not possible to get urgent help if you have a communication problem."

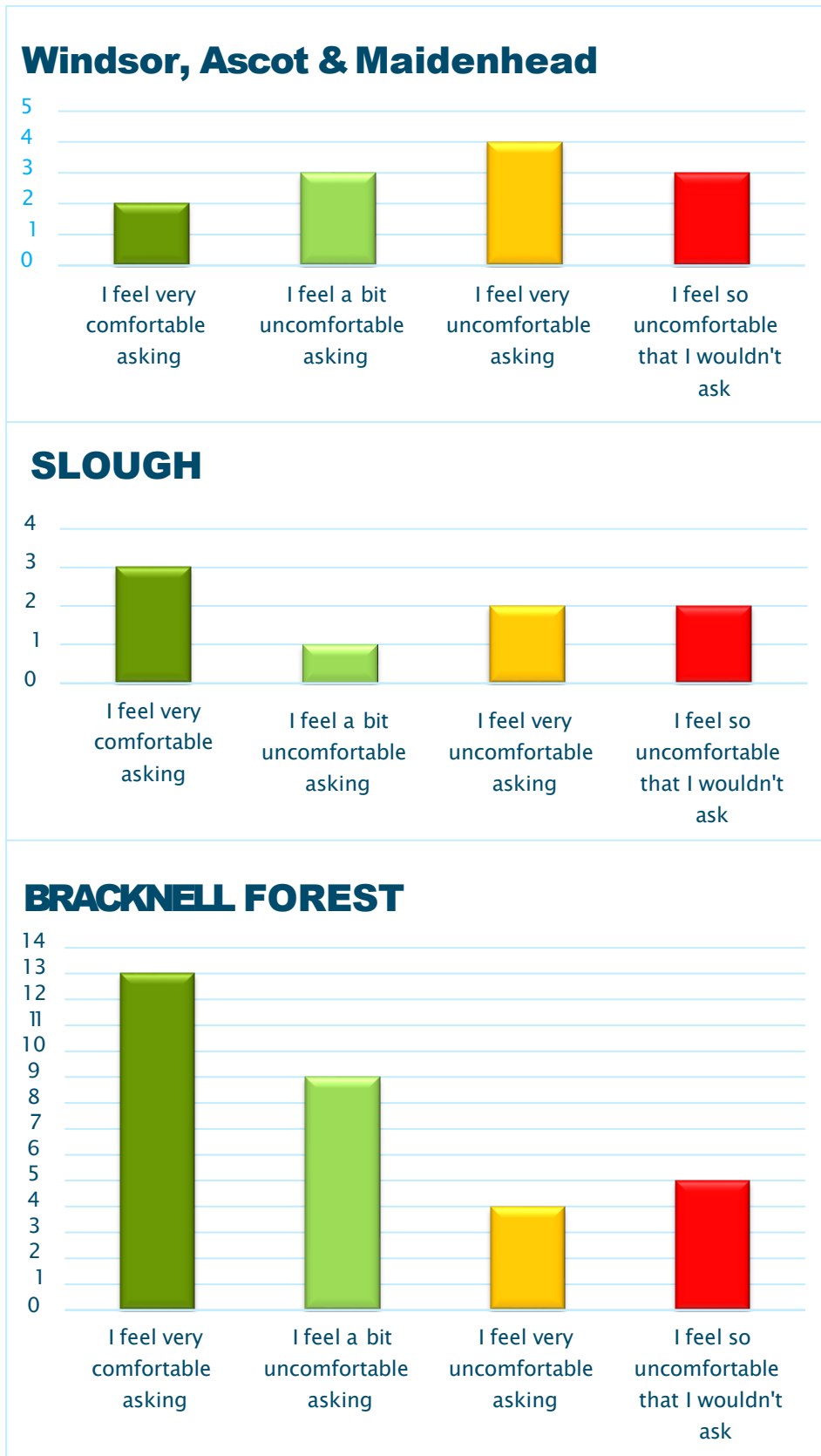
65-74 female with chronic fatigues (Healthwatch Slough).

"As is the usual circumstance deaf people give up and don't bother."
55-64 deaf male (Healthwatch Bracknell Forest).

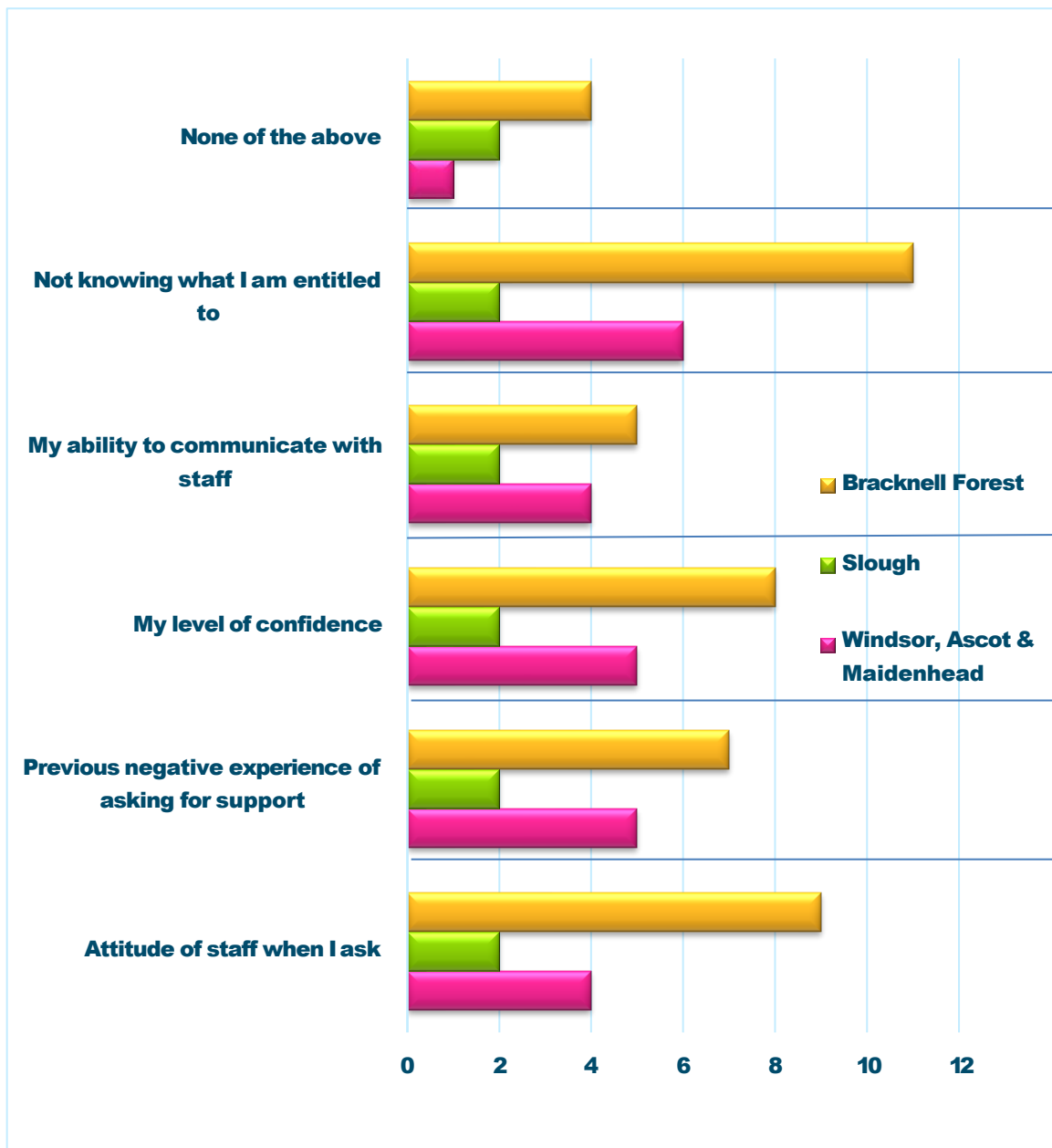
"Had a big heart attack and aftercare offered afterwards was difficult for me to understand it all because of my sight and communication need."
85+ female with sight loss (Healthwatch Bracknell Forest).

"I doubled up my blood pressure pills as was not sure about the amounts as I didn't understand the information"
55-64 male with learning disability (Healthwatch Bracknell Forest).

9) How do you feel about asking health or care services to provide you with your accessible information and/or communication needs?



10) Which of the following affect your ability to ask health or social care services to provide you with your accessible information and/or communication needs?



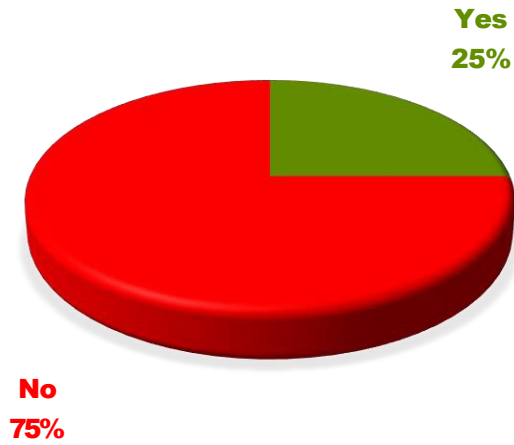
Comments Received for Question 12:

“No one ever listens so why bother, or they listen and do nothing.”
75–84 female with sight loss (Healthwatch Bracknell Forest)

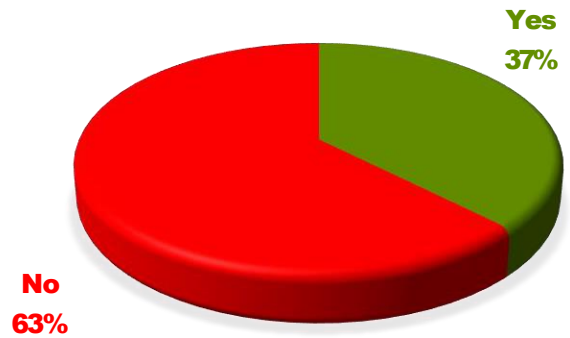
“I like to be independent and feel I can cope mainly. Family are busy so prefer not to ask.”
Over 80 female with sight loss (Healthwatch Bracknell Forest).

11) Do you know how to complain if you are not given your accessible information and/or communication needs?

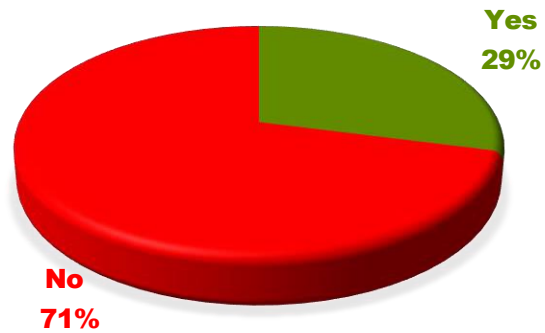
Healthwatch Windsor, Ascot & Maidenhead



Healthwatch Slough



Healthwatch Bracknell Forest



Demographics:

Age	Number of Responses			
	Windsor, Ascot & Maidenhead	Slough	Bracknell Forest	TOTAL
18-24	3	1	2	6
25-34	1	1	2	4
35-44	3	1	1	5
45-54	4	2	1	7
55-64	1	1	6	8
65-74	0	2	2	4
75-80	0	0	8	8
Over 80	0	0	9	9
Prefer not to say	1	0	0	1

Gender	Number of Responses			
	Windsor, Ascot & Maidenhead	Slough	Bracknell Forest	TOTAL
Female	8	7	16	31
Male	3	1	14	18
Prefer not to say	2	0	1	3

Ethnicity	Number of Responses			
	Windsor, Ascot & Maidenhead	Slough	Bracknell Forest	TOTAL
White British	7	2	26	35
Asian/Asian British: Pakistani	2	2	0	4
White Other	1	2	1	4
Asian/Asian British: Indian	0	1	2	3
White Irish	0	1	1	2
Black/Black British: Caribbean	1	0	0	1
Any Other Mixed/Multiple Ethnic	1	0	1	2
Prefer not to say	1	0	0	1

Patient Story

For the purposes of this case study and to protect confidentiality we shall call the individuals concerned Sarah and Tom

Healthwatch Bracknell Forest were contacted late 2023 by Sarah, who is deaf, about her deaf partner Tom who lived in Bracknell. Sarah told us that Tom died in July. Tom had some underlying health problems and was under 50 years old. Tom had a heart attack in his mid 30s. Sarah told us Tom, like many other deaf people, had some mental health problems trying to live in a hearing world.

Sarah said that Tom did not receive the accessible information he needed in primary care, secondary care and urgent care.

“Tom got no access to BSL interpreter, no access to easy read information, no access to receive mobile phone text/emails”.

Sarah explained this issue applied during treatment in primary care, Frimley Park hospital, Heatherwood hospital, Wexham Park hospital and Bracknell Urgent Care.

Sarah told us that the GP practice would phone Tom, but he is deaf so can't hear what they are saying.

“Tom went to see his GP. He explained to his GP that he was Deaf, he pointed to his mobile phone to say, 'I can read'. He described in British sign language and had gestures (pointing to his ears) to say, "I am Deaf”.

Sarah mentioned that Tom's GP wanted to put her name down as Tom's interpreter, but she told the GP that she wasn't an interpreter and that she too was deaf.

Sarah told us that in one hospital visit Tom was told that he had one stent, that's what Tom thought he was told, when in fact Tom had two stents. Sarah told us that mis understandings like this had happened numerous times and that these misunderstandings would have been avoided if Tom had a BSL interpreter at hospital visits and would have improved his care.

Sarah explained that Tom went to hospital as he was worried about his heart. They did the ECGs but there was no BSL interpreter to explain everything to Tom.

“There should be a flag on his GP and Hospital records to ensure they meet his communication needs with BSL, it just never happened”

Sarah told us Tom went to Bracknell Urgent Care Centre as he had pains in his stomach, his right leg, his foot. No provision for Tom's accessible information requirements were made.

"Why in primary care, three hospitals and Bracknell Urgent Care no one had asked Tom if he needs BSL interpreter. Tom was high risk because he had heart conditions, DVT and was Deaf. Why was there no posters about the Accessible Information Standard in GP surgeries, hospitals, urgent care, explaining what it is and your rights?"

Sarah explained that she felt Tom had been neglected by the NHS who had a duty of care for him and were supposed to look after his well-being, his mental health as Deaf person and provide him with accessible information. Sarah feels Tom wasn't heard and this affected his care.

Sarah told us that Tom went to hospital as he was feeling very unwell and was in a lot of pain. There was no one to interpret what was happening. Sarah went to the hospital and was told by nurses that Tom was dying because his liver and kidneys were failing. The nurses could only communicate what was happening with some words written on a piece of paper.

Sarah explained that they had to withdraw the treatments for his kidney/liver and they switched Tom's life support machine off.

"I tried to communicate with the nurse and ask where they were going to take Tom's body. I had not had to deal with this before so I didn't know what would happen and with no access to a BSL interpreter it made it very difficult for me. It destroyed my goodbye to my partner. It left me with no closure. Would this happen to people who have hearing?"

Response – Frimley Health NHS Foundation Trust



The Trust is grateful for the Healthwatch report and the feedback from our service users.

The content of the report is in keeping with feedback we have received through other methods and supports the current improvement workstreams.

We want our patients to feel comfortable in requesting information in any format, and our staff to feel confident in delivering this.

The Trust is in the process of creating a new website, and the design phase will include exploring options for how our information will be accessible for people with varying communication needs. We have updated the current website to include information about the Accessible Information Standard.

The advances in our digital capability with the introduction of the Electronic Patient Record and the My FrimleyHealth Record app provide great opportunity for recording and flagging where adjustments are required. There has been work to raise awareness amongst staff on how to book BSL interpreters and we now have access to video BSL.

Patient information has been identified as a key area for improvement this year, with additional resource being dedicated to this. Ensuring compliance with the Accessible Information Standard will be part of this workstream.

Our Patient Advice and Liaison Service (PALS) continues to be a point of contact for patients if they have any concerns or require any assistance.

Response – NHS Frimley Integrated Care Board



NHS Frimley would like to thank Healthwatch East Berkshire for sharing their report on accessible information.

As a partner in the Frimley Health and Care Integrated Care System (ICS), we are committed to meaningful, consistent and timely involvement with local people and communities. Ensuring equality, diversity and inclusion is at the heart of thinking, planning and delivery.

Working in partnership with patients, carers, families and local people within their own communities brings a different perspective to our understanding and can challenge our view of how we think services are received and should be delivered in the future. To ensure we are capturing those views and providing the best services for all local people we must understand our community's needs, experience and aspirations for health and care, build relationships with excluded groups, especially those affected by inequalities and provide clear and accessible public information about vision, plans and progress.

NHS Frimley is currently in the process of redesigning the Frimley Health and Care website. This redesign has specifically highlighted accessibility as an area of focus and the design process will explore how best to ensure the content and materials available via the site are accessible for those with varying communication needs.

NHS Frimley run a wide range of communications campaigns throughout the year. Many of these campaigns have supporting resources and materials to support accessibility requirements. This includes the availability of materials in the most widely spoken languages across the Frimley geography, audio recordings and subtitled videos. It is not possible to create accessible materials for all content, reports and campaigns but focusing our limited resource on maintaining the most-used accessible content on our website and ensuring that new documents are accessible where they are required for essential services or used by people with disabilities is our priority.

NHS Frimley work closely with a wide range of health and care providers including primary, secondary and community care. We are committed to ensuring that we continue to raise awareness of the Accessible Information Standard and, as a result of this report, will share further information through our internal staff and stakeholder networks.



healthwatch

Healthwatch East Berkshire (HW Slough, HW Windsor, Ascot & Maidenhead and HW Bracknell Forest)

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