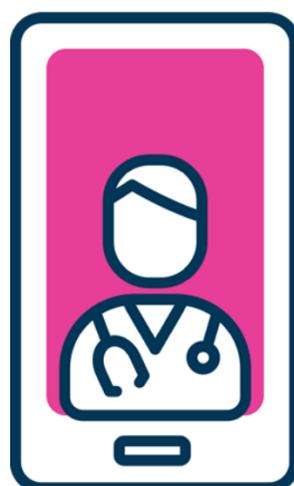




Because we all care

Voices of disabled
residents and Covid 19

North East London July 2021



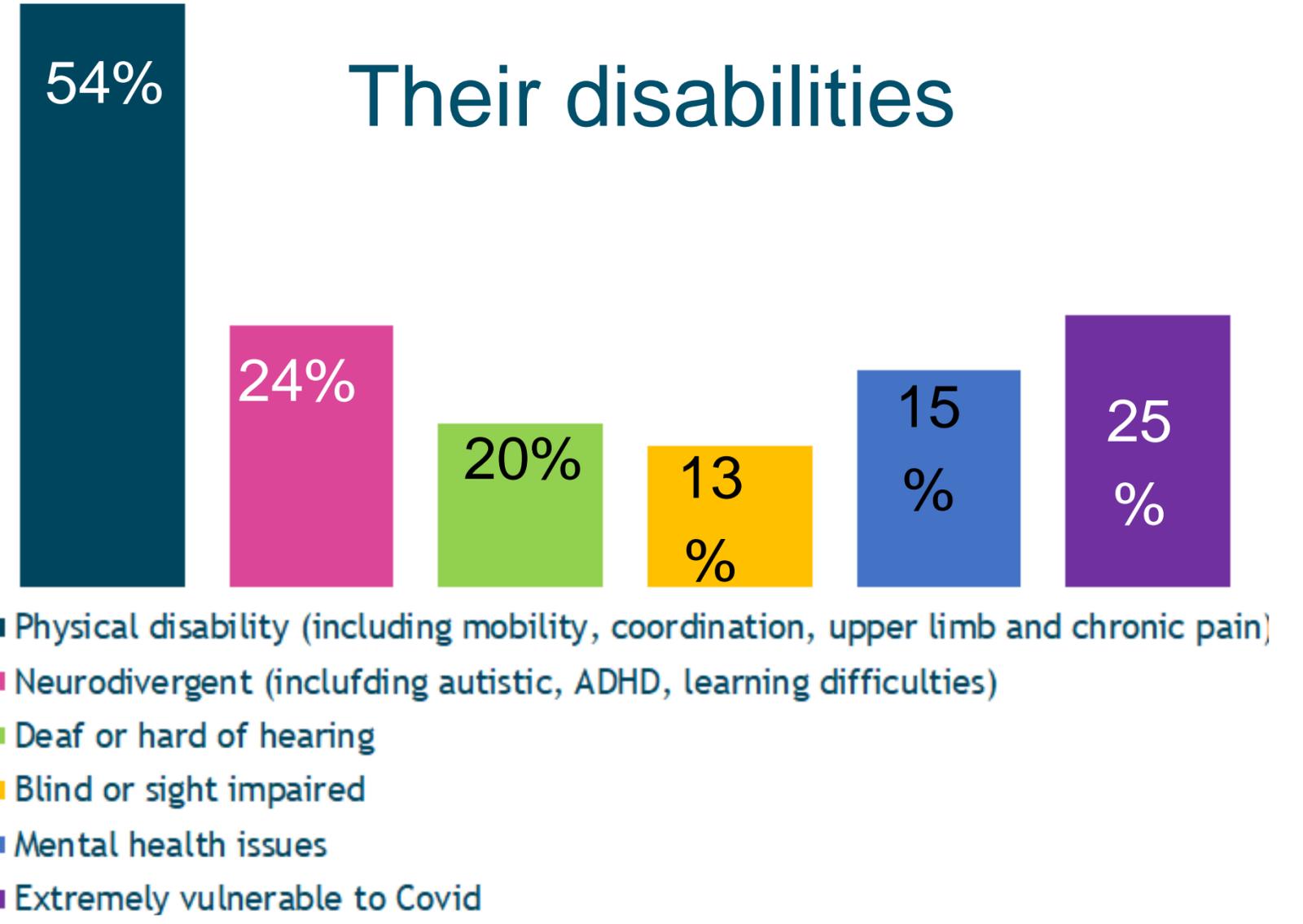
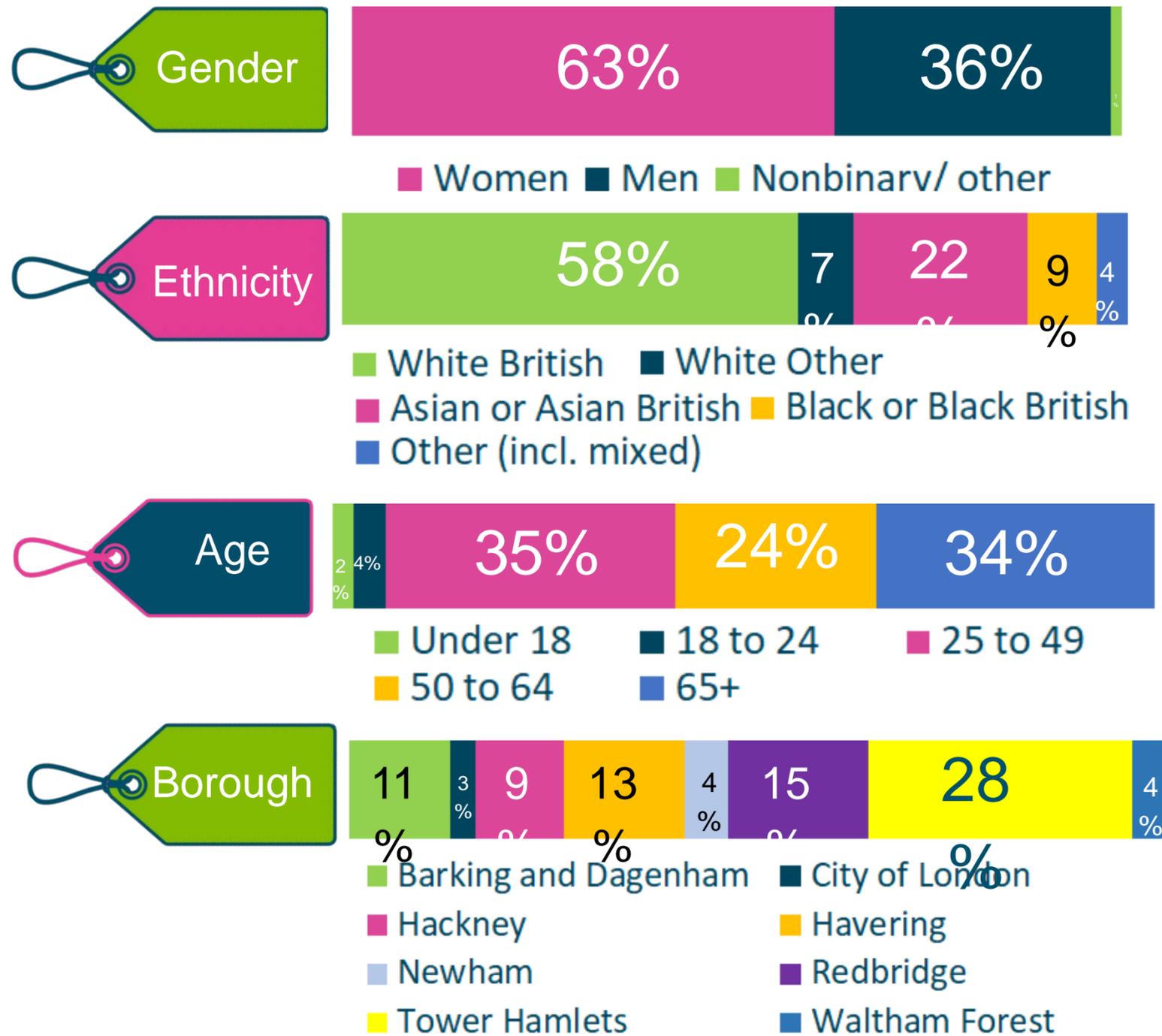
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An illustration of a large laptop computer. The screen displays the text "Voices of disabled residents Summary". On the laptop's keyboard, several people are shown: an elderly man with a cane on the left, a man with glasses sitting cross-legged in the center, a woman sitting on the floor to his right, and a man in a wheelchair on the right being assisted by a woman. On the laptop's bezel, three more people are shown: a woman on the left, a man in the center, and a man on the right. The background is blue with various white icons: speech bubbles, a pencil, a thumbs up, a thumbs down, a starburst, and clouds. A pink mouse cursor icon is also present.

Voices of disabled residents Summary

Who we engaged

We carried out a survey **580 residents** who were disabled or living with a serious long-term conditions



No "one size fits all" solution

Strategies that work well:

41%

used the internet to stay informed about Covid.



Clear, straightforward online and email information is useful for younger people, those who are economically active and for some autistic people; but less accessible for those with learning disabilities and from ethnic minorities (especially Black) communities.



32%

were digitally excluded



Easyread materials featuring graphic illustrations, large fonts and strong contrasts are useful not just for users with learning disabilities, but also for people with some sight impairments or neurological disorders, and for those who are not fluent in English, including Deaf BSL speakers.



15%

preferred information that does not involve the written word.



An easyread front page containing essential information could be added by default to all letters sent by the NHS or Government regarding health and social care.

Information which is not in writing could entail online videos, podcasts, radio broadcasts as well as outreach by telephone or in person. It would be more accessible to those who are sight impaired, have learning disabilities or who prefer oral communication for cultural reasons.



No "one size fits all" solution

GPs could play a crucial role in disseminating information.

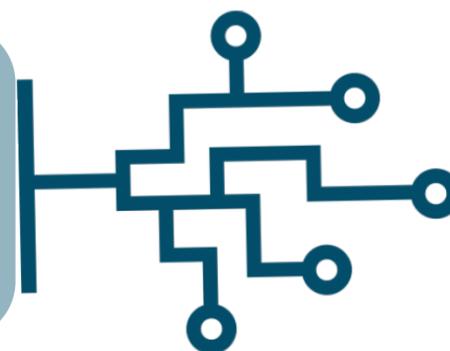
- They are already seen by most patients as a trusted authority when it comes to health and social care information.
- Through patient records, they have (or could obtain) specific information on each person's communication needs

Personalised outreach can make information more accessible

Collecting and recording data on each person's specific communication needs and offering different options (such as contact by phone, text or online video sent by email) would empower health and social care professionals to contact them in the way they prefer to be contacted, and to ensure accessibility.



Disabled people could communicate their contact preferences ONCE, through GP surgeries; and through integrated care systems these would be used across the NHS



What we learned

Access to health & care services

53%
experienced disruption
in their healthcare or
social care.

Services experiencing the most cancellations:

- Hospital outpatients
- Community services (such as chiropody or physiotherapy)
- Day centres

People most affected by disruptions in healthcare/ social care are also the most vulnerable:

- People with more severe disabilities (unable to work or leave home, in need of personal care).
- People with learning disabilities.
- People living with chronic pain.
- People aged under 65, particularly children under 18.
- People from BAME backgrounds
- Digitally excluded people

Covid-19 related disruptions have created a backlog of untreated cases in non-urgent healthcare; especially affecting secondary and specialist care.

To manage this backlog we need a fair and transparent prioritisation system.

- ➔ Prioritise issues that would be likely to worsen and become more resource-intensive to treat if not addressed promptly.
- ➔ Work with primary care providers, social care providers and community services to offer temporary alternatives, including pain management, occupational therapy, reablement care and social prescribing.
- ➔ Communicate transparently about waiting lists; update patients regularly on the time they have to wait and how they can manage in the meantime; offer reassurance that it is safe to wait.
- ➔ Consider de-centralising some hospital-based services to community healthcare hubs.



Some Covid-19 safety measures can make clinical spaces less accessible to disabled people.

For example, the requirement to wear a mask and ring the door before entering can be challenging for people with hearing impairments who need to lip-read.



Most respondents experienced telephone or online consultations:

More online and telephone consultations can be beneficial for some, such as those who cannot easily travel because of constraints in their physical or mental health; but are not accessible to all. **Those with sensory impairments, learning disabilities or a language barrier are the most likely to struggle.**

Investment in both telephone infrastructure and online access pays off in the long run:

While telemedicine is not suitable for/ accessible to everyone, a responsive telephone and e-consult system, free of technical errors and adequately staffed, can offer a good service to those who do benefit from it, and free up capacity for those who do not.

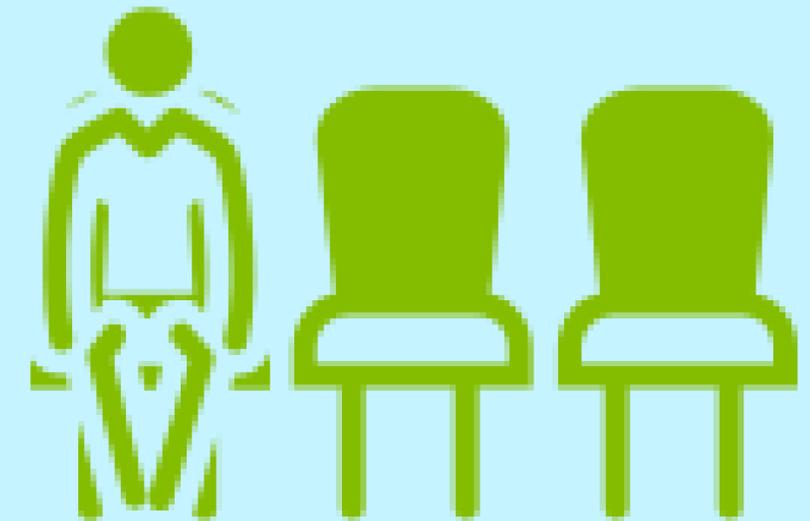


Meeting accessible standards

- Can we enable a system where a patient/user can choose their communication preferences (e.g BSL, Easyread, online/not online) once and then those preferences can be shared across the health and care system if people wish?
- Should we be co-designing tools for key impairment groups? People with learning disabilities seem to be the most effected, should we start with this group? If you can get things right for people with learning disabilities it will also help a wide range of other groups. How can we make it easier for people to contact us and communicate with us?

Delays in care

- How can we support people while they wait for treatment that has been delayed due to Covid?
- How can we make communication about waiting lists as transparent as possible?
- Can we improve the appointments process giving people?
 - as much advance notice as possible.
 - more regular updates on waiting times, where they are in the list and any changes.
 - a clearer point of contact within the service.
 - more information and support on how to manage their condition while they wait
- Can we build stronger links with community care particularly around mental health and long term care?
- What role can GPs, community services and the voluntary and community sector play re: pain management, mental health, occupational therapy, reablement care and social prescribing e.g supporting better mental health.



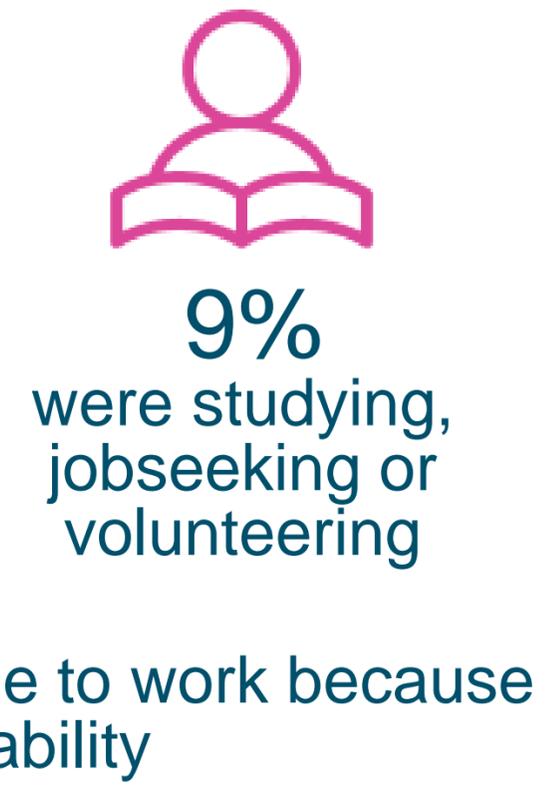
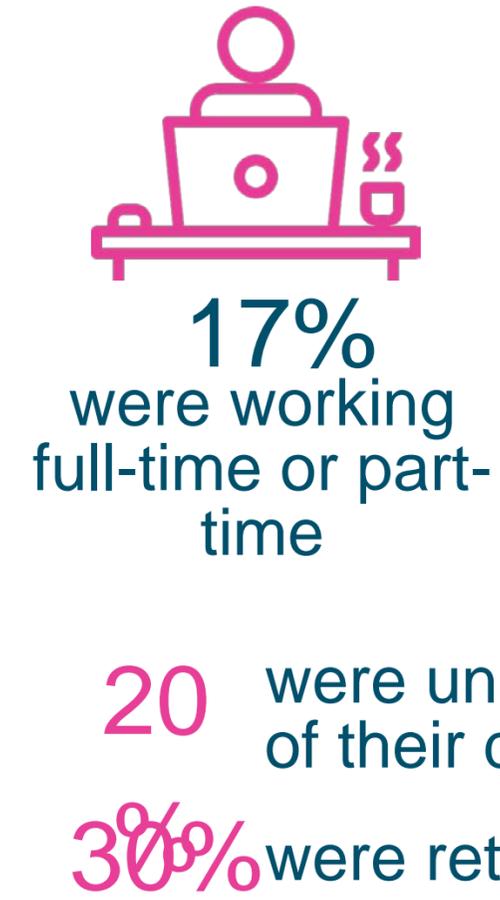
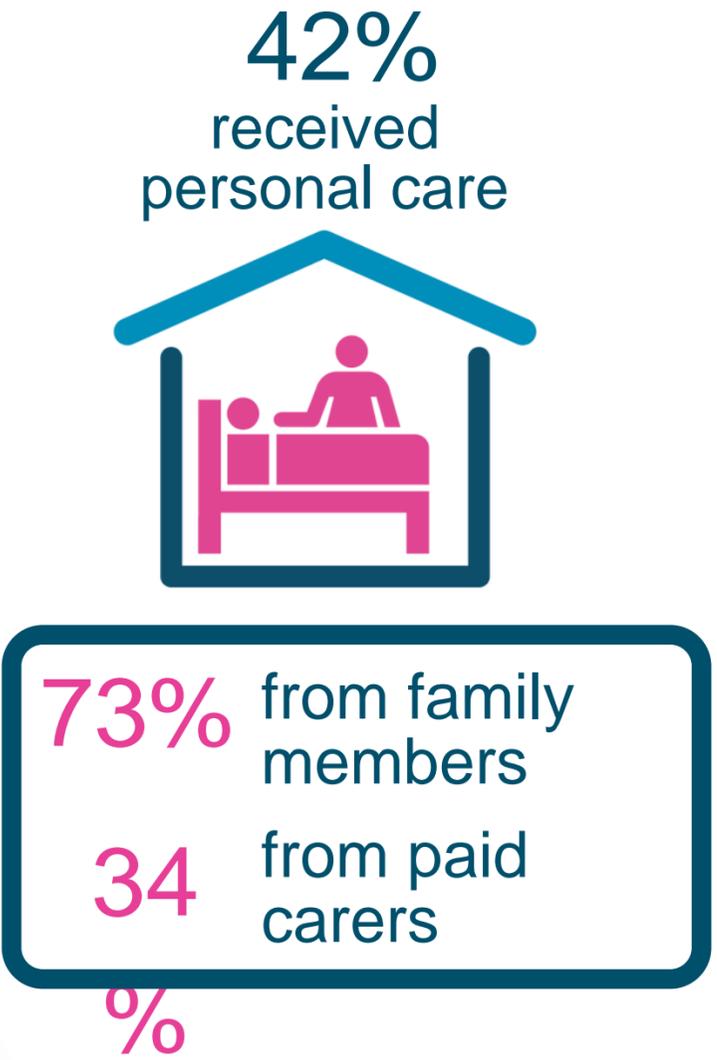
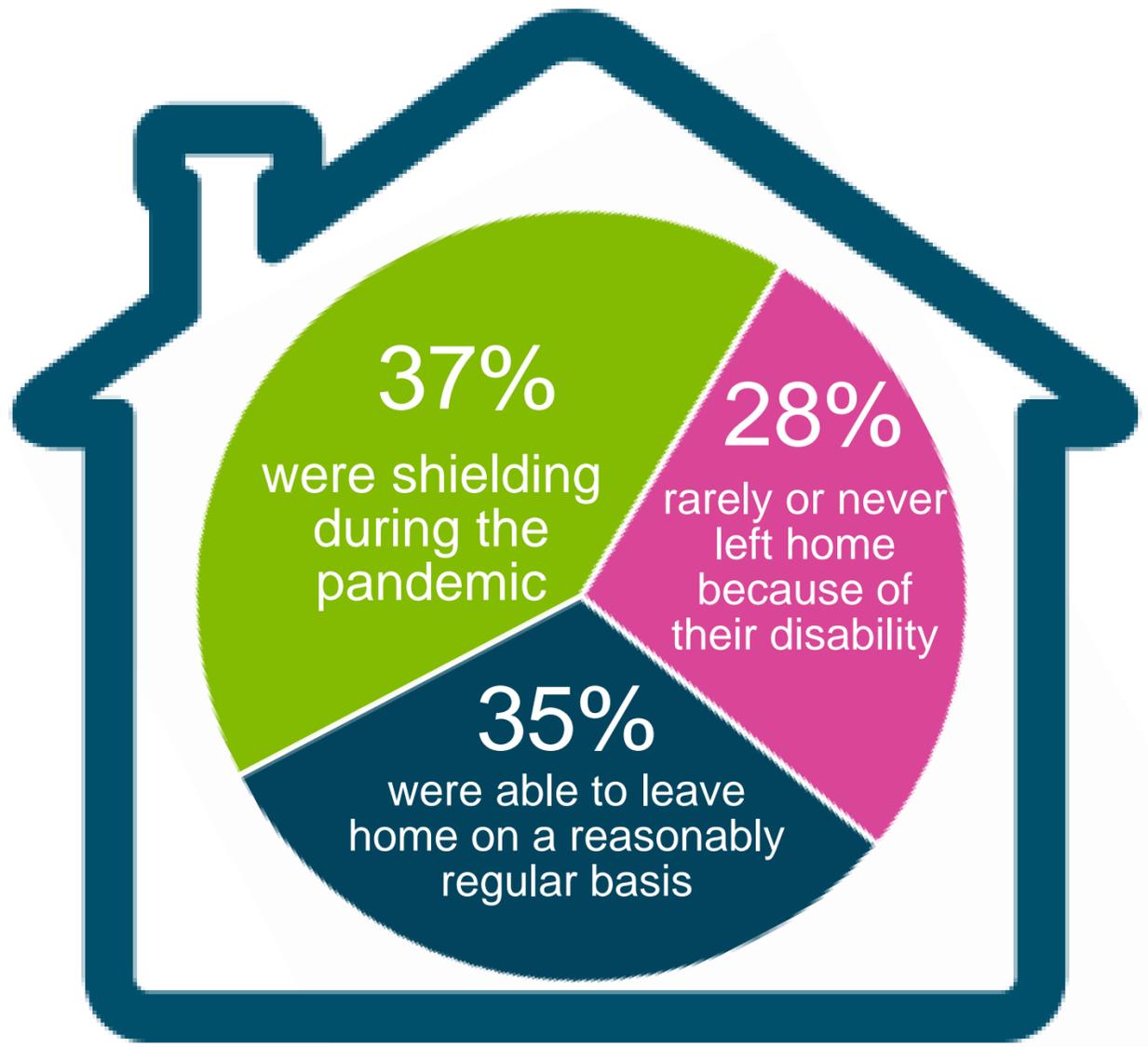
Telemedicine

What kind of investment would we need to improve telephone and online access? Is such investment available at the moment?

Our respondents

Living circumstances and wider context

- Respondents were diverse in terms of care needs and living circumstances, ability to work, leave the house and use online services.



Impact of Covid

- Disruptions to health and social care were an issue for most respondents, but they disproportionately affected the most vulnerable and those with the more severe disabilities.
- Young people with disabilities were at risk of social isolation.

Most affected by disruptions in healthcare/ social care:

- People living with chronic pain
- People from BAME backgrounds
- People aged under 65, particularly children under 18.
- people with learning disabilities
- Digitally excluded people
- People with more severe disabilities (unable to work or leave home)

17%
said they can no longer travel or engage in their hobbies

53%
experienced disruption in their healthcare or social care.

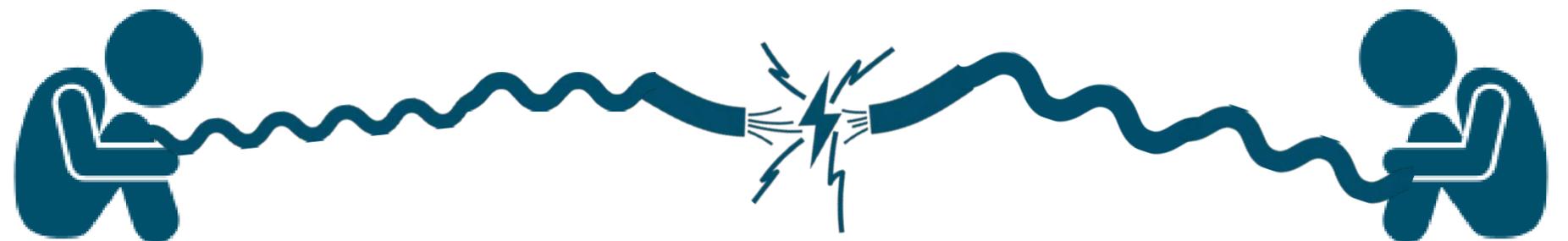
12%
became unable to see friends or loved ones

9%
experienced poorer mental health

5%
became less physically active

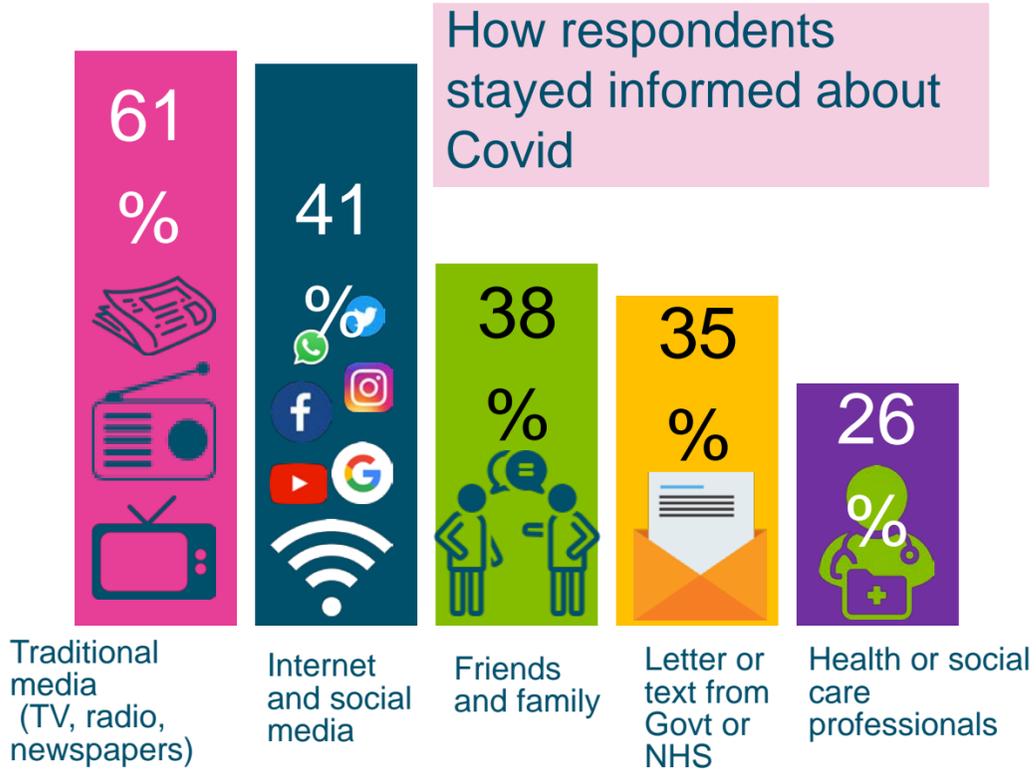
Most affected by social isolation:

- People aged under 25
- People of White non-British ethnicities



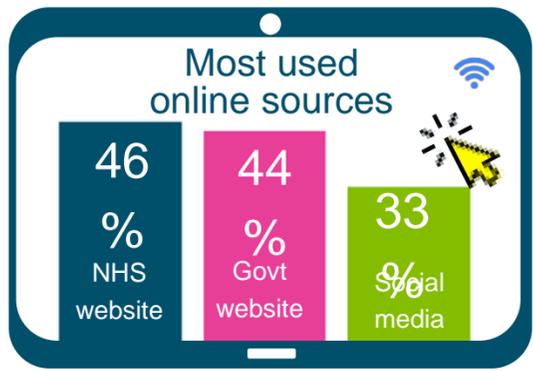
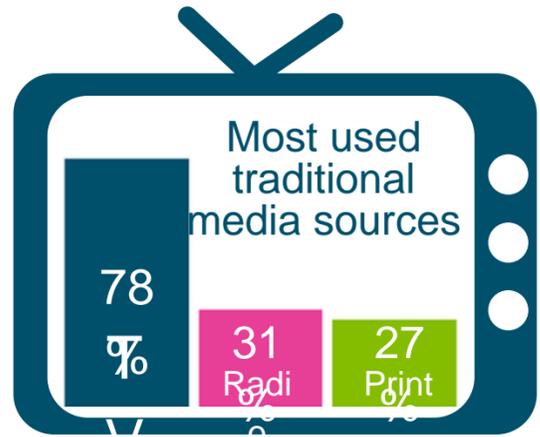
Staying informed

- Mass-media was the most popular source of information about Covid-19
- TV news, the NHS website and Gov.uk were trusted sources of information.
- People with learning disabilities or sight impairments may struggle with online and mass media .
- BAME respondents rely more on word of mouth and less on online sources for staying informed.



4% depended exclusively on friends and family for information. They were more likely to belong to these groups:

- Neurodivergent/LDs
- Sight impaired
- Women
- BAME, especially black ethnicities
- Digitally excluded



* as % of those who said they use the respective source

Most likely to use online sources

- Mental health-related disability
- White non-British ethnicities
- Aged under 65
- Economically active (worker or jobseeker)

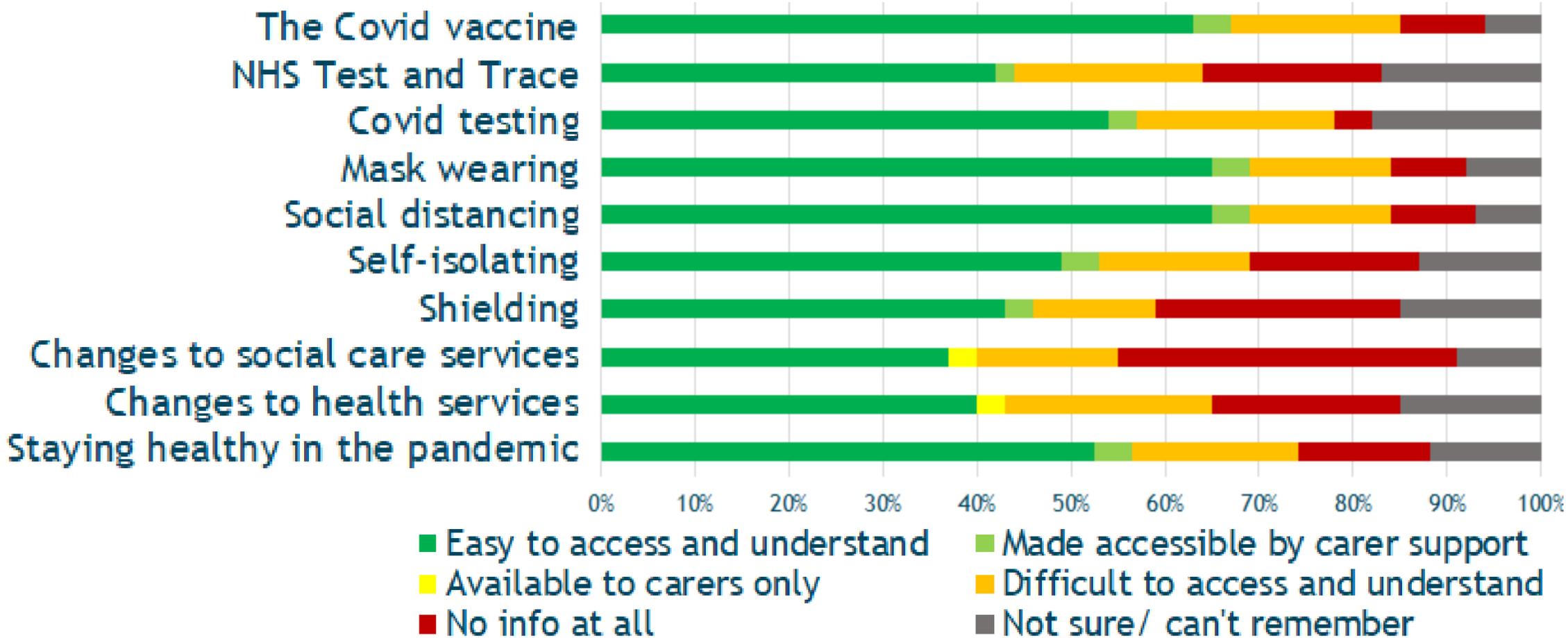
Least likely to use online sources

- Neurodivergent/ learning disability
- Blind or sight impaired
- Severely disabled (requires personal care, rarely leaves home)
- Black ethnicities
- Aged over 65

Staying informed

- Respondents felt quite well-informed about the Covid vaccine, social distancing and mask-wearing, but poorly informed about changes to their social care and about NHS Test and Trace.
- Respondents who were autistic, living with learning disabilities or with sensory impairments were less likely to find accessible information.

Information about Covid-related topics



Most likely to find accessible information:



- Those in work or education.
- Those aged 25 to 64.
- Those living with a partner or children.

Least likely to find accessible information:



- Autistic respondents.
- Respondents with learning disabilities.
- Respondents with sensory impairments.
- Digitally excluded respondents.
- Those who only had info from friends and family.

11% found the font in printed materials too small
8% found the language too complicated
14% felt there was too much information
14% felt there was not enough information

Accessible information

- There is no 'one size fits all' solution for communicating with disabled people on topics such as their health services in the pandemic and Covid vaccination.
- Information presented simply, with clear explanations, is accessible to more people.
- Written materials can be made more accessible with large print and plain formatting; however, some may do better with information that is not in written English.

24%

of respondents expressed a need for information to be presented in plain, jargon-free language with simple explanations.

15%

expressed a need for written materials to be formatted in a disabled-friendly way (large print, plain background, no unnecessary embellishments)

15

preferred to receive information in formats that did not involve the written word (such as by telephone, video call or in person)

Information which is NOT in writing may be more accessible to:



Those with sight impairments;



Deaf people who use British Sign Language;



People with learning disabilities;

41%

of respondents with a sight impairment preferred info that was NOT written.

Accessible information

- Since different groups have different needs, it is necessary to have a bespoke, individualised approach that feels relevant to those targeted.
- Bespoke strategies should be formulated for reaching out to disabled people who are digitally excluded or unable to communicate.

Individualised Outreach

entails targeting and addressing certain groups of people specifically, including tailoring the message and presentation to their own needs.

Information sent directly or addressed specifically to the target audience is less likely to be ignored; though special consideration needs to be given to whether it is accessible and suitable.

I prefer to receive official communication from the government either via post addressed to me personally, or via an official email where there aren't too many links to click on to find the information. (Havering resident)

My elderly, stroke survivor husband watches the news, but he doesn't see himself as vulnerable. If the doctor rings he gives it to me to deal with. He just doesn't really see the vulnerable as being him. (Tower Hamlets resident)



The information that I receive needs to be relevant to me. (Hackney resident)

Some people, like those with profound learning disabilities or advanced dementia, may not be able to understand information, therefore outreach should target **THEIR CARERS**.

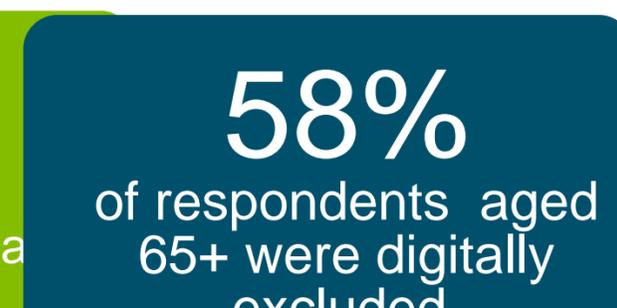
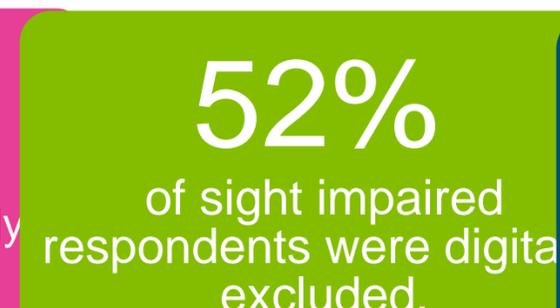
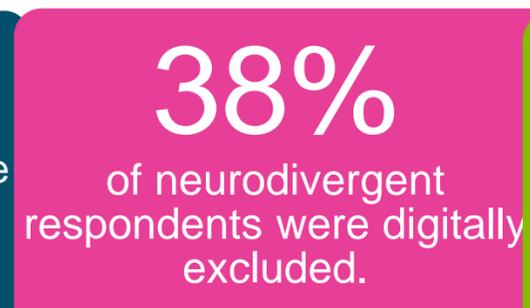
My father has dementia. You would need to pass information onto him via family and carers, and we would convey to him. We would like to be mailed and emailed the information.

(Barking and Dagenham resident)

Accessible information

Online communication

- Online information should be simple, easy to read, free of clutter and optimised for smartphone access.
- Communication should not excessively rely on online information, as many disabled people, particularly the elderly, those with cognitive and sight impairments are likely to experience barriers to accessing online services.



Messages should be sent electronically by text and email and include clickable links for easy access on a mobile phone.
(Tower Hamlets resident)

Do not use two columns on an iPhone and ensure text is at a reasonable size (not necessarily to be large as standard, just not small)
(Havering resident)

Easier access via a smartphone. Too much information is available only as a PDF which is best viewable on a much larger screen
(Havering resident)

I've received an email from the council- but those who are digitally excluded must have missed out on information. These people will only be informed by their families and sometimes the information is very minimal.
(Tower Hamlets resident)

Send me information at home as a leaflet, that way people who can't go outside or go on the internet can access it and not miss anything.
(Tower Hamlets resident)

Some people don't have smartphones for Test and Trace- this should be made easier for them.
(Tower Hamlets resident)

Accessible information

People with sight impairments

- Written text should be in large print, with bold fonts, contrasting colours and avoiding unnecessary clutter.
- Alternatives to written information (such as audio/video, contact by telephone or in person) should be considered for those who cannot read.



People with sight impairments may not always be able to read written text; providing information in **other formats, such as audio or video**, may be more accessible for some of them.

For those who are able to read, the use of **large print, bold fonts and contrasting colours** (such as black lettering on white background) can help.

Online resources should consider **compatibility with adaptive software** such as screen readers.

41%

of respondents with a sight impairment said they would like to receive information in formats other than written text.

41%

of respondents with a sight impairment said they would like to receive written information in large text, with accessible formatting.

There should be more use of telephone access for enquiries, as people wish to speak to a person. Being vision impaired, websites and social media platforms are not easy to access and use. Older people have enough to deal with with their sight loss and don't want a battle to find information. (Haverling resident)

The accessible information standard is not being applied in many health settings. Despite filling a form in at my GP surgery they had no record of my preferred format and kept sending me letters which I cannot read.

(Haverling resident)

I received info by phone from Healthwatch Hackney and it was critically helpful. (Hackney resident)

Health professionals should have the various degrees of visual impairment their patients have highlighted so they are aware when contacted.

(Tower Hamlets resident)

Accessible information



Easyread materials may be more accessible to native speakers of British Sign Language than standard text; simple, accessible formatting is better for those who experience both sight and hearing loss.

People with hearing impairments

- Subtitling informative videos can make them more accessible to people with hearing impairments; but it is important to make them large and easily legible, as some people with hearing impairments are also sight-impaired.
- Written text is accessible for those who experienced hearing loss or who are partially impaired, but may be less so for native speakers of BSL.

16% of respondents with a hearing impairment also had a sight impairment.

11% of respondents with a hearing impairment said they found it harder to access the information they needed because the language used was too complicated.

6% of respondents with a hearing impairment said they found it harder to access the information they needed because it was not available in BSL.

9% of respondents with a hearing impairment said they found it harder to access the information they needed because it was not subtitled.

There should be information posted to residents who have disabilities, in large writing and easy to digest.
(Tower Hamlets resident)

Plain language, and videos being subtitled and signed would help me a lot.
(Newham resident)

Face coverings make it harder for me to understand people. You don't know how much you rely in reading lips until you cannot see them, if there is background noise it's impossible - try listening to someone with your head in a bucket of water and the person wearing a mask - that is what it sounds like.
(Havering resident)

Health briefings should be subtitled, and Relay UK should be used when talking to doctors. I'd like to receive leaflets through the door.
(Redbridge resident)

Accessible information

Neurodivergent, & people with learning disabilities

- Easyread materials, featuring visuals and simple explanations using plain, jargon-free language may help neurodivergent respondents stay informed.
- The written language is not a suitable medium for all; some respondents would be better able to understand information presented visually or in a face to face conversation



Easyread materials
 combining images, basic explanations in plain language and simple formatting may be more accessible than standard text.

15% of neurodivergent respondents said they found it harder to stay informed about Covid because they found the language too complicated.

59% of neurodivergent respondents said they would like the informative materials they receive to contain images and illustrations

30% of neurodivergent respondents said they would like to receive information in plain language, with easy to understand explanations

30% of neurodivergent respondents said they would like to receive information in formats other than written text.

Use social stories or videos suitable for younger people and children who have communication difficulties.
 (Barking and Dagenham resident, parent of child with learning difficulties)

Easy Read is not difficult to produce and I need it in these situations. (Tower Hamlets resident)

Someone visiting the sheltered accommodation staff members could give information and explain to residents. It is difficult when someone has dementia and we as a family are trying to support, but lodge has restrictions.

(Redbridge resident, family of adult with dementia)

Information could be provided in an audio format as well as a written document. For example a podcast.
 (Barking and Dagenham resident)

Speak to the general public with clearer information and language rather than changing/chopping advice constantly
 Easy to read visuals are easy - with good colour schemes and accessible information. TfL posters and promotions are eye-catching and effective but could do with updating e.g. relating to the vaccine
 (City of London resident)

Accessible information

Black, Asian and Minority Ethnic communities

Written materials in a variety of languages may be helpful to some BAME respondents, but wider cultural considerations may need to be taken into account; such as the fact that people with more oral cultures may be more responsive to direct outreach and multimedia materials than to written information.

BAME respondents were more likely to prefer information that is not in writing.

7%

of respondents of non-White ethnicities said they would need to receive information in languages other than English.

3%

of respondents of White non-British ethnicities said they would need to receive information in languages other than English.



Voice recording or perhaps some form of taping of news from like BBC Somalia or something similar. When we were back home we did shared information over the radio so maybe something similar to that.

(Tower Hamlets resident, Somali)

I prefer telephonic communication in my native language so I can understand.
(Tower Hamlets resident, Bangladeshi)

It's easier for me when it's a diagram rather than words or even when someone is talking at me, I miss stuff or my mind wanders. If they had a visual version it would have been easier
(Tower Hamlets resident, Bangladeshi)

Make informative materials much shorter and simpler. with colourful pictures, sketches, cartoons and regular cheerful prompts, videos and voice messages.
(Newham resident, Malay)

Doctors should explain things clearly, step by step.
(Tower Hamlets resident, Black African)



Covid vaccine

- Most respondents are willing to be vaccinated, and prefer to receive information from their GP.
- Vaccine hesitancy in the BAME community can be tackled by addressing myths and rumours circulating.
- A small number of respondents living with long-term conditions feel that they are not receiving sufficient information specific to their circumstances.

85%
intend to have the Covid vaccine or have had it already



66%
of those who intend to have the vaccine would prefer to be informed by their GP



Some respondents living with long-term conditions expressed a desire for more specific information relating to their specific circumstances.

I have no doubts about the safety of the vaccine, but I know that I am Immunosuppressed and I am susceptible to catching infections, so I am unsure if the vaccine will work effectively, and I have not been able to ascertain the information about ME and the Covid vaccine, and if any particular vaccine will be more efficacious.

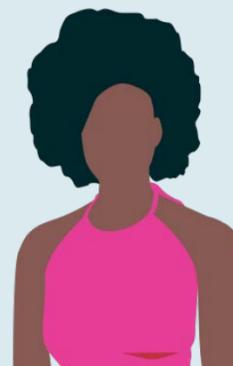
(Tower Hamlets resident, diagnosed with ME/CFS)

I'm waiting from a call from my MS nurse to be 100% clear that I can have it; she OKd this and I am ready to take it.

(Tower Hamlets resident, diagnosed with Multiple Sclerosis)

Respondents most likely to be vaccine hesitant:

- Only received info about Covid from friends and family.
- Felt poorly informed about Covid-related topics.
- Were neurodivergent.
- Were of Black ethnicities.



A lot of people of BAME heritage are very reluctant to take the vaccine as they've been exposed to many conspiracy theories.

(Hackney resident, Black African)

The BAME community have the lowest take up rates this needs to be addressed. The wider issue is equal access for all to health services the perception is that this community believes it does not have equal access. The outcomes for them are also poorer.

(Redbridge resident, Asian British)

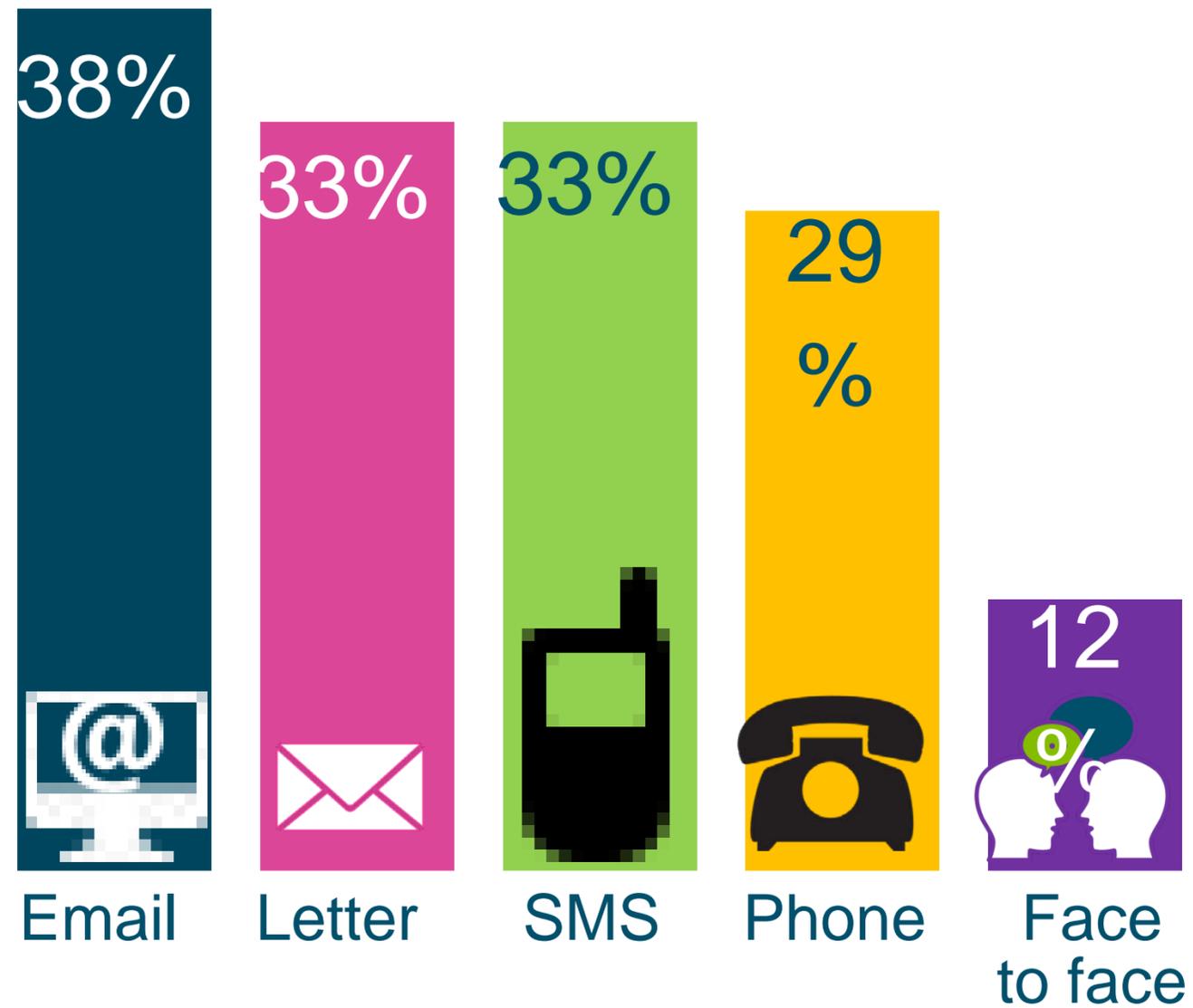


Covid vaccine

Many prefer to be contacted via email, text or letter. However, written info is not accessible to all; some groups such as those who are sight impaired, Deaf or neurodivergent could benefit from alternative methods of communication.

How respondents prefer to be contacted about the vaccine

Not a "One size fits all" approach



12% would prefer to only be contacted verbally, via phone or face to face, without written text.



Covid vaccine

Not a "One size fits all" approach

Email was preferred by:

- Autistic respondents;
- Respondents with hearing impairments;
- Respondents who were shielding;
- Respondents who were economically active.

Email was less popular for:

- Respondents with learning disabilities;
- Respondents with sight impairments;
- BAME respondents, particularly Black ethnicities;
- Respondents aged under 24 or over 65.

SMS was preferred by:

- Respondents with mental health issues;
- Respondents of White non-British ethnicities;
- Women.

SMS was less popular for:

- Respondents with sight impairments;
- Respondents aged under 18 or over 65;
- Respondents of Asian ethnicities.

Phone was preferred by:

- Responding with sight impairments;
- Respondents with learning disabilities;
- Respondents who are shielding;
- Respondents who are digitally excluded;
- Respondents aged 65+.
- Respondents of ethnicities other than White British

Phone was less popular for:

- Autistic respondents;
- Respondents with mental health issues;
- Respondents aged 18 to 24.

Letter was preferred by:

- Respondents aged 25 to 49;
- White British respondents.

Letter was less popular for:

- Autistic respondents;
- Respondents with sight impairments.

Face to face was preferred by:

- Respondents with learning disabilities;
- Respondents with sight impairments;
- Respondents of Asian ethnicities;
- Respondents of White non-British ethnicities.

Face to face was less popular for:

- Autistic respondents;
- Respondents with hearing impairments;

Covid vaccine

- Accomodation needs to be made for wheelchair users, as well as for those who cannot stand for too long.
- Access to toilets is essential for people with some long-term conditions.
- People need to be able to get to vaccination centres easily; helpful measures include keeping them local and near public transport, providing parking and a transport service.

Measures to make vaccination sites accessible for people with physical disabilities



Ensure wheelchair accessibility, including ramps and lifts.



Provide access to toilets, including for wheelchair users.



Provide seating for people who cannot stand for long. Ideally, this could include reclining or lying down.



Provide parking and a free or cheap transport service. Ensure locations are easily accessible by public transport.



Ensure everyone has access to vaccination in their local area. (For example, through their GP surgery)



Offer vaccination at home for those who cannot leave it easily. (For example, through district nurses or carers)



Excel didn't have toilets on same level, this is a problem especially if you have a long journey from home (we don't all have cars).
(Tower Hamlets resident, walking stick user)

Ensure there are enough vaccination sites, so that they are near to home and that they are well managed when one gets there.
I thought all of this was good as site was near to my home and well managed, and friendly.
(Tower Hamlets resident with asthma)

Make sure if they haven't got a car they can use something like hospital transport and the place is wheelchair accessible, with lifts if it is on a different floor.
(Tower Hamlets resident with chronic pain)

Any disabled person should be vaccinated at home in my view. Going out into the community was senseless when people have shielded for several months.
(Barking and Dagenham resident, carer)

See if we can access the site without having to wait outside or stand; this was a huge issue for me. I'm unable to walk properly and stand caused more intense pain.
(Tower Hamlets resident with severe arthritis)



Covid vaccine

- Communication (including signage and direct contact with vaccination centre staff) must be accessible to people with sight and hearing impairments, as well as learning disabilities. Training staff in guiding and communicating with people with various types of needs can help in this respect.
- People who are anxious or sensitive to sensory overload could benefit from booking specific "quiet" slots.

Measures to make vaccination sites accessible for people with sensory and learning disabilities



Signage and other communications on-site need to be accessible for those with visual and hearing impairments, or learning disabilities. (Example: plain language, contrasting large print, Braille)



Provide vaccination centre staff with disability awareness training, including communication strategies for different disabilities.



Provide vaccination centre staff with training on supporting people who are experiencing anxiety or fear of the needle.



Avoid loud noises, bright lights and other sensory overload. Consider offering "quiet slots" for those who need them.



Avoid overcrowding and long waiting times.



Allow a degree of flexibility in rescheduling.



I'd like to have specified times per week where you can use check in machines so you don't need to speak to anyone until you see vaccinator person. No bright lights, no screaming children, as quiet as possible, phones on silent in waiting areas, no pressure to make eye contact with anyone. Easy access to toilets. I'd like to have an Autism-friendly time range and book my appointment during that slot. There should be people trained to help severely anxious people.
(Tower Hamlets resident, autistic)

Just don't be mean to me when I don't immediately 'get' what I'm supposed to be doing or feel panicky because there are too many people or I don't know where you're pointing to.
(Tower Hamlets resident, autistic)

I would need to have a BSL interpreter or BSL access via iPad/ mobile.
(Tower Hamlets resident, Deaf)

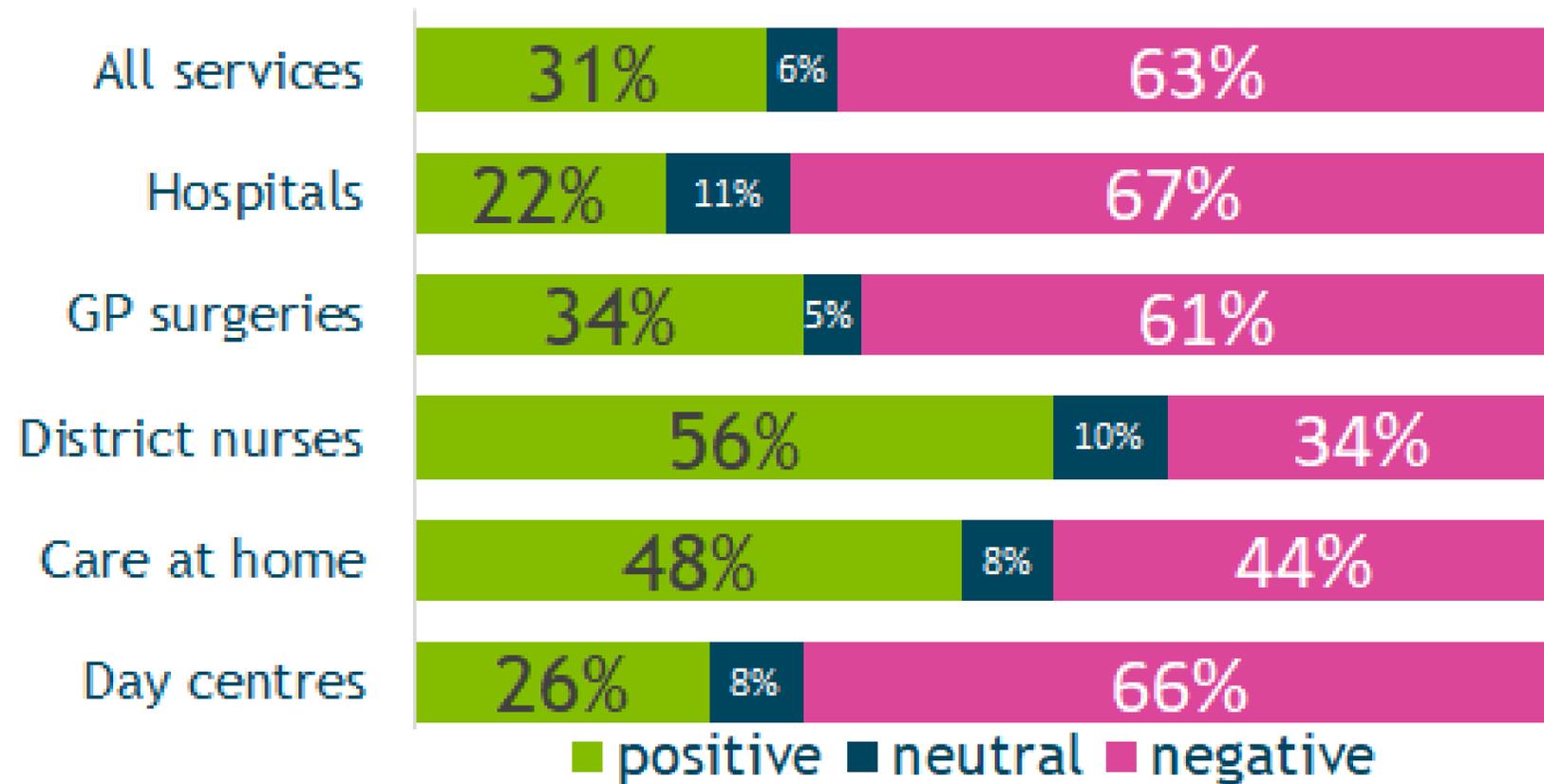
Brightly displayed signs and volunteers on-site to guide people.
(Tower Hamlets resident, sight impaired)



Health & Care services

- Disruptions in health and social care services have affected people's experience with health and social care services.
- People with hearing impairments and children under 18 had the most negative experience with health and social care services.

Overall, disabled people's experience of health and social care services **leaned negative**.



Most positive experience

- Young adults (18 to 24)
- People with sight impairments



Most negative experience

- Children (under 18)
- People with hearing impairments



➔ Disruptions to routine hospital-based procedures, hospital outpatients and provision of day centre services impacted patient experience.

➔ Those who received healthcare or personal care in their own homes had positive or mixed experiences with it.

Health & Care services

- Disruptions in health and social care services have been particularly hard on the most vulnerable respondents: those with more severe disabilities, those from BAME communities and digitally excluded.
- Hospital outpatient services, community services (such as chiropody and physiotherapy) and day centres have been the most affected by cancellations.

53%

of respondents experienced disruption in their healthcare or social care.

People most affected by disruptions in healthcare/ social care:

- People with more severe disabilities (unable to work or leave home, in need of personal care).
- People with learning disabilities.
- People living with chronic pain.
- People aged under 65, particularly children under 18.
- People from BAME backgrounds
- Digitally excluded people

Services experiencing the most cancellations:

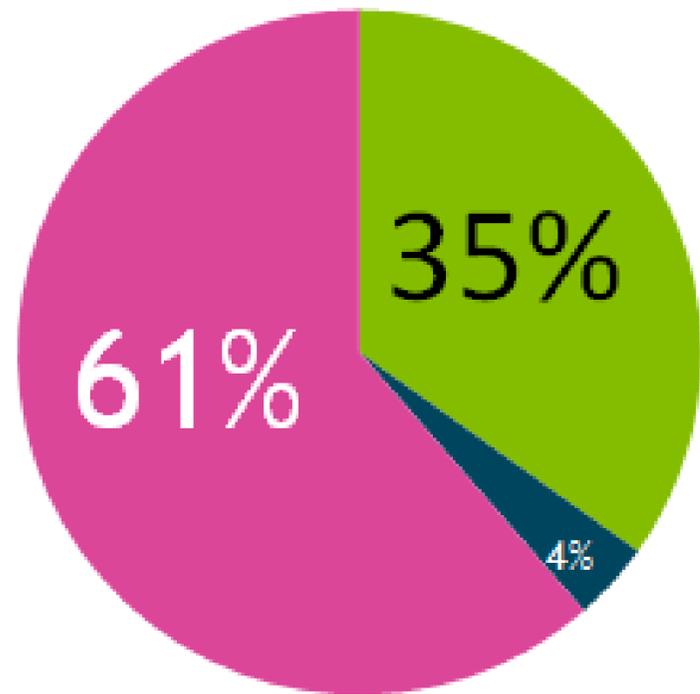
- Hospital outpatients
- Community services (such as chiropody or physiotherapy)
- Day centres



GP surgeries

- GP practices have adapted to dispense and prescribe medicine efficiently during the Covid-19 pandemic
- In some cases, Covid protection measures may make practices less accessible.

Overall opinion of GP surgeries



■ positive ■ neutral ■ negative

What works well

- Medication is handled efficiently.
- Quality of treatment is good.
- Doctors are kind and compassionate.

I have been able to talk to my GP over the phone and not had any problems getting my medication. Going forward I would like to see the telephone service stay the same as I have found it to be very convenient.

(Hackney resident with lupus)

I was Covid positive and was hospitalised for 10 days and was on Oxygen for 10 days. My GP was very supportive.

(Tower Hamlets resident with chronic respiratory issues)

The amount of people seeing a GP lessened during the pandemic and so the doctors were more accessible. The service became more personable.

(Tower Hamlets resident with mental health issues)

What needs improvement

- Not all GP practices are accessible.
- Online systems are not always functional.
- Practices are difficult to contact by phone.
- Communication with doctors is poor.
- People wait too long for appointments.

I cannot hear without lip-reading, and now my GP has to wear mask and I have to use the intercom to get through a locked door; this is difficult for me.

(Redbridge resident, partly deaf)

I have found the GP appointments have been ok just via video call. But information from surgery staff has been inconsistent. Have been asked to call and book my flu jab several times although have had it in last 6 months.

(Newham resident with asthma)

Don't like online consultation and telephone consultation: hard to explain things that are not visible. Prefer to see the doctor/nurse: they can see what the problem is.

(Tower Hamlets resident, autistic)

The nurses from the surgery have been pulled away to carry out delivery of vaccines elsewhere, therefore I can't get an appointment for my usual regular injections.

(Redbridge resident, carer)

GP surgeries- remote service

- Most of those who used GP services had telephone consultations.
- Repeat prescription requests were the most widely used online service.

Out of the 430 respondents who used GP services...



25%
used
e-consult
forms.

23%
had an
online
consultation.

80%
had a
telephone
consultation.

19%
booked an
appointment
online.

37%
ordered repeat
prescriptions
online.

Upsides

I had a consultation over the phone at home, so I had my daughter explain to me what the doctor was saying and ask questions, I felt much more comfortable, I prefer it like this.
(Tower Hamlets resident, fibromyalgia)

The telephone appointments seemed a good option for me, but I've been couple of times to the practice as well for routine blood tests etc. I've booked them through the app Patients Access, but I was using the system before and nothing particularly has changed.
(Newham resident, autistic with anxiety disorder)

The phone and zoom consultations have worked well for me and not having to go traipsing down to the practice is a time saver whilst getting the right care.
(Barking and Dagenham resident, diabetes)

My GP does phone calls only- I had to beg to be seen face to face, there are things you just can't do in a phone call.
(Tower Hamlets resident, fibromyalgia)

My GP surgery don't answer their phone and I can't access the internet. I have to get someone to go on website and do online consultation.
(Tower Hamlets resident, multiple chronic conditions)

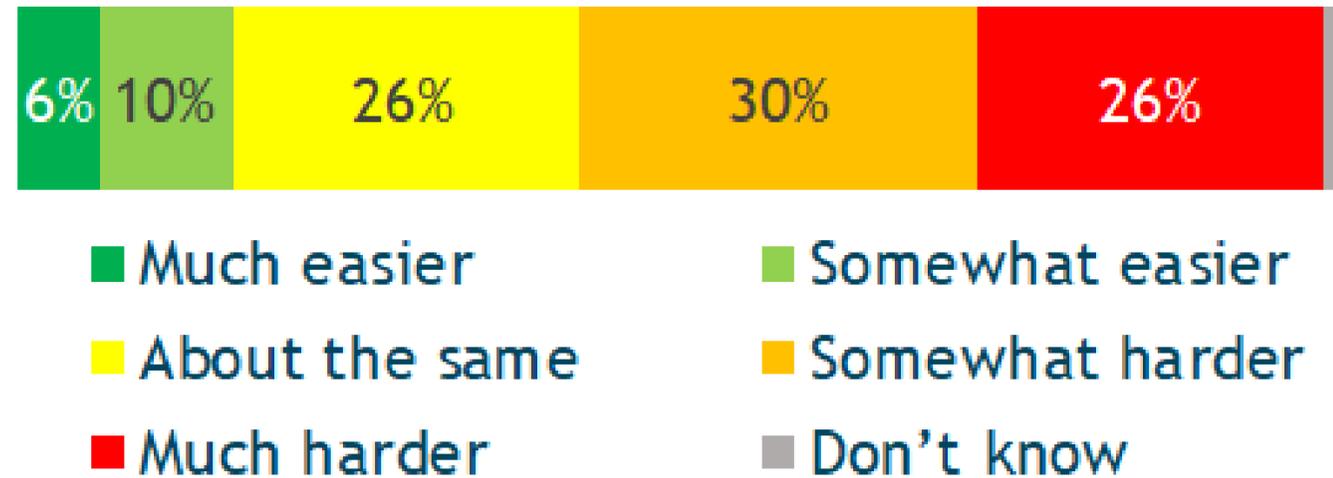
Trying to make an appointment online no longer exists. They need to make this happen. Long forms and telephone calls to make an appointment is crazy.
(Barking and Dagenham resident, cerebral palsy)

Downsides

Access to GP surgeries

- Most respondents found it harder than before to book GP appointments.
- In some cases, Covid protection measures may make practices less accessible.

Do you find it easier or harder to book GP appointments now?



When I contacted my GP surgery regarding getting a vaccination locally where I know the area, they were very unhelpful. I had received my letter inviting me for a vaccination, but I was made to feel that I was not important and that I was jumping the queue. This could be improved by having staff with some understanding of the difficulties people like myself have.

(Havering resident, partly blind)

Who had the hardest time getting GP care?

- People with sight impairments;
- People with hearing impairments;
- People with mental health issues;
- People of Asian ethnicities;
- People aged 50 to 64.



Getting the care I need from my GP is much harder now. Harder to have them on the phone. Harder to schedule appointments. A lot of appointments moved to remote calls, but then when that isn't sufficient there are delays in being seen face to face, which means delays in care. I'm having to schedule my routine appointments myself rather than having the surgery call me to schedule them. Repeat medication needs to be requested every month rather than automatically renewing. I'd rather not see any of those continue.

(Tower Hamlets resident with severe IBS)

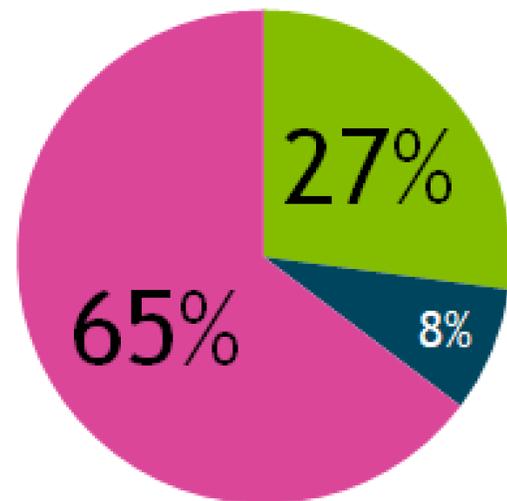


Health & Care services

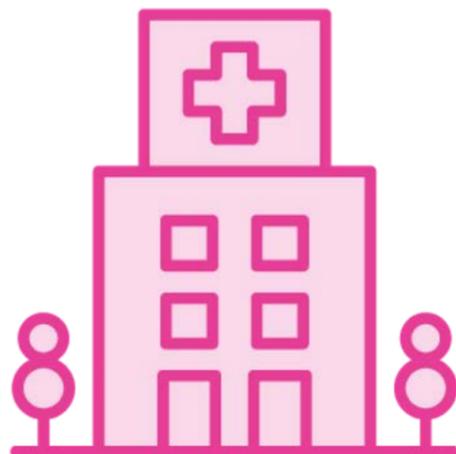
Hospital services

- Hospitals are praised for the quality of the treatment they offer and the attitude of medical staff. Those who received treatment as inpatients for Covid in particular report a good experience.
- Long waiting lists and cancellations impact upon patients' access to care.
- Remote service provision makes communication with doctors harder for some patients.

Overall opinion of hospital services



■ positive ■ neutral ■ negative



What works well

- Quality of treatment is good.
- Doctors and nurses are kind and compassionate.
- Those hospitalised with Covid report a good experience.

I found hospital services easier to access, but this is just because I'm a cancer patient.
(Tower Hamlets resident, deafblind cancer patient)

I was scared to be admitted to the hospital because of Covid. But I seen they took a high standard on health and safety and hygiene issue. I am really happy about their service.
(Tower Hamlets resident with heart disease)

Very good service, and caring; even though I was affected by cancellations a great deal.
(Barking and Dagenham resident, learning disability)

What needs improvement

- Cancellation to routine procedures and appointments impact patient experience.
- People wait too long to be seen.
- Communication with doctors is poor.

I don't understand a lot on the phone. but the doctor won't see me face to face so I can explain my health better.
(City of London resident, learning disability)

I have had no reply whatsoever from the Audiology Department to a message I left some weeks ago.
(Waltham Forest resident, sight and hearing impairment)

Because of pandemic most of appointments I have are cancelled until this summer. This affected me a great deal.
(Tower Hamlets resident, immunosuppressed)

Hospital outpatients- remote service

- Three quarters of those who used hospital services had telephone consultations.
- Phone appointments can be more convenient for some, but they pose accessibility challenges and not everything can be done remotely.

Out of the 298 respondents who used hospital services...



18%
had an
online
consultation.

74%
had a
telephone
consultation.

8%
booked an
appointment
online.

Online appointments through video calls means avoiding the commute which can cause me anxiety. It also means if the consultant is late I don't just waste time sitting in the waiting room. As they call me on a video app on my phone I don't miss appointments even if I've forgotten about them.

(Tower Hamlets resident with mental health issues)

When I was recovering from surgery, still getting test results and making decisions about chemo, doing that over the phone was incredibly difficult. At times I wish I could easily see a nurse in the breast clinic to ask about side effects and have them check physical symptoms. On the positive side, phone consultations can be a lot more convenient than travelling and waiting for inevitably delayed meetings.

(Newham resident, cancer survivor)

My consultant was aware of my deafness but still contacted me via TELEPHONE on the day of my appointment (was only notified of switch to telephone a few days prior) - no consideration for Accessible Information Standards and no response to the email I had sent that morning to advise and explain the situation.

(Havering resident, Deaf BSL user)

Appointments are either being cancelled at the last minute, or changed to a telephone appointment; my mum, who is my carer, has to deal with it. Some appointment would be good to keep as telephone, but vagus nerve stimulation clinic and dental must be face to face. I was also referred to the Eye Clinic at Queen's Hospital, and my appointment was then changed to telephone, which was useless.

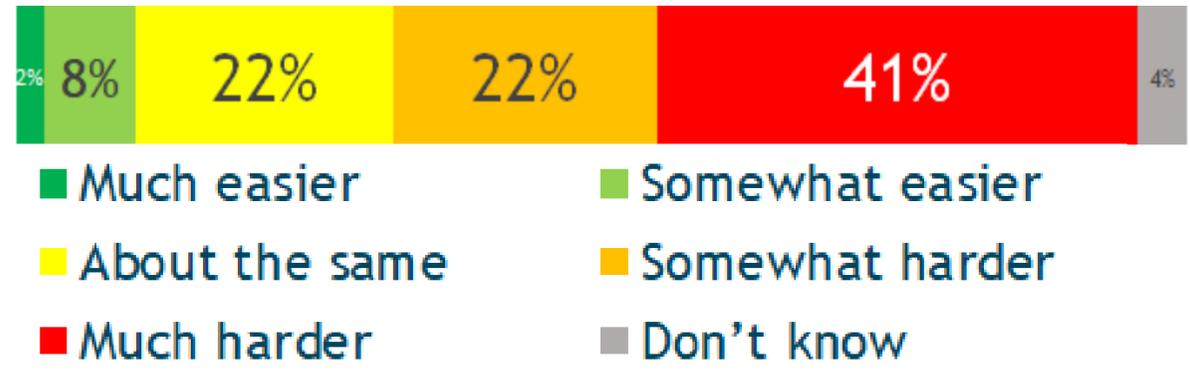
(Havering resident with cerebral palsy)

Health & Care services

Access to hospital services

- Most respondents found it much harder than before to book hospital appointments, with many being affected by service cancellations and delays.
- Those who experienced cancellations felt unsupported, as most of them received no help in managing their health in the meantime.

Do you find it easier or harder to access hospital care now?



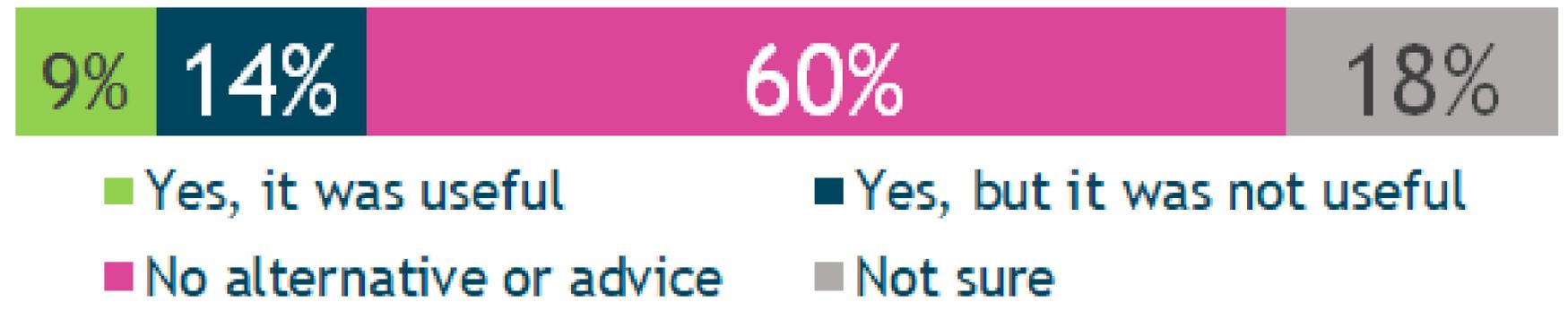
77% of those who used hospital services experienced cancellations.
48% of them said cancellations affected them a great deal.

To what extent did hospital cancellations affect you?



Those who experienced cancellations felt poorly supported to manage their own health, with only a minority receiving any alternative or advice:

Did you receive any other alternatives or advice on how to manage your health after your hospital appointments were cancelled?



“ Accessing the hospital has been much harder since all appointments have been cancelled and have not yet been offered any new ones. I need to see a neurologist, a Parkinsons specialist nurse and the eye clinic for glaucoma. (Haverling resident with Parkinsons)

I have had a number of appointments cancelled, and I waited over 7 months for a new hearing aid mould after one broke. (Haverling resident, hearing impairment)

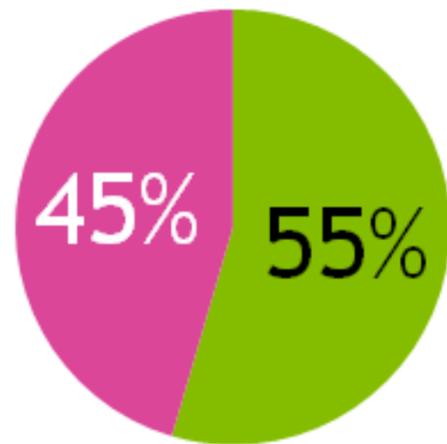


Health & Care services

Mental health services

- Access to mental health services is difficult for many, as services are overstretched and waiting lists are long.
- When people can access mental health services, they have positive experiences and adapt well to online or telephone sessions.
- Communication about changes to services in the pandemic needs improvement.

Overall opinion of mental health services



■ positive ■ neutral ■ negative



What works well

- People find therapy and/or treatment helpful.
- Online systems for accessing mental health support work well.



Mental health services have been very responsive via emails and can do online video call - really straightforward.

(City of London resident)

I wasn't feeling great, so I reconnected with the IMPART service and they got me help. I have experienced some cancellations, but useful alternatives were provided.

(Havering resident with psychosis)

What needs improvement

- Communication with mental health services is poor.
- People wait for a long time to get any kind of mental health support.
- There is limited choice for where and how to receive mental health support.

I had to rearrange some counselling appointments, so I missed some. They should have been clearer that they changed all the appointments to over the phone in the beginning. This would have made things clear and I may not have missed my appointments.

(Tower Hamlets resident, depression)

I tried to self refer at a crisis point during 1st lockdown; I also tried to get a referral to the counsellor attached to the Renal team at The London. Unfortunately, all were too busy and other known orgs such as Mind etc just signposted my to mindfulness on line - this was so not what I needed at the time.

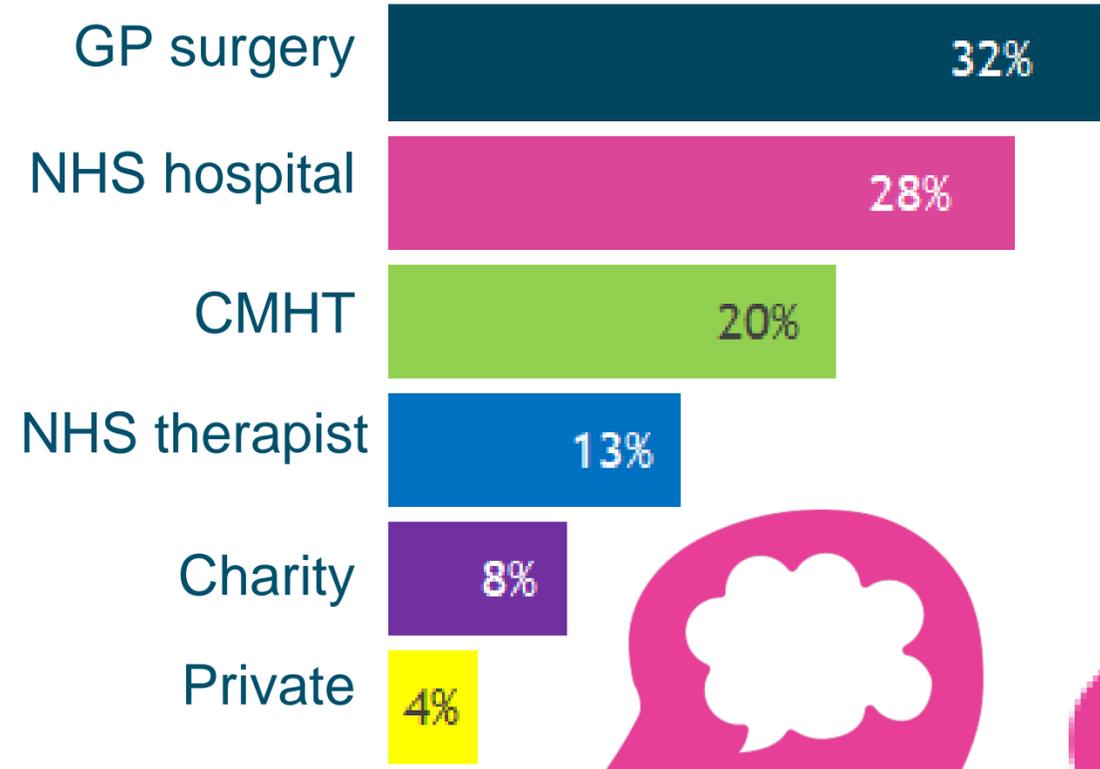
(Hackney resident, kidney disease)

Health & Care services

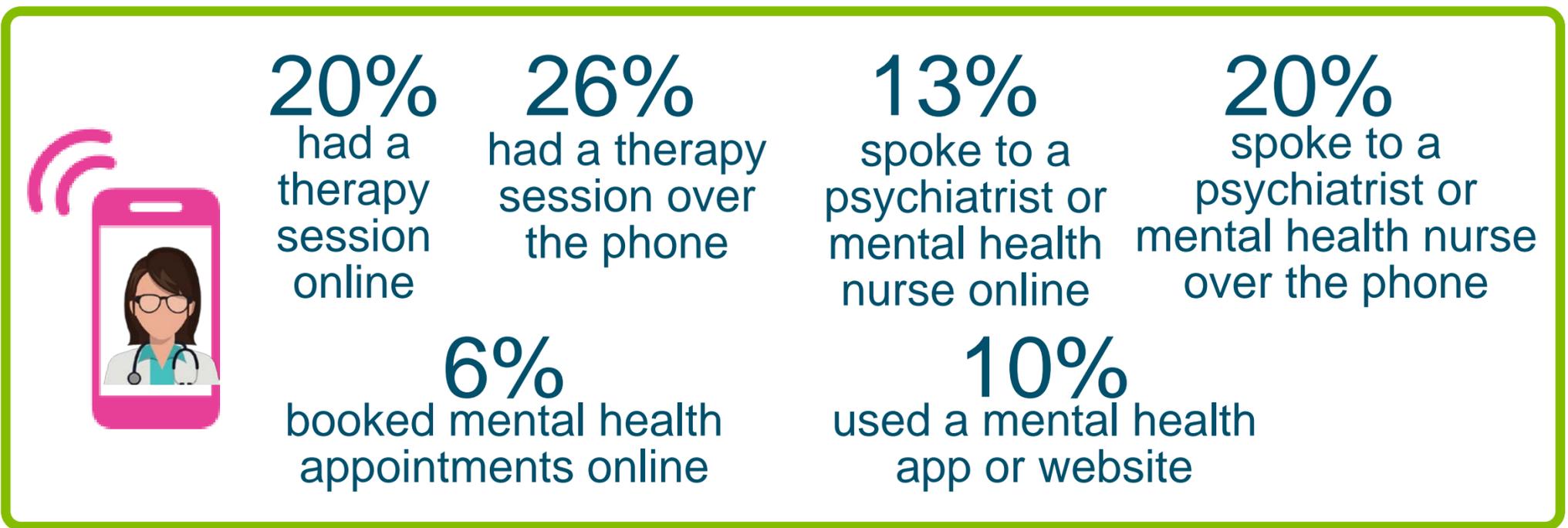
Mental health- remote service

- Most respondents who received mental health treatment or support did so through their GP, a hospital-based service or Community Mental Health team.
- Most types of consultation and mental health treatment have been carried out over the phone or online.

Who respondents received mental health treatment or support from:



Out of the 143 respondents who used mental health services...



My mental health problems started during the pandemic. So it was difficult initially to speak to my GP without having to explain everything to the receptionist. They were helpful because as soon as I told them I am blind and my daughter is partially sighted so cannot access online services I got a call from my doctor.

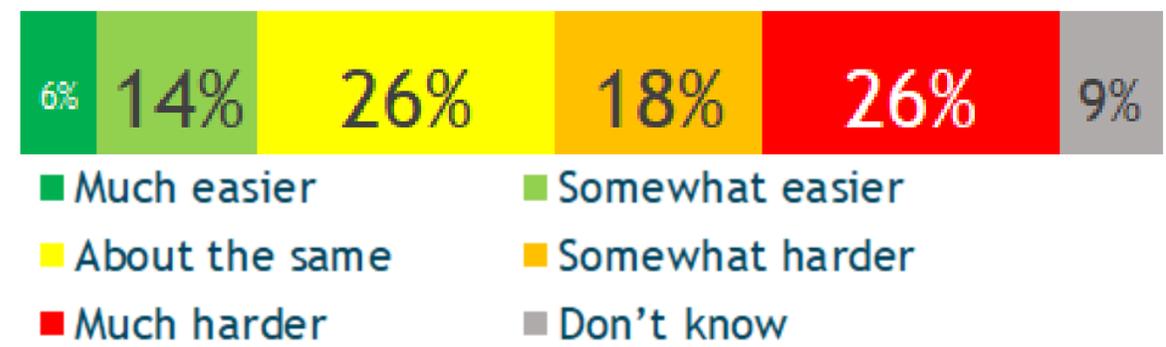
(Tower Hamlets resident, blind)

Health & Care services

Access to mental health services

- Mental health services experienced cancellations and disruption in the Covid-19 pandemic, though not to the same extent as hospital outpatient services.
- Those who experienced cancellations felt unsupported, as most of them received no help in managing their health in the meantime.

Do you find it easier or harder to access mental health support now?



Those who experienced cancellations felt poorly supported to manage their own health, with only a minority receiving any alternative or advice:

Did you receive any other alternatives or advice on how to manage your health after your hospital appointments were cancelled?



31% of those who used mental health services experienced cancellations.

66% of them said cancellations affected them a great deal.

38% of those not currently accessing any mental health services felt they needed mental health support but couldn't get it.

I have waited for over a year and nothing has happened.
(Hackney resident, hearing impaired)

Because of the pandemic all face to face appointments have been canceled. so I'm having a very hard time.
(Tower Hamlets resident)

Covid stopped face to face assessments so my Asperger's diagnosis took much longer.
(Havering resident, autistic)

I find access to the Community Mental Health Nurse somewhat harder. Too many restrictions, barriers, it's dehumanising. Too much delay, long waiting time/list, having to tell your story again and again is exhausting.
(Tower Hamlets resident, autistic)

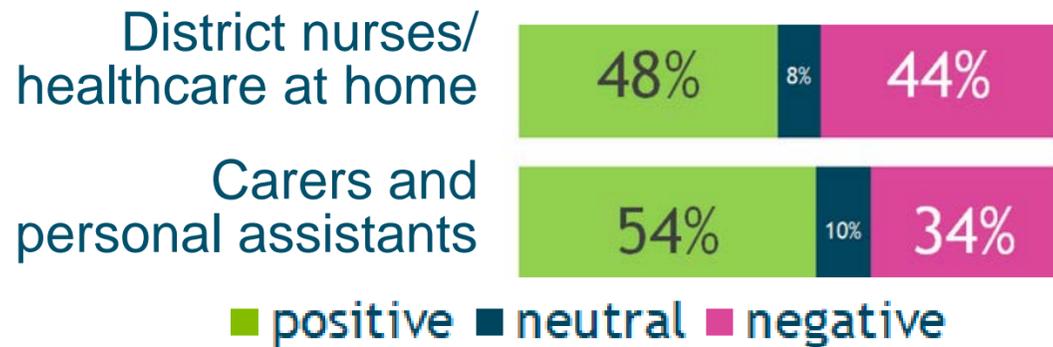
Unable to use mental health services. It is much harder to access mental health services. A waiting time of 4 months occurred, where 4 months later they said they don't see children under 11.
(Barking and Dagenham resident, mother of child with learning disabilities)

Health & Care services

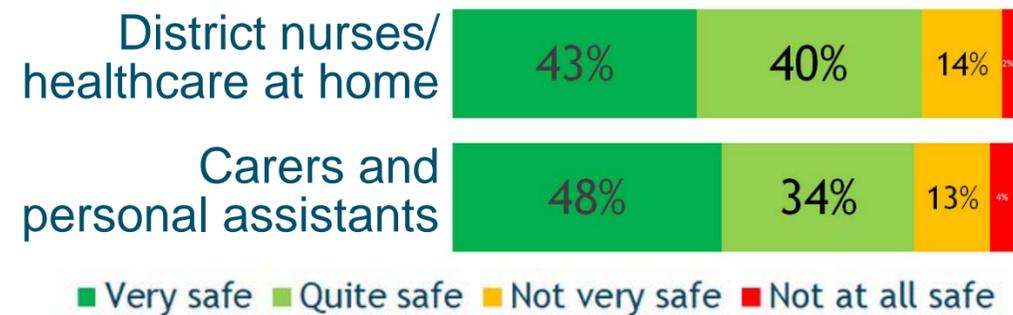
Healthcare and personal care at home

- Communication between patients and healthcare providers, particularly around changes in service provision caused by the Covid-19 pandemic can be lacking.
- Most nurses and carers started wearing appropriate PPE as soon as the pandemic started; but in a minority of cases there were delays in implementing Covid safety measures.

Overall opinion of care at home



How safe do you feel having care professionals in your home?



It has been somewhat harder to access community health services since the lack of communication was really bad. The district nurse turned up un-announced and let herself in which was very worrying and disrespectful behaviour. Said she could do it because she's a nurse!
 (Barking and Dagenham resident, family member of stroke survivor)

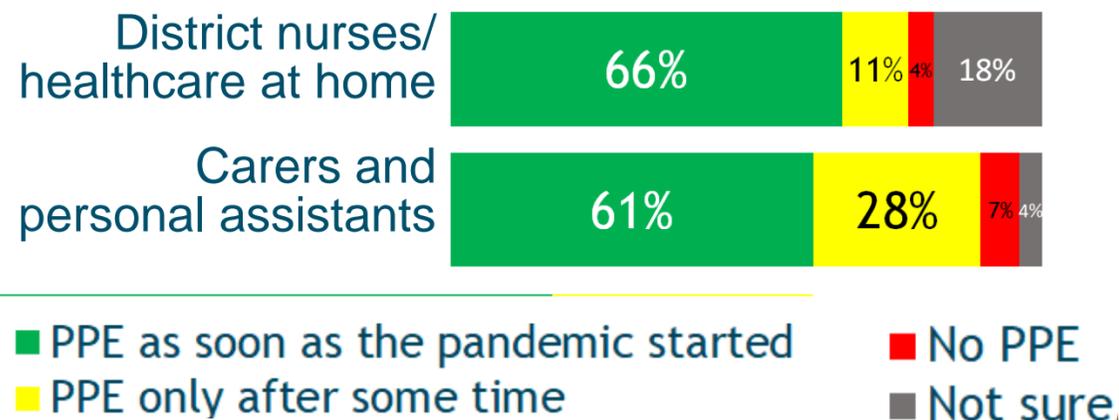
What works well

- District nurses and carers offer a good quality of care and support, with a pleasant attitude.

What needs improvement

- Because of Covid-related disruptions, people see their carers less often.
- Communication around changes in service is often poor.

Did health professionals wear personal protection equipment?



Government allocated extra hours for Carers to come to our home but the Care Agency didn't have any knowledge about this. It took multiple phone calls to the local council and the care agency to resolve this and finally get the extra help. A big let down mentally.
 (Redbridge resident, carer for wheelchair user mother)

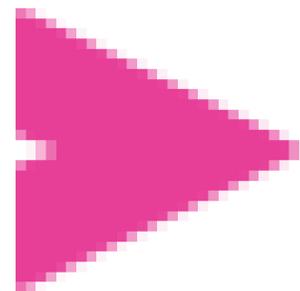


Health & Care services

Day centres

The closure of day centres negatively impacted disabled people, leading to poorer mental health outcomes and social isolation.

15%
of respondents were using day centres pre-pandemic



89%
of them stopped attending while day centres were closed in the Covid-19 pandemic.



54%
of them took part in online activities organised by their day centre/



71%
of those whose day centre closed said closures affected them "a great deal".

Most affected:

- People aged under 65.
- People of Black ethnicities.
- Men
- People with learning disabilities.
- People with hearing impairments.

Those who took part in online activities were as likely to feel impacted as the ones who did not.

ONLY 34%
of those whose day centres were closed received any alternative care arrangements or support.

I had less to do and I was not able to meet up with my friends. The center was running some online stuff but I am not comfortable with all that.
(Tower Hamlets resident, living with chronic pain)

He's more isolated. We've seen so few people for the last year. I'm responsible for him 7 days per week 24hrs per day. The morning at the day centre used to give me headspace and a chance to clear up!
(Tower Hamlets resident, spouse of stroke survivor)

What difference has it made

Vaccine roll out

Feedback on the best methods to reach different impairment groups was implemented by the ICS Comms and engagement team as soon as they received the information. This helped inform the location and re location of vaccine centres and the production of videos, Easy Read and webinars for specific impairment groups. We are now informing the third phase of the vaccine programme

Health care services

Our profiling of those at risk of digital exclusion was used to train hospital and GP staff to help them to continue to reach everybody in the community.

communication preferences are being used to inform both improvement in hospital accessible information standards but also to help manage the long delays in elective care that will be a consequence of Covid.

We are participating in a wide range of quality improvement, transformation and co-design programmes including improving hospital communication systems and helping to even out GP services across the ICS

Acknowledgements

This report is the combined work of the eight North East London Local Healthwatch, the North East London Clinical Commissioning Group and Healthwatch England. The Local Healthwatch also worked with their own voluntary and community sector partners to reach residents from a wide range of backgrounds and impairment groups.

We would particularly like to thank all of the local residents who took the time to complete the survey during what were very difficult times. We are committed to ensuring that your insights continue to make a difference to health and social care and hope you will continue to work with us we help the health and care system to build back better.

