



Because we all care

Voices of disabled
residents and Covid 19



North East London July 2021

Summary

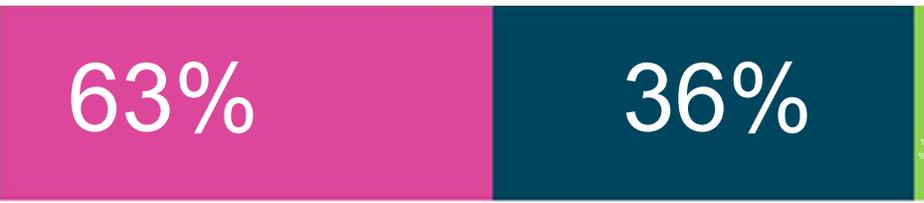
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Voices of disabled residents Summary



or living with a serious long-term conditions



Women ■ Men ■ Nonbinary/ other



White British ■ White Other
Other Asian British ■ Black or Black British
(incl. mixed)

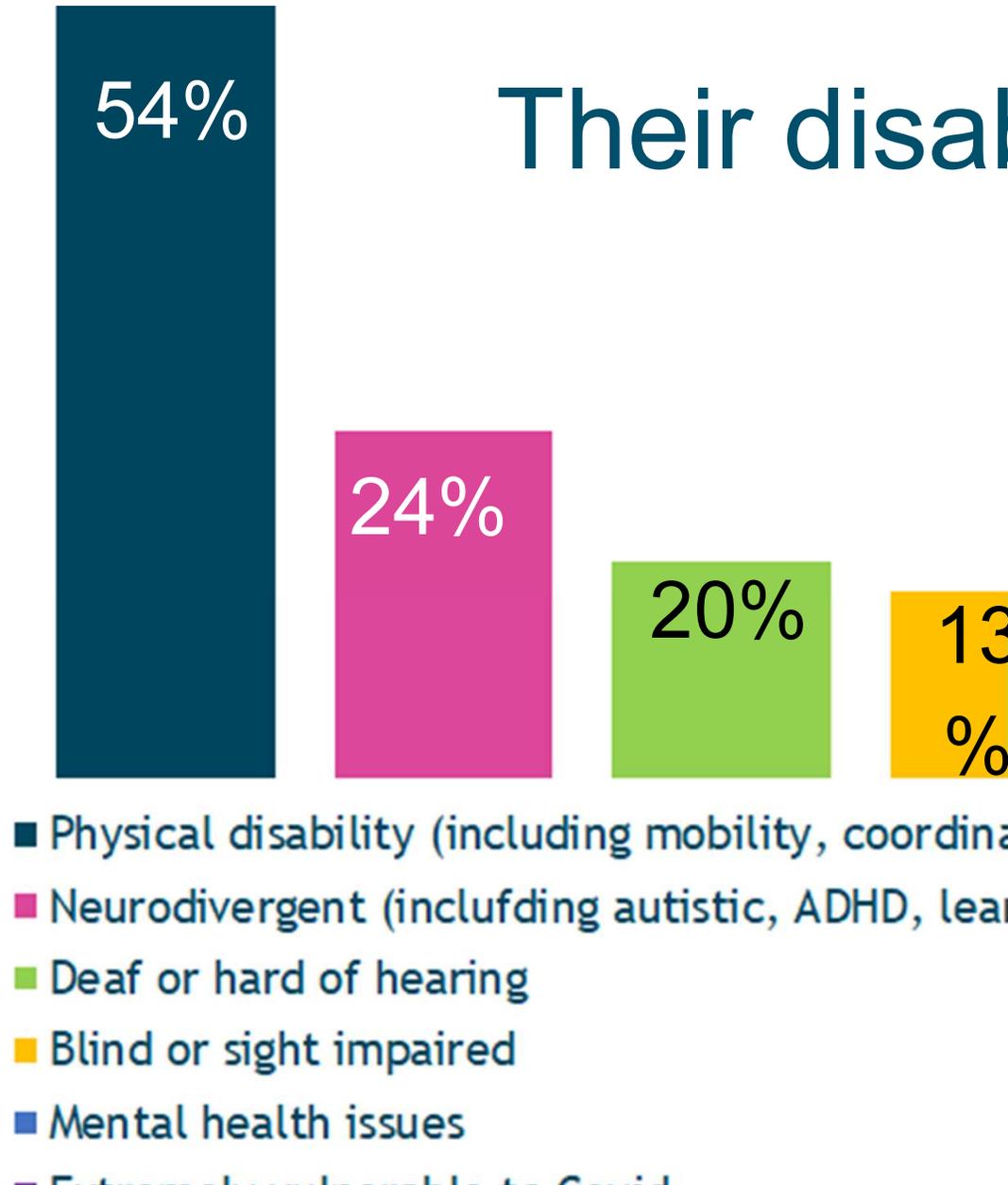


18-24 ■ 25-49
65+



Havering and Dagenham ■ City of London

Their disa



■ Physical disability (including mobility, coordination)
 ■ Neurodivergent (including autistic, ADHD, learning difficulties)
 ■ Deaf or hard of hearing
 ■ Blind or sight impaired
 ■ Mental health issues
 ■ Extraordinary health conditions

No "one size fits all" solution

Strategies that work well:

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

Easyread materials featuring graphic illustrations, large font and high color 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.

An easyread front page containing essential information could be used for letters sent by the NHS or Government regarding health and social care.

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

No "one size fits all" solution

crucial role in
information.

already seen by most
trusted authority when
health and social care

nt records, they have
) specific information
son's communication



Personalised outre
information more a

Collecting and recor
person's specific com
and offering differen
contact by phone, to
sent by email) wou
and social care profe
them in the way
contacted, and to ens



people could communicate their contact preferences ONCE, t
ies; and through integrated care systems these would be used

Services experiencing the most cancellations:

Hospital outpatients

Community services (such as chiropody or physiotherapy)

Day centres

Groups most vulnerable to disruptions in healthcare:

People with disabilities (unable to work or receive personal care).

Elderly.

People with long-term conditions.

People with mental health issues, particularly children under 18.

Covid-19 related disruptions have caused a backlog of untreated cases in non-urgent health services, affecting secondary and specialist care.

To manage this backlog we need to implement transparent prioritisation.



Prioritise issues that would be likely to cause the most harm or be more resource-intensive to treat if not addressed.



Work with primary care providers, social prescribing, and community services to offer temporary support such as pain management, occupational therapy, 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.

safety
make
less
abled

ement to
he door

with
who need



Most respondents experienced online consultations

More online and telephone consultations can be such as those who cannot easily travel because physical or mental health; but are not accessible **sensory impairments, learning disabilities or a la most likely to struggle.**

Investment in both telephone infrastr access pays off in the lon

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

ards

where a patient/user can choose their communication preferences (e.g BSL, Easy Read)
Can communication preferences be shared across the health and care system if people wish?
Are there any tools for key impairment groups? People with learning disabilities seem to be particularly affected.
If you can get things right for people with learning disabilities it will also help a wide range of other people to contact us and communicate with us?

How do we support people while they wait for treatment that has been delayed due to Covid?

How can we communicate about waiting lists as transparent as possible?

How can we improve the appointments process giving people?

more notice as possible.

How can we provide updates on waiting times, where they are in the list and any changes.

How can we improve contact within the service.

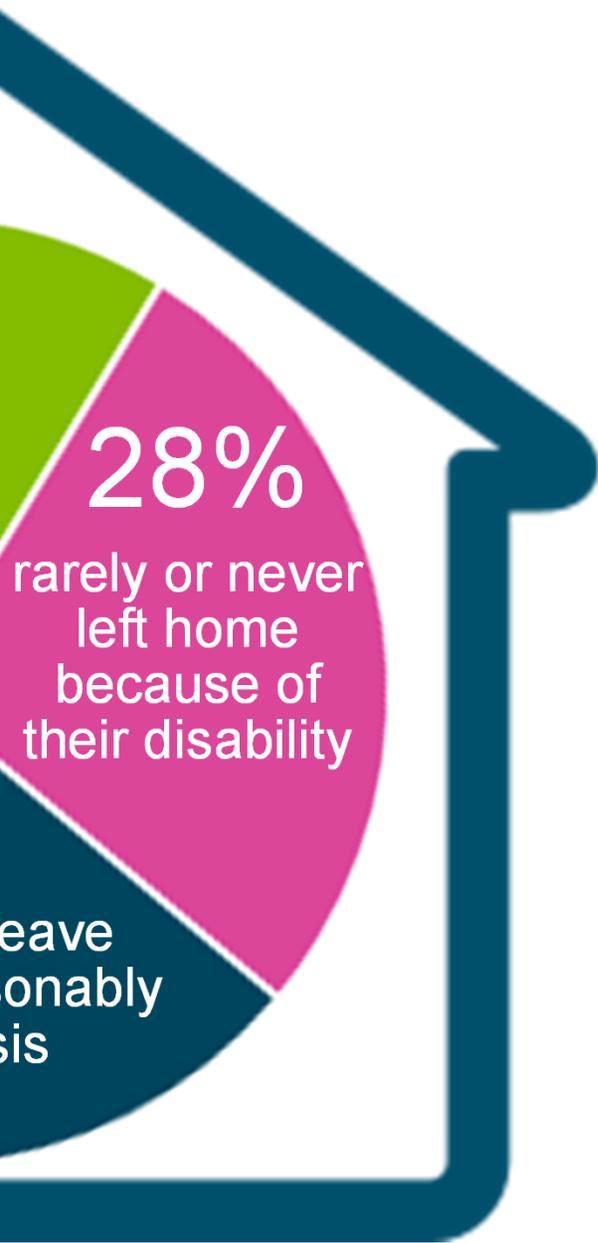
How can we provide information and support on how to manage their condition while they wait

How can we work with community care particularly around mental health and long term care?

How can we ensure community services and the voluntary and community sector play re: pain management

How can we improveablement care and social prescribing e.g supporting better mental health.

Respondents were diverse in terms of care needs and living arrangements, with many living in their own home and use online services.



42% received personal care



73% from family members

34% from paid carers



17% were working full-time or part-time

20% were of the

30% were

32% were digitally excluded

- Young people with disabilities were at risk of social isolation.

Disruptions in healthcare/ social care:

Chronic pain

Diverse backgrounds

Age 65, particularly

- people with learning disabilities
- Digitally excluded people
- People with more severe disabilities (unable to work or leave home)

53%

experienced disruption in their healthcare or social care.

Most affected by social isolation:

- People aged under 25
- People of ethnic minority

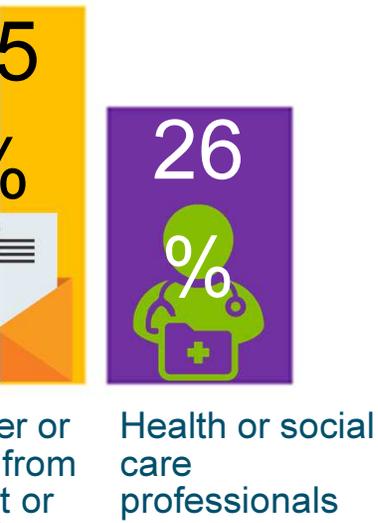
5%



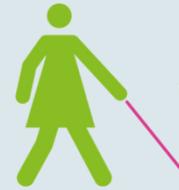
- People with learning disabilities or sight impairments may struggle with...
- BAME respondents rely more on word of mouth and less on online sources

Students
learned about

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



Neurodivergent/LDs



Sight impaired



BAME, especially black ethnicities

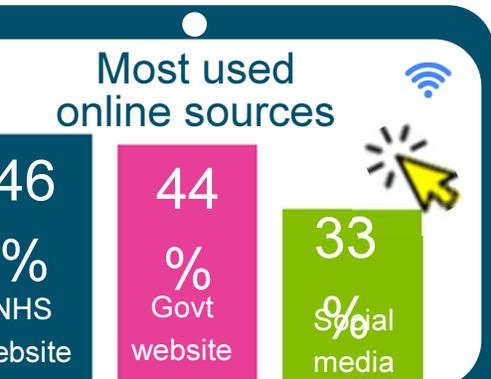


Most likely to use online sources

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

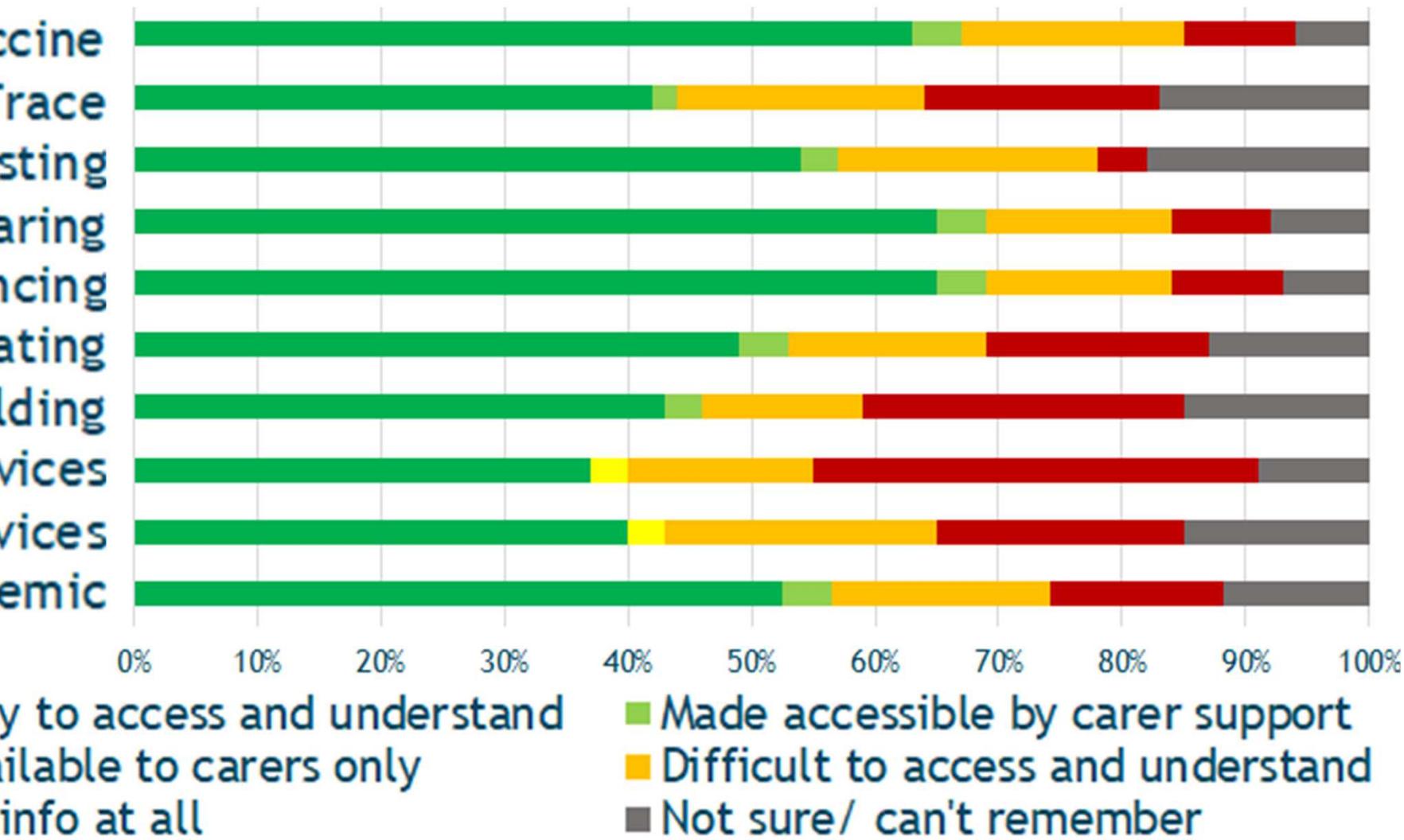
Least likely

- Neurodivergent
- Blind or sight impaired
- Severe mental health condition
- Black or BAME
- Aged over 65



• Respondents who were autistic, living with learning disabilities or with sensory impairments often struggle to find accessible information.

Covid-related topics



Most likely to find information



- The easiest to find
- The most useful
- The most relevant
- The most accurate

Least likely to find information



- A lot of information
- Really difficult to find
- Really hard to understand
- Difficult to read
- The information is not relevant
- The information is not accurate

11 respondents found the font in the document difficult to read
 8 respondents found the font in the document hard to read
 14 respondents felt there was a lot of information in the document
 14 respondents felt there was a lot of information in the document

- Information presented simply, with clear explanations, is accessible to more people
- Written materials can be made more accessible with large print and plain language, however, some may do better with information that is not in written English

Participants expressed a need for information to be presented in plain, jargon-free language with simple formatting.

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

Participants expressed a need to receive information in formats that did not rely on written word (such as by telephone, video call)

Information which may be more accessible to people with hearing or vision impairments



Those with hearing or vision impairments



Deaf and hard of hearing people in the UK



People with learning difficulties

41%

of respondents with hearing or vision impairments

- Bespoke strategies should be formulated for reaching out to disabled, excluded or unable to communicate.

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)

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access.

- Communication should not excessively rely on online information, particularly the elderly, those with cognitive and sight impairments, barriers to accessing online services.



32%
of all respondents were digitally excluded.

38%
of neurodivergent respondents were digitally excluded.

52%
of sight impaired respondents were digitally excluded.

sent electronically and include clickable links on a mobile phone.

(Tower Hamlets resident)

links on an iPhone and a reasonable size (not too large as standard, just

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 as a leaflet for those who can't use the internet and not miss out.

Some smart

unnecessary clutter.

- Alternatives to written information (such as audio/video, contact b... should be considered for those who cannot read.

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

...hose who are able to read, the use of **large print, bold**
...s and contrasting colours (such as black lettering on
...e background) can help.

...ne resources should consider **compatibility with**
...otive software such as screen readers.

...use of
...nquiries, as
...o a person.
...websites and
...are not easy
...er people
...ith with their

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.

(Havering resident)

41%

41%

I received info
Healthwatch
critically help

Health profes
various degre
their patients

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

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

6% of respondents with hearing impairment could not access the information because...

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.

9% of respondents with hearing impairment could not access the information because...

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

Face coverings make it hard to understand people. You have to rely in reading lips until you can hear. If there is background noise, listening to someone wearing a mask, a glass of water and the person speaking, it's hard to hear what it sounds like.

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

Health briefings should be more accessible...

- Easy-to-read materials, featuring visuals and simple explanations used in written language may help neurodivergent respondents stay informed.
- The written language is not a suitable medium for all; some respondents may not understand information presented visually or in a face-to-face conversation.

Materials

Images, icons, and illustrations in written language and audio may be more accessible than written 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 found it harder to stay informed about Covid because they found the language too complicated.

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 plain language, with easy-to-understand explanations.

videos suitable for children who have autism.

resident, parent of child with learning difficulties)

to produce and I need

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)

Speak to staff for information. Changing the way we communicate. Easy to understand. Good communication. Information. Promotion.

Written materials in a variety of languages may be helpful to some BME cultural considerations may need to be taken into account; such as the fact that oral cultures may be more responsive to direct outreach and multimedia information.

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ely
nat
ng.



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 words or even when someone says stuff or my mind wanders. In written version it would have been harder.

(Tower Hamlets resident, Somali)

Make informative materials much shorter and simpler. Use colourful pictures, sketches, cartoons and regular check prompts, videos and audio messages.

(Newham resident, Bangladeshi)

Doctors should explain things clearly, step by step.

Non-White
y would
ormation in
an English.

White non-
aid they
eive
essages

vaccine uncertainty in the BAME community can be tackled by ad
circulating.

- A small number of respondents living with long-term conditions fe
receiving sufficient information specific to their circumstances.

66

66% of respondents who intend to
take the vaccine
prefer to be
informed by
their GP



Some respondents living with long-term conditions expressed a desire for more specific information 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 M.E and the Covid vaccine, and if any particular vaccine will be more efficacious.

(Tower Hamlets resident, diagnosed with ME/CFS)

be



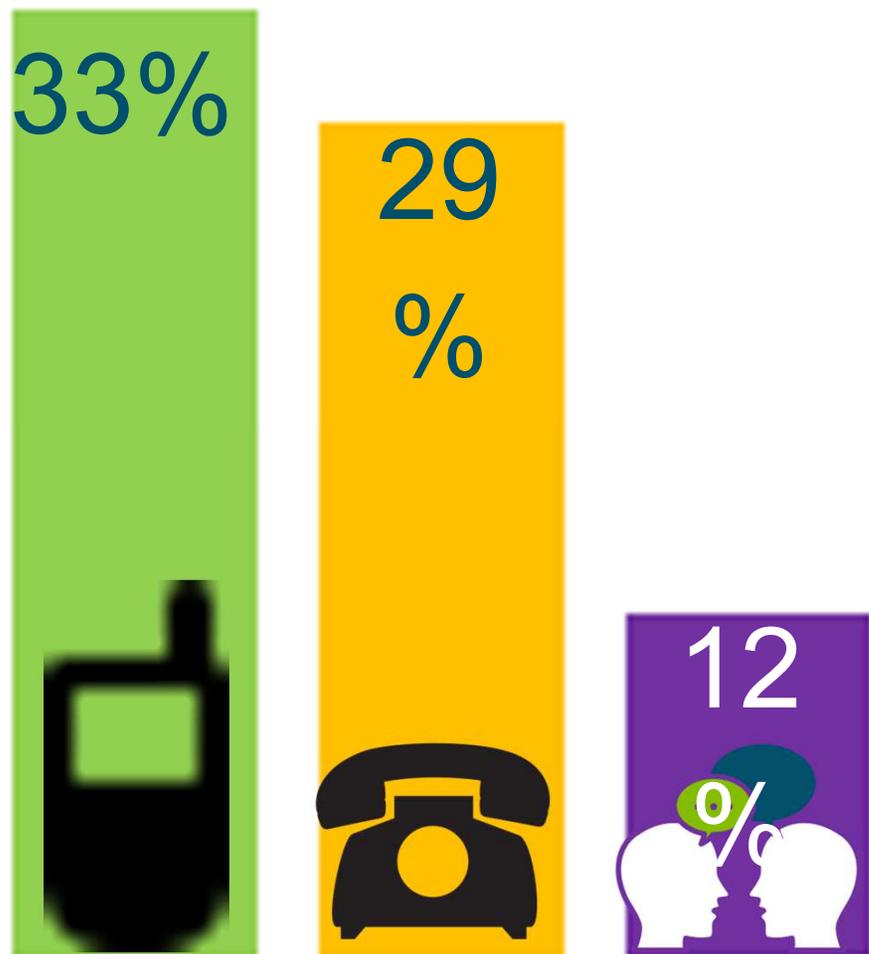
A lot of people of BAME heritage are very reluctant to take the vaccine as they've been exposed to many conspiracy theories.

The BAME community have the lowest rates this needs to be addressed. The issue is equal access for all to health, the perception is that this community it does not have equal access. The out



alternative methods of communication.

Not a "One size fits all" approach



12

would prefer to only be contacted verbally, via phone or video, without written text.

54

of respondents with sight impairments preferred to be contacted by phone





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.



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- 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 making them local and near public transport, providing parking and a transport service

Vaccination sites accessible for people with disabilities

Ensure good accessibility, including ramps and lifts.

Ensure accessible toilets, including for wheelchair users.

Ensure seating for people who cannot stand for long. Consider including reclining or lying down.

Ensure a free or cheap transport service. Ensure sites are easily accessible by public transport.

Ensure people have access to vaccination in their local area. (Including through their GP surgery)

Ensure home visits for those who cannot leave it easily. (Including through district nurses or carers)



*Excel didn't have a lift, which was a problem especially for people who can't get home (we don't all have cars).
(Tower Hamlets)*

*Ensure there are enough toilets, especially if they are near to a bus stop. I managed when one was out of order. I thought all of the other people at my home and well.
(Tower Hamlets)*

*Make sure if they have a wheelchair something like hospital. Make sure wheelchair accessible on a different floor.
(Tower Hamlets)*

*Any disabled person who can't get in my view. Going to a vaccination centre is senseless when people are waiting months.
(Barking and Dagenham)*

*See if we can accommodate people who wait outside or sit on the ground.
(Tower Hamlets)*

- People who are anxious or sensitive to sensory overload could benefit from quiet slots.

Vaccination sites accessible for people with hearing disabilities

• All communications on-site need to be accessible for those with hearing impairments, or learning disabilities. (e.g. sign language, contrasting large print, Braille)

• Train centre staff with disability awareness training, and communication strategies for different disabilities.

• Train centre staff with training on supporting people who are nervous or have anxiety or fear of the needle.

• Avoid bright lights and other sensory overload. Consider offering quiet slots for those who need them.

• Offer quiet slots and long waiting times.



I'd like to have a quiet slot where you don't need to be vaccinated screaming. I'd like to have phones or a sign to make it easier to get to toilets. I'd like to have a time range for that slot to help severe anxiety.

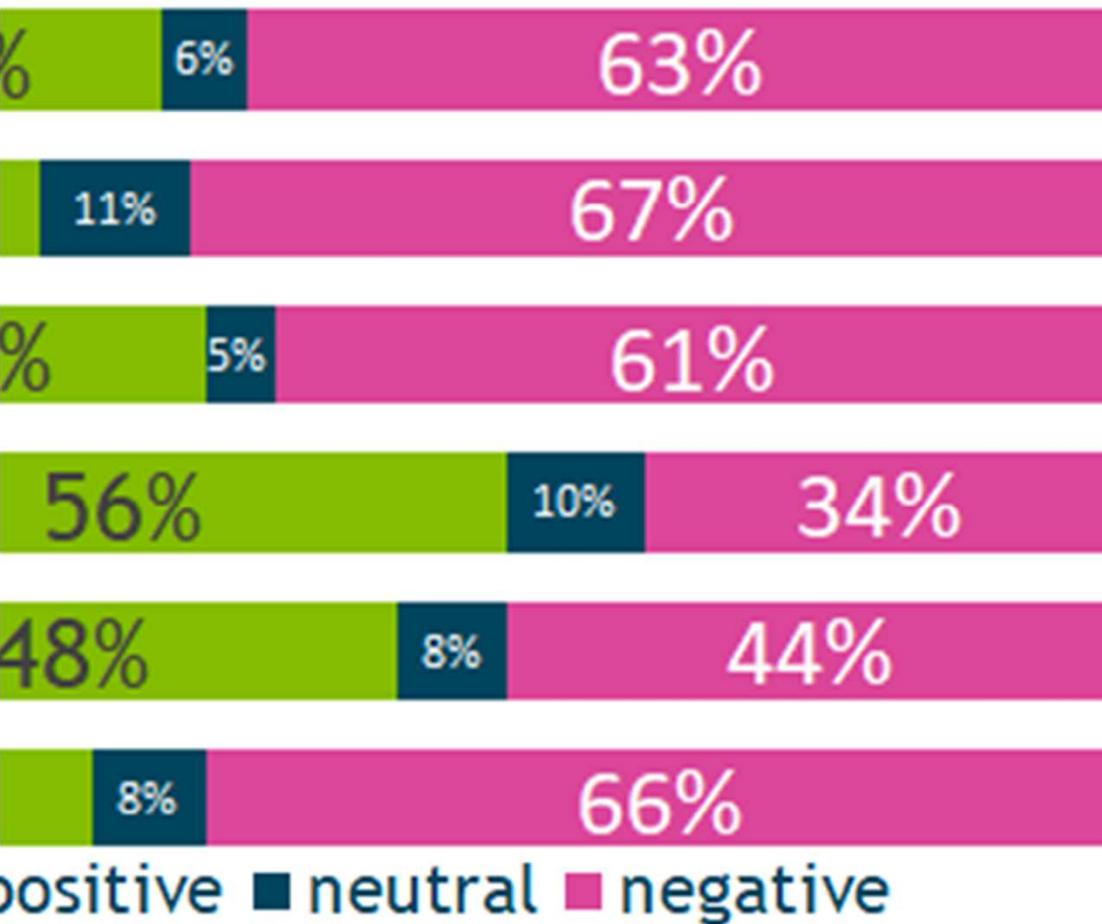
Just don't have any noise, immediate help if you're doing or anything. I'd like to have many people pointing to the slot.

I would like to have BSL access.

Brightly

- People with hearing impairments and children under 18 had the most health and social care services.

people's experience of health services **leaned negative.**



Most positive experiences

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

Most negative experiences

- Children (under 18)
- People with hearing impairment

hospital-based procedures, hospital outpatients and provision of day care

excluded.

- Hospital outpatient services, community services (such as chiropractic centres) have been the most affected by cancellations.

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 most cancelled:

- Hospital
- Community services (such as chiropractic, physiotherapy)
- Day centres



pandemic

- In some cases, Covid protection measures may make practices less

GP

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

What needs im

- Not all GP practices a
- Online systems are n
- Practices are difficult
- Communication with c
- People wait too long f

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

ive

- Repeat prescription requests were the most widely use online serv

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.

... on the phone at home, so I had my daughter explain to me
... trying and ask questions, I felt much more comfortable, I
(Tower Hamlets resident, fibromyalgia)

... ents seemed a good option for me, but I've been couple of
... well for routine blood tests etc. I've booked them through
... but I was using the system before and nothing particularly
(Newham resident, autistic with anxiety disorder)

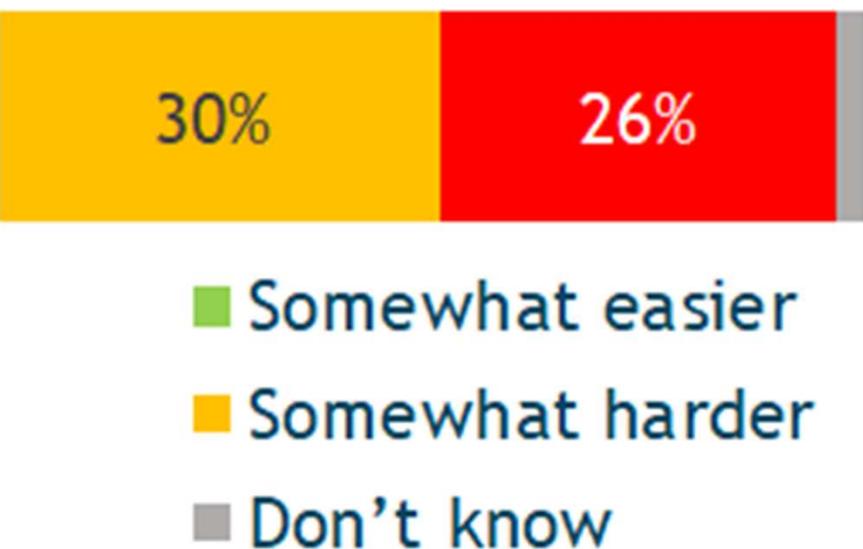
*My GP does phone calls only- I
... face to face, there are things
... phone call. (Tower Hamlet*

*My GP surgey don't answer their
... the internet. I have to get sor
... and do online consultation.
(Tower Hamlets resident, r*

Trying to make an appointment

- In some cases, Covid protection measures may make practices less

er or harder to book
now?



regarding getting a vaccination locally where I know the
ad received my letter inviting me for a vaccination, but I
ortant and that I was jumping the queue. This could be
understanding of the difficulties people like myself have.

Who had the hardest time ge

- People with sight impairment
- People with hearing impairment
- 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
on the phone. Harder to schedule appointments
to remote calls, but then when that isn't sufficient
seen face to face, which means delays in care
routine appointments myself rather than having
schedule them. Repeat medication needs to be
than automatically renewing. I'd rather not see a*

Those who received treatment as inpatients for Covid in particular re

- Long waiting lists and cancellations impact upon patients' access to
- Remote service provision makes communication with doctors harde

What works well

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

What needs im

- Cancellation to r
- appointments im
- People wait too
- Communication

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)

I don't understand a lot on me face to face so I can ex

(City of

I have had no reply whatso to a message I left some w

(Waltham Forest

Because of pandemic m cancelled until this summer

- Phone appointments can be more convenient for some, but they pose challenges for some 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 a
appointment
online.

through video calls means avoiding the commute and waiting room anxiety. It also means if the consultant is late I don't have to wait in the waiting room. As they call me on a video app I can book appointments even if I've forgotten about them.

(Tower Hamlets resident with mental health issues)

from surgery, still getting test results and making appointments, doing that over the phone was incredibly difficult. I can't easily see a nurse in the breast clinic to ask about my appointment.

My consultant was aware of my deafness but I had to switch to TELEPHONE on the day of my appointment (I had to switch to telephone a few days prior) - no communication standards and no response to text messages in the morning to advise and explain the situation.

(Haverhill resident)

Appointments are either being cancelled at the last minute or I have to go to a telephone appointment; my mum, who is deaf, has to go with me. Some appointment would be good to keep.

being affected by service cancellations and delays.

- Those who experienced cancellations felt unsupported, as most of them were managing their health in the meantime.

harder to access



somewhat easier
somewhat harder
don't know

and hospital services
cancellations.

cancellations affected
al.

cancellations affect you?



Those who experienced cancellations felt it was harder to manage their own health, with only a small number receiving any alternative or advice:

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



- Yes, it was useful
- Yes, but not very useful
- No alternative or advice
- Not sure



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

I have cancelled my new hospital appointments (

are long.

- When people can access mental health services, they have positive e online or telephone sessions.
- Communication about changes to services in the pandemic needs im

What works well

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

What needs improvement

- Communication with mental he
- People wait for a long time to g health support.
- There is limited choice for whe mental health support.

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

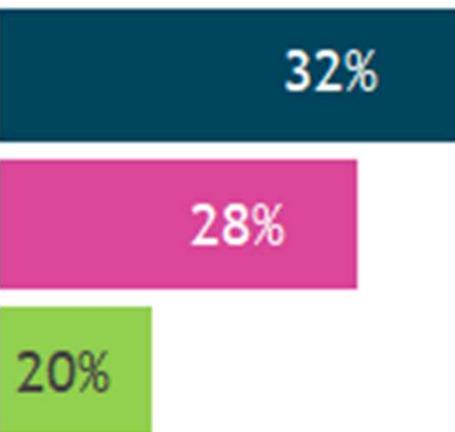
I had to rearrange some counselling appointments, so I missed some. They should have been clearer that they changed all the appointments to over the phone in the beginning. This would have made things clear and I may not have missed my appointments.

(Tower Hamlets resident, depression)

hospital-based service or Community Mental Health team.

- Most types of consultation and mental health treatment have been online.

Used mental health support from:



Out of the 143 respondents who used mental health support from:



My mental health problems started during the pandemic. I can now speak to my GP without having to explain everything to them, which is helpful because as soon as I told them I am blind and my daughter cannot access online services I got a call from my doctor.

- Those who experienced cancellations felt unsupported, as most of them were managing their health in the meantime.

It's harder to get support now?



what easier
what harder
I know

Those who experienced cancellations felt poor at managing their own health, with only a minority receiving an alternative or advice:

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



■ Yes, it was useful ■ Yes, but it was somewhat harder
■ No alternative or advice ■ Not sure

Experienced mental health cancellations. Cancellations affected mental health.

Currently accessing mental health services felt they were not getting the health support but



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 mental health services somewhat harder. It's very dehumanising. Took a long time having to tell your story.

Unable to use mental health services. I had to access mental health services where 4 children under 11.

(Barking and Dagenham resident)

service provision caused by the Covid-19 pandemic can be lacking.

- Most nurses and carers started wearing appropriate PPE as soon as in a minority of cases there were delays in implementing Covid safety

at home



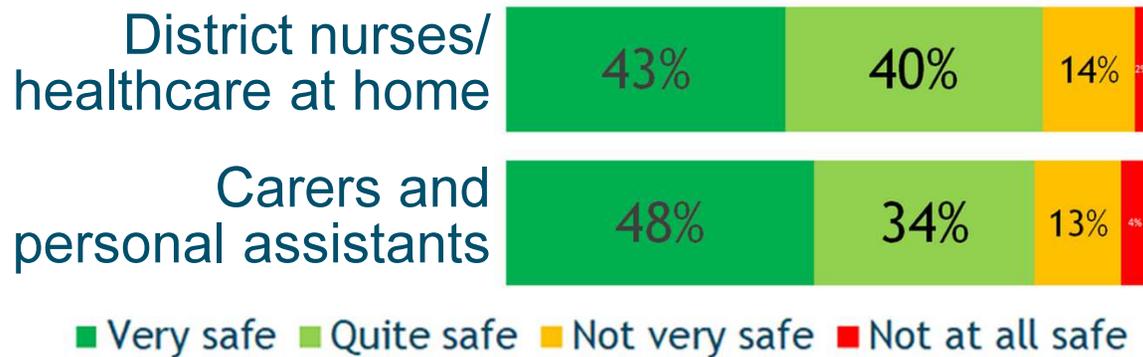
ral ■ negative

offer a good
, with a pleasant

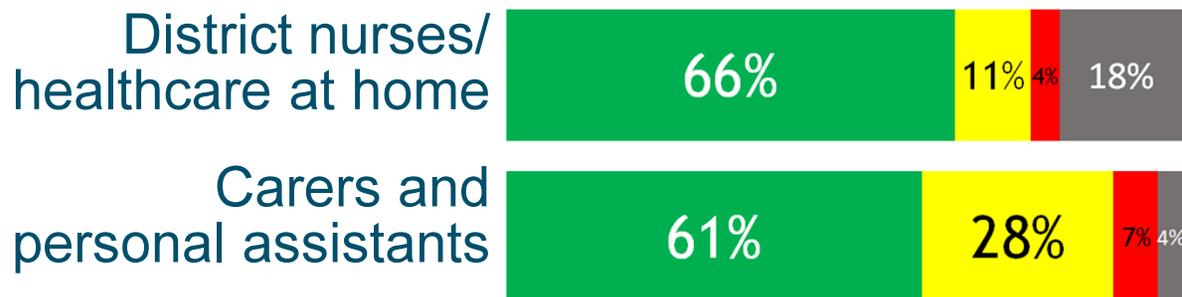
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disruptions,
s often.
anges in service

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



Did health professionals wear personal protection equipment?



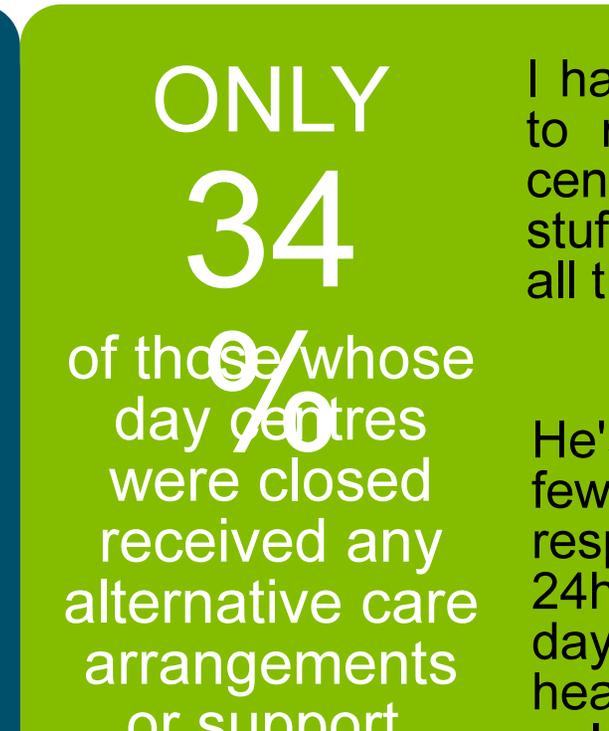
■ PPE as soon as the pandemic started ■ No PPE

outcomes and social isolation.



Most affected:

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



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

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

Our communication preferences are being used to inform both improved accessible information standards but also to help manage the additional care that will be a consequence of Covid.

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

with their own voluntary and community sector partners to reach resident grounds and impairment groups.

We would particularly like to thank all of the local residents who took the during what were very difficult times. We are committed to ensuring that make a difference to health and social care and hope you will continue to health and care system to build back better.

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healthwatch
Hackney

healthwatch
City of London

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healthwatch
Newham

healthwatch
Redbridge

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Real
Disabled people
working together
for real choices

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Challenge
Motivate

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