



# Disabled Voices: Learning from Covid

January/February 2022 – Context and practical recommendations



# Setting the Scene

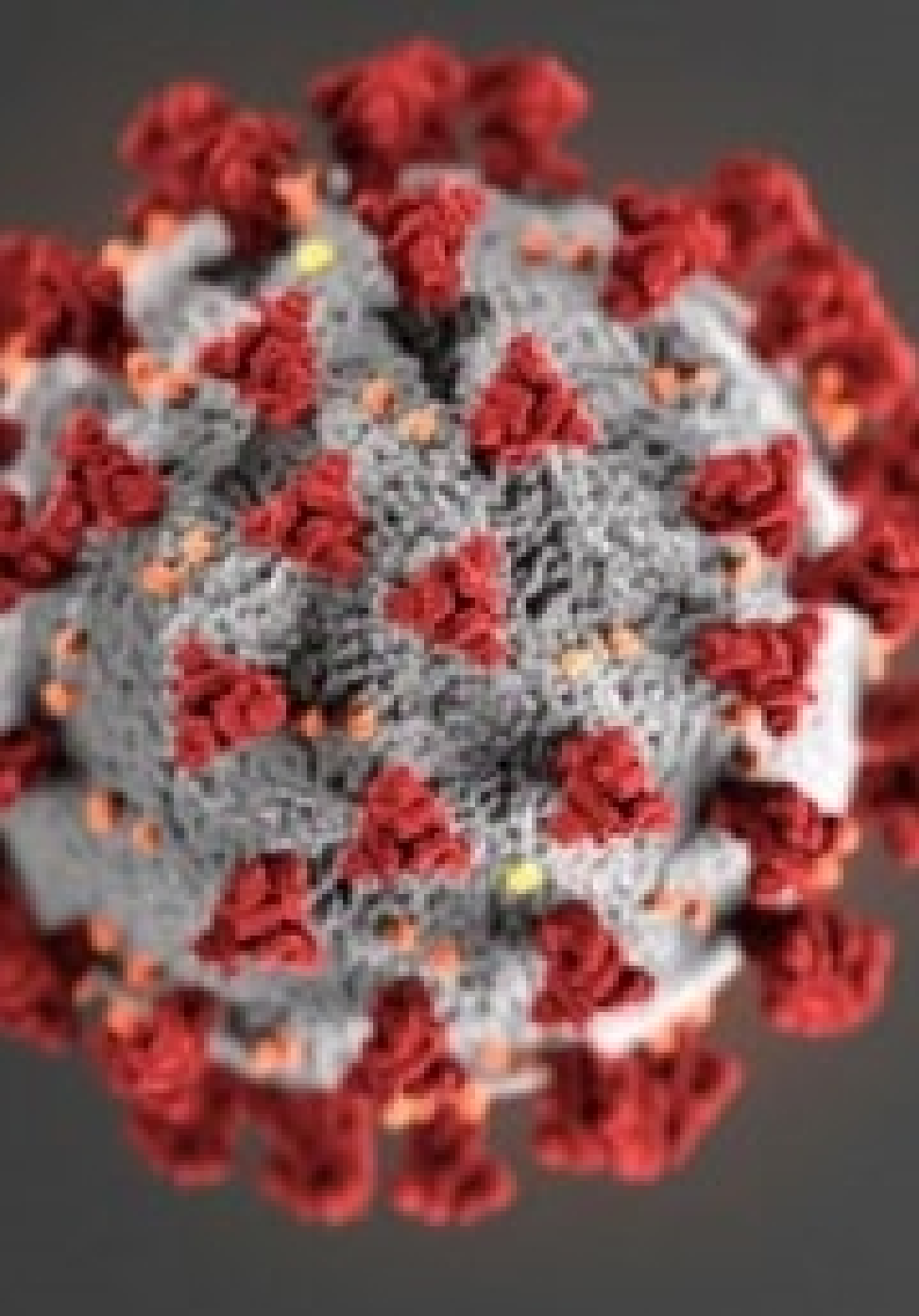
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- **The Accessible Information Standard has not been enforced**
  - Resulting in many disabled people not receiving vital safety information relating to Covid.
- **The Equality Act 2010 has not been complied with**
  - In the areas of indirect discrimination and failure to make reasonable adjustments.
  - Lack of accessibility to Covid health services, including vaccine and test centres, placed disabled people at a direct disadvantage of receiving equal healthcare.

"We feel like we have been treated like second or third class citizens, only considered as an after thought"

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# What we found out

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## **Covid has affected disabled people differently**

- Higher mortality rates
- Shielding has exacerbated people's mental health (isolation, loneliness)
- Lack of accessible information has:
  - Increased anxiety
  - Increased confusion and frustration
  - Increased vaccine hesitancy
  - Lowered Covid testing amongst certain impairment groups
  - Reduced people's independence
  - Increased reliance on family/friends
  - Not permitted disabled people to make informed decisions about their healthcare

“Shohid arrived at the vaccine centre and there was no interpreter. They tried to explain they were deaf and none of the staff knew how to respond and kept talking to the person. They asked if information could be written down. Staff refused. They asked if masks could be removed to aid in communication. They refused. There was no deaf awareness.”

\*Name has been changed for confidentiality reasons

# Covid Testing - 1

1. Uptake of testing is very low amongst some impairment groups
2. Test kits are not designed for visually impaired people
  - Packaging
  - Instructions
  - Registering kits
3. Ensure staff support available to assist disabled people to carry out tests
4. Walk in sites for LFT (pharmacies/doctors) with support staff to administer and register tests
5. PA/Carers/Family member should be allowed to accompany disabled people into tests centres
6. Ensure confidential spaces when recording personal information (Filling out test details)
7. Staff should not ask children/family/friends to interpret or carry out the tests for them



# Covid Testing - 2

## 1. Information at test centres in accessible format

- Videos with BSL and subtitles (made by Deaf people – testimonies)
- Clear audio information
- QR codes at centres and on packaging to instructional videos e.g BSL videos (QR codes not accessible to all)
- Staff wearing transparent masks (for lip reading)

## 2. Accessible LFT/PCR kits

- Easy packaging , Braille, Colour contrast, Bright, Large font, Bullet points, Simple language
- One page instructions on card that can be propped up
- Audio information
- Connect to 'Be My Eyes App'
- BSL video (with subtitles) clearly explaining how to register and carry out tests
- More visuals showing process



# Covid Testing - 3

1. Registering kits is very difficult for particular impairment groups and if you are digitally excluded (long process, complicated, requires technical skills)
2. Staff at testing centres should be trained in Deaf and Disability Awareness
3. More accessible information about how to get tests and where tests centres are located
4. Parents who are blind should be offered support to help their children carry out (and register) tests for going to school
5. Nurses/test staff carrying out tests increases confidence (am I doing it right?)
6. People preference of in-person vs. at home tests varies across groups
7. Recognition experience of disabled people during pandemic is different (clinically vulnerable). Still more wary of going out in public, and accessible testing must be made available to promote independence
8. Lack of trust in accuracy of tests





# Accessible Vaccines - 1

- Disabled people should be able to book vaccines/boosters at local GP/pharmacy (familiar setting)
- Specific vaccine clinic times should be made available for disabled people (can adapt setting, e.g. dim lights)
- If vaccine is not possible at local GP, disabled people should be offered the nearest location, and disabled access must be guaranteed (e.g. bus stop close by, accessible parking)
- PA/Carers/Family member should be allowed to accompany disabled people into vaccine/tests centres
- Appointment times should be given to avoid queues, busy times, maintain social distance



# Accessible Vaccines - 2

- If a patient has to wait for 15/20 minutes after vaccine, staff should ascertain whether they can read the time, and if not, assist them
- Health professionals should have knowledge of patient's disability/health condition and access needs before vaccine appointment to discuss any potential complications and support them appropriately (integrated health information)
- Disposable elbow bands should be available at clinics to assist blind people to their seats/appointment rooms. Staff should be aware of the correct way to guide someone
- Staff at testing/vaccine centres should be trained in Deaf and Disability Awareness
- Booking vaccine online and/by phone not accessible for everyone. Ensure option to book via GP and by text

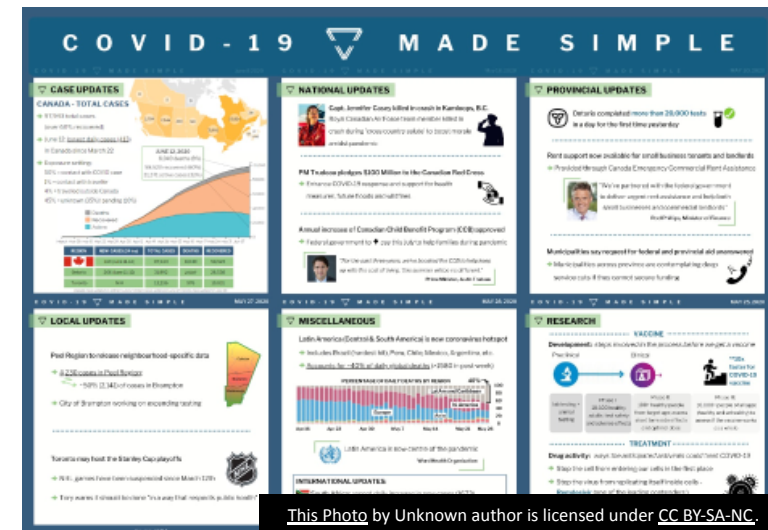


# Accessible Covid Information

1. Accessible Covid health information
  - Easy read leaflets
  - CDs/USBs with audio information
  - Braille, large font
  - TVs with BSL/subtitles
  - Simple language
  - At vaccine clinics/GPS/Pharmacies/TV/Social media/NHS website etc.
2. Information about vaccines sent to people in advance
3. Ensure a BSL interpreter is present at all clinics
4. Staff should wear transparent masks so Deaf people can lip read
5. GP/health professional available at vaccine clinic so that disabled people can ask questions before and after the vaccine
6. Clearer information about how to access Covid passport, especially for those digitally excluded



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# Accessible Healthcare

## - Promoting independence

- PA/Carers/Family member should be allowed to accompany disabled people into health appointments
- Invest more in accessible telemedicine (E-consults can be beneficial for some but the option of face-to-face appointments for disabled patients must continue)
- Health professionals should have knowledge of patient's disability and access needs before appointment to advise appropriately (flagging system)
- Specific clinic times for disabled people (e.g flu vaccine, Covid jab)
- Location of appointments should be local (ideally at patient's own GP surgeries)
- Accessible venues (bus stops close by, step free, automatic doors, pavements)



# Loneliness and Isolation

- Recognition that the experience of disabled people during the pandemic has been different (and harder)
- Isolation has exacerbated many disabled people's mental health and increased loneliness
- Services should be made available specifically for people who have been shielding, and on clinically vulnerable list to help with mental health and anxiety
- Services should 'check in' with disabled people during lockdowns (and more generally)
- Services for disabled people isolating due to Covid (particularly those isolating on their own/without support from family/friends)
- Primary care staff may be the only point of contact for some disabled people



# Living Independently in a pandemic

1. Support for disabled people to do online shopping/get shopping delivered to home
2. Advice/Guidance as to how disabled people can access support when isolating with Covid
3. More support for disabled people to learn digital skills to get online to access health (and other) services
4. Ensure ongoing Carer/PA support during pandemic

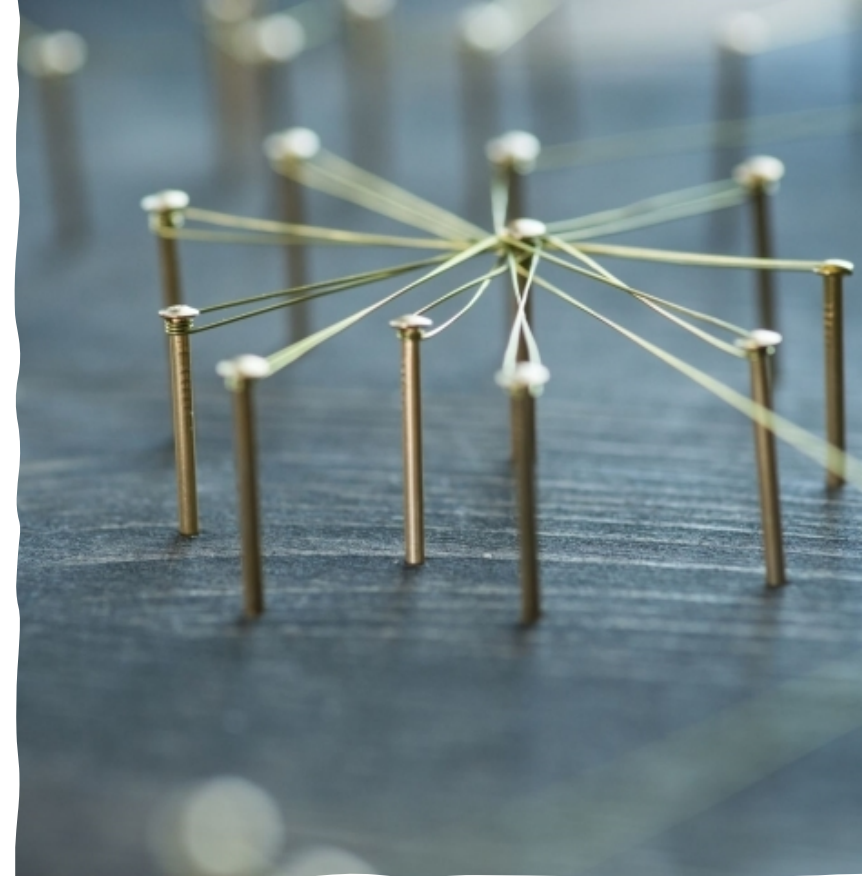
Has relevance to social care, personalisation workstreams and potentially CHC/PHBs



# Navigating the system

**“The system has become even more broken and neglectful (for disabled people) due to covid”**

1. Covid restrictions have prevented disabled people accessing the support they need (e.g day centres closed, Carers refused into appointments)
2. Home care system has let down disabled people (frontline staff not coming in when someone has Covid, people left to fend for themselves)
3. Non-urgent health appointments have been cancelled (e.g physio, surgeries, secondary and specialist support)



# Navigating the system - Recommendations

1. Disability and Deaf Health Helpline (Advice/support service for disabled people that has no assessment criteria attached to it)
2. Disability and Deaf awareness training for frontline staff (promoting compassion and empathy)
3. Review of the home care system and how it supports disabled people during the pandemic
4. Manage the backlog of untreated cases in non-urgent healthcare through 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, e.g. pain management, occupational therapy
  - Communicate transparently about waiting lists






# Public Awareness

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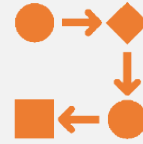
- Public support - messages disabled people have experienced things differently - some many need assistance, but some might also need you to keep distance because they are more vulnerable
- Campaign about consent. Physical contact is now an issue of consent



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# Discussion points



Who needs to do what to get things done?



How do we get traction/ownership?



What is immediate?

# About the Project Partners



Real is a user-led organisation run by disabled people who live, work, volunteer or study in Tower Hamlets. 100% of our board and a significant majority of our staff and volunteers are disabled. We are a registered charity (number 1061671) and a company limited by guarantee (company number 3213172).

Real primarily works with disabled people who live, work, study or volunteer in Tower Hamlets, but our constitution allows us to work beyond borough boundaries and to contribute to regional and national issues too. We support disabled people of all impairment types, all age groups, all ethnicities and all other protected characteristics.

We are deeply rooted in the history of the disability rights movement, whose slogan “Nothing about us, without us” led to disabled people taking control of their future, because they knew what they needed to achieve equality. Being user-led is fundamental to who we are and what we do, which is why our tagline is “Disabled people working together for real choices

# About the Project Partners



**DeafPLUS:** DeafPlus offers a wide range of services to deaf and hearing impaired clients to develop their potential and promote independence and wellbeing. Based in Tower Hamlets, they provide one-to-one confidential Information & Advice services across England.



**ICM Foundation:** ICM Foundation runs CORE projects, an initiative that supports people with learning disabilities. They run a day centre, and provide a range of opportunities for disabled people to get involved with social events and influence local decision making.



## Healthwatch Tower Hamlets:

Healthwatch are an independent charity giving a voice to children, young people and adults who use health and social care in Tower Hamlets. We champion what matters to you and work with others to find ideas that work. They are independent and committed to making the biggest difference to you.

### Their aims are to:

1. Support you to have your say.
2. Provide a high-quality service to you.
3. Ensure your views are heard and help improve local health and social care.