Disabled Voices:
Learning from Covid

August 5th, 3-5pm, 2021

Virtual event

Project Summary

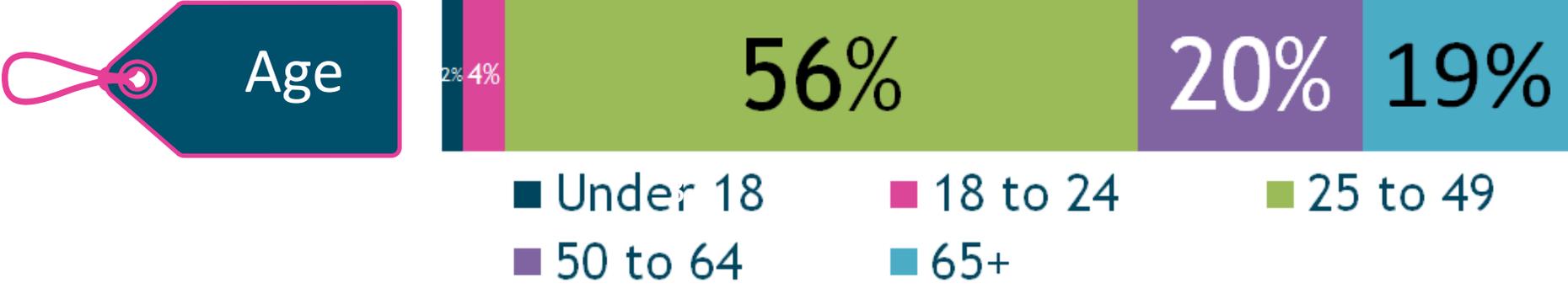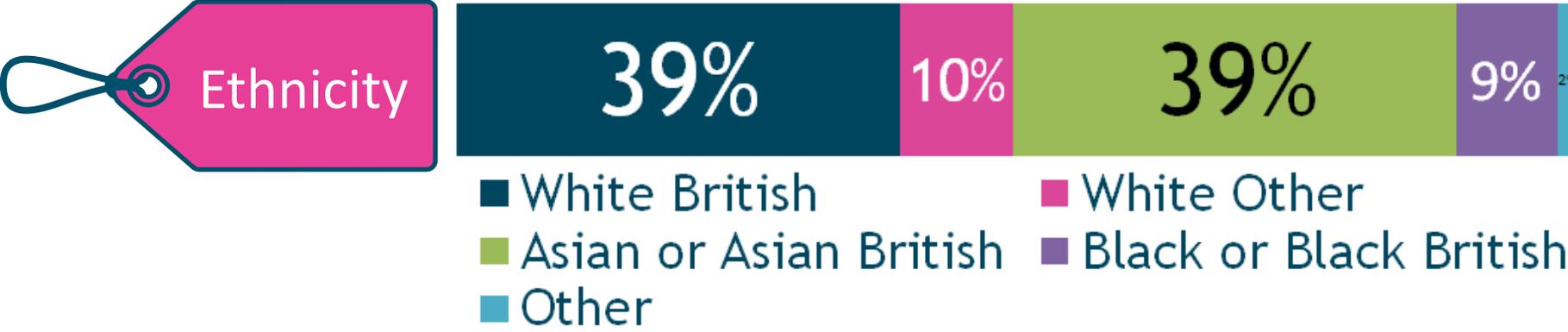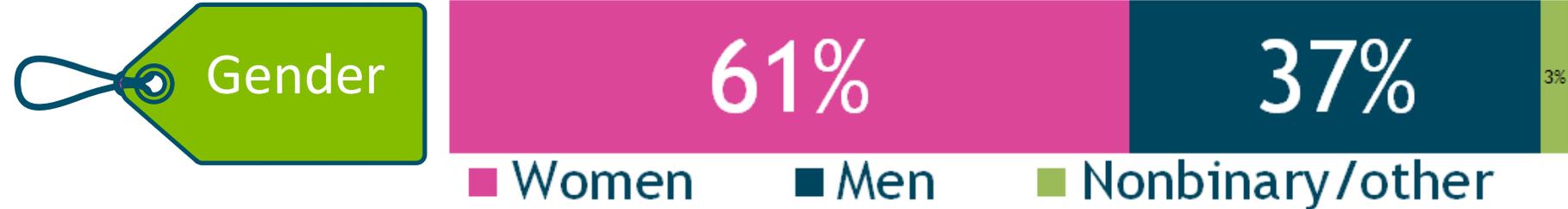|			
Over 450 disabled participants	14 partner organisations	Healthwatch survey	25 Co-production workshops
Over 80 1-1 phone calls	45 questionnaires to organisations, carers and disabled people	27 insight reports sent to public health	Covid-19 community champions
	Information webinars	Accessible messages created	

Voices of disabled
residents findings

Who we engaged

We carried out a survey 186 residents who were disabled or living with a serious long-term conditions

Gender

- 61% Women
- 37% Men
- 3% Nonbinary/other

Ethnicity

- 39% White British
- 10% White Other
- 39% Asian or Asian British
- 9% Black or Black British
- 2% Other

Age

- 2% Under 18
- 4% 18 to 24
- 56% 25 to 49
- 20% 50 to 64
- 19% 65+
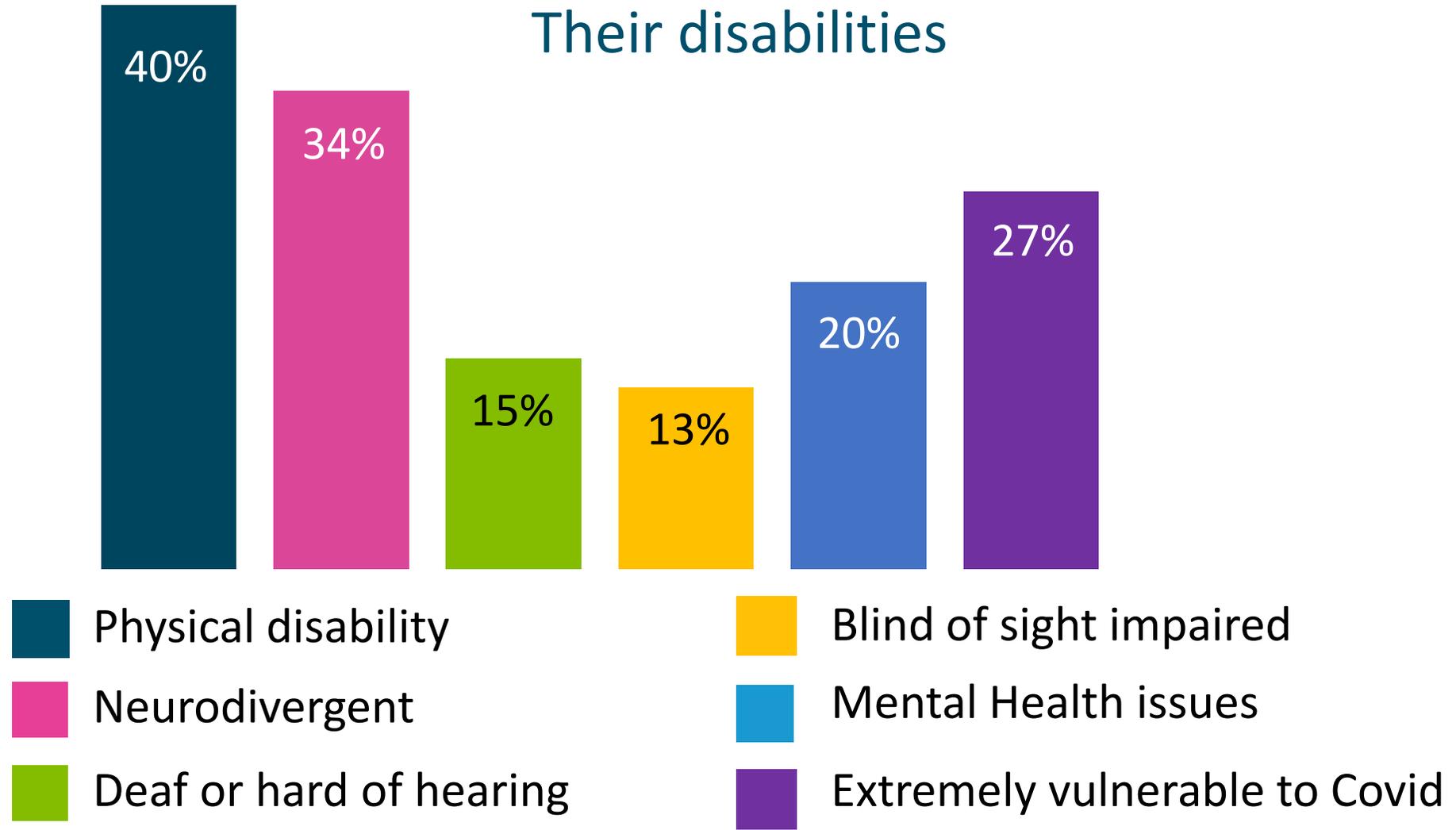
Communication & information

41% used the internet to stay informed

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

32% were digitally excluded

→ Easyread materials with pictures, 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, people not fluent in English, including Deaf BSL speakers.

15% preferred non written information.

→ Information through online videos, podcasts, radio broadcasts as well as outreach by telephone or in person would be more accessible to those who are sight impaired, have learning disabilities or who prefer oral communication for cultural reasons.

An Easyread front page containing essential information could be added to all letters sent about health and social care.

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.
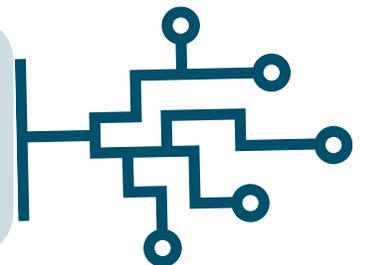
Through patient records, they have (or could obtain) specific information on each person's communication needs

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

Access to health & care services

People most affected :

- People with more severe disabilities.
- People with learning disabilities.
- People living with chronic pain.
- People aged under 65 and children under 18.
- People from BAME backgrounds
- Digitally excluded people

53% experienced disruption in their care

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

➤ Prioritise issues likely to worsen and become more resource-intensive to treat if not addressed promptly.

➤ Work with GPs, 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.

Key Issues Affecting Different Impairment Groups

1. Key Issues differ depending on access needs

2. One size does not fit all

3. Participants have not had equal access to all media sources

4. Participants have missed out on important Covid-19 information due to the lack of accessible communications

5. Disabled people have been left out of the Covid narrative

Key Issues Affecting Deaf and Hard of Hearing People

Where information is in BSL it's often hidden and they find it difficult to navigate NHS and Public Health websites.

Masks are an immediate barrier as BSL users rely on lip patterns and facial expressions. Not being able to lipread

COVID 19 information was inaccessible for people who are deaf. English is their second, third or even fourth language and they struggle to understand the level of English information is produced in.

Key Issues Affecting Blind and Partially Sighted People

Accessible information	Priority information received (e.g. letters through post) is not in large print or braille
	A lot of information is online, which is not accessible to some blind people
Vaccines	People expressed difficulty in booking vaccines online – the system is not compatible with screen reading software
	Some centres did not have accessible parking
Covid-19 testing	There is little or no accessible information to guide blind people as to how to carry out Covid-19 tests
	Lack of staff willing to help carry out tests at test centres
Social distance:	During restrictions less people assisted blind people when crossing roads due to social distancing measures
	It is difficult for a blind person to gauge social distance and no guidance was issued to help blind people do this and stay safe

Key Issues Affecting People with Learning Disabilities

Information has not been in a format that is easily accessible

Flow of information has stopped before reaching some people

Key health messages have been mixed and confusing

People felt isolated at home and their anxiety increased as face to face services closed and information became difficult to understand

People with learning difficulties want information to be presented in a clear, accessible format from people they know or who have the same learned experience as them

Key Issues Affecting other Impairment Groups

1.   **Sources of Covid information:**
     - Main source differed hugely dependent on their impairment
     - TV, Radio, Social Media, Family and friends, Health and Social Care professionals, NHS website/texts
     - Many people are reliant on carers, family and friends to relay information

2.   **Digital Exclusion:**
     - Most Covid information is online
     - QR codes are not accessible
     - Challenges for people to booking vaccine appointment online

3.   **Trusted sources of information:**
     - Mixed messages and inconsistencies reduced people's trust in Government and local authority
     - Scam text messages have increased people's anxieties

Key Issues Affecting other Impairment Groups

4. **Accessible vaccine and test centres:**
   - Distance
   - Queues – long and often no seating
   - No quiet spaces
   - No accessible parking

5. **Covid testing**:
   - Appears to be low amongst some impairment groups due to lack of knowledge and accessible information
   - Staff helping to fill out forms at testing centres have compromised people's confidentiality

6. **Clinically vulnerable and shielding:**
   - Some people weren't clear if their condition was classified as clinically vulnerable, so didn't know if they needed to shield
   - Since shielding ended, many people have not heard anything from the government or local authority
   - Lack of guidance for clinically vulnerable after shielding
   - The impact of shielding on people's mental health (cared-for and carers) has not been addressed

Key Issues Affecting other Impairment Groups

7.   Importance of GP:

- People expressed they feel more comfortable going somewhere they know for their vaccine, e.g. GP surgery
- Some people found it difficult to access GPs during pandemic
- People tended to trust Covid information they received form their GP

8.   Lack of support and training:

- Carers felt they didn't have the necessary information or support from local authority and heavily relied on each other
- People felt they were not offered the support they needed to get the vaccine
- Lack of training of helpline staff, and other frontline staff on different impairments and access needs

Key Insights

Accessibility of Covid Information

Vaccines

Post lockdown

Support and health

Accessibility of Covid Information – Key Insights

Around 50% of participants found some or all Covid health information to be inaccessible and hard to understand. This rate is much higher amongst people with a learning disability.

1. Language too complicated
2. Too much information is online
3. Low literacy levels amongst some groups
4. Communications were not targeted towards disabled people (e.g easy reads, images, BSL)
5. Lack of coordinated approach in Covid messaging across agencies
6. Contradictory information and advice
7. Not enough information in community languages
8. Some information was out of date (Helpline, Council website, NHS letter)

Vaccines – Key Insights

1. Booking vaccines online is not accessible (screenreaders, confidence, digital skills)

2. Lack of BSL interpreters available at vaccination centres

3. Lack of information about how people's underlying conditions may interact with the vaccines

4. Lack of guidance as to who is eligible for home vaccines

5. Lack of information (same 2nd dose vaccine, blood clots, side effects, ingredients, differences between vaccines)

6. No information sent out in advance to clinically vulnerable about what to expect when getting the vaccine

7. Accessible vaccine centres (no designated clinics for different impairment groups e.g. quiet times, dim lighting, support staff, seating in queues)

8. No information about the booster jabs (who is eligible, what will it do, expected timeframe)

9. Vaccine hesitancy (Misinformation from social media, views of some support staff and families blocked information reaching people with learning difficulties, which impacted on people making informed choices)

Post lockdown – Key Insights

1. Many people are experiencing anxiety as social distancing measures ease

2. People have been shielding for a long time and the experience has been different for the clinically vulnerable

3. Important to recognise the experience of shielding on people's mental health

4. Lack of support and guidance for clinically vulnerable about how to stay safe

5. Lack of information to general public about how to continue to keep clinically vulnerable people safe

6. It's now an issue of consent

7. People with learning difficulties and other health conditions really want to get out again but are fearful about how other people will behave – no 2m distancing, no masks and people getting close to them and touching them without their consent

Support and health – key insights

Meeting accessible standards

1. Can a person choose their communication preferences once and have those preferences shared across the health and care system if they wish?

2. 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? How can we make it easier for people to communicate with services?

3. At present helpline staff do not understand the needs of different disabled people, and a disability helpline run by trained professionals could help provide disabled people with the advice and support they need

Support and health – key insights

Delays in care

1. How can we support people while they wait for treatment?
2. Can we improve the appointments process?
3. Can we build stronger links with community care particularly around mental health and long term care?
4. What role can GPs, community services and the voluntary and community sector play?
5. What kind of investment would we need to improve telephone and online access? Is such investment available at the moment?

Moving Forward

1. People are unsure about what will happen in the future and they feel unsafe to resume normal activities
2. People reported that there is a lack of information and support for people suffering from long covid, especially relevant to those who are clinically vulnerable.

Coming Up

More videos

Quick break

Recommendations

Breakout rooms and panel discussions

Top 5 Recommendations

1. Post lockdown and safety
2. Accessibility of information
3. Vaccines
4. Testing
5. Planning ahead and training

RECOMMENDATION 1: POST LOCKDOWN AND SAFETY

When planning, remember that one size does not fit all.

1. Communications coming out of lockdown:

- Tailored guidance for different impairment groups as lockdown ends (staying safe and dealing with anxiety)
- Reinforcing safety measures, e.g. mask wearing, social distance
- Public message - 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.

2. Disposable elbow bands in public spaces to assist blind people

3. Support services for people who have been shielding, and on clinically vulnerable list to help with mental health and anxiety

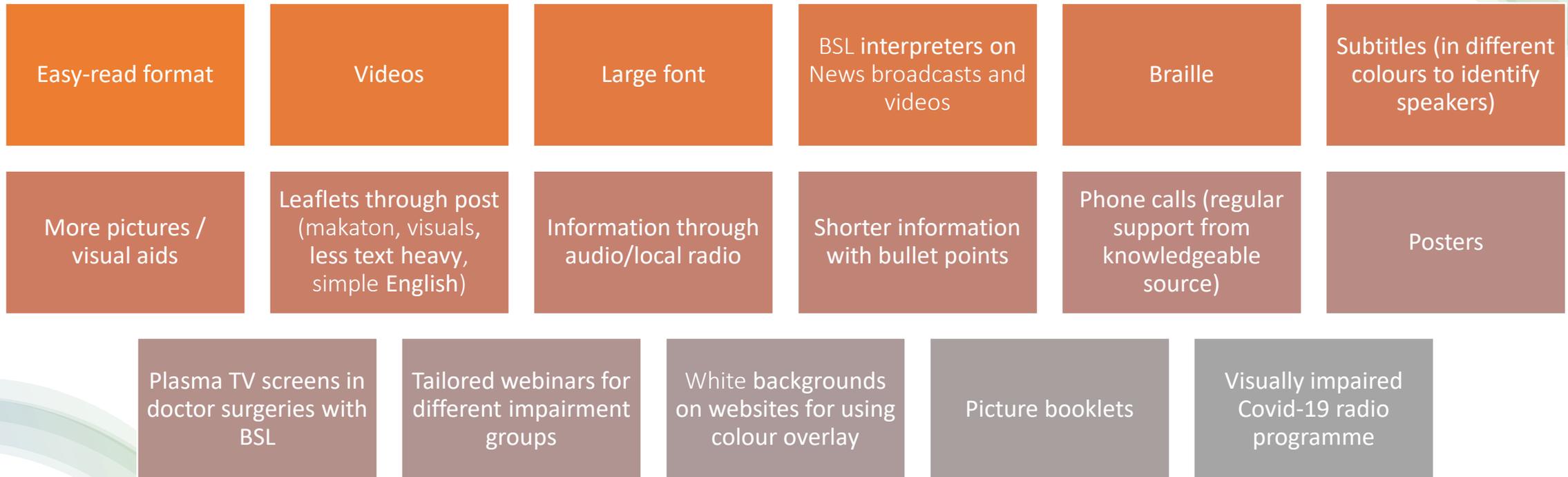4. Additional support to address isolation and exclusion

RECOMMENDATION 2: ACCESSIBILITY OF INFORMATION

1. Accessible and tailored Covid resources available to different impairment groups
2. A disability helpline/phone support to offer Covid advice and information by trained professionals who understand the needs of different impairment groups
3. Co-production of accessible resources with different impairment groups

What accessible resources disabled people want:

Each impairment group requires a tailored approach to communications – one size does not fit all

Easy-read format	Videos	Large font	BSL interpreters on News broadcasts and videos	Braille	Subtitles (in different colours to identify speakers)
More pictures / visual aids	Leaflets through post (makaton, visuals, less text heavy, simple English)	Information through audio/local radio	Shorter information with bullet points	Phone calls (regular support from knowledgeable source)	Posters
	Plasma TV screens in doctor surgeries with BSL	Tailored webinars for different impairment groups	White backgrounds on websites for using colour overlay	Picture booklets	Visually impaired Covid-19 radio programme

RECOMMENDATION 3: VACCINES

1. Designated vaccine clinics for different impairment groups
2. Clearer and tailored guidance on vaccines (e.g. how to book BSL interpreter, vaccine safety, home vaccine appointments)
3. Information sent in advance about the vaccine so people have time to digest and understand
4. Clear information on who needs to have the booster jab - which impairment groups/health conditions are eligible
5. Clear guidance on how to book an accessible venue for vaccination and a list of accessible venues in the Borough
6. Seating available in queues at vaccine centres for those who have mobility issues and other health conditions which makes it difficult for them to stand

RECOMMENDATION 4: COVID TESTING

1. More accessible information about where and how to get tests
2. More accessible information on doing tests:
   - Instructions in bullet points with small diagrams
   - Instructions on card with all the key points that you can lean against the wall
   - Instructions in large font
   - Instructions in braille
   - Video and audio instructions at test centres
3. Support staff available and willing at test centres to help disabled people carry out the tests

RECOMMENDATION 5: PLANNING AHEAD AND TRAINING

1. Closer partnership between Tower Hamlets Council with community organisations to understand different impairment needs and offer the necessary support
2. Clearer information about what to expect in the future (e.g. further lockdowns, eligibility for booster jabs)
3. Greater support to GPs for them to play central role (providing Covid-19 information and support)
4. Information and support for people suffering from long covid
5. Additional support measures and information needed for those living at home alone
6. Disability and deaf awareness training to all Council and NHS staff
7. Ensure disabled people are actively involved in the Covid narrative

Appendices

Demographics of project

Across Real, ICM Foundation and Real on average particpation was:

- 40% male, 60% female

- 20 – 70 years old

- White British, White Other, Black British, Black Carribean, Asian (Bangladeshi, Pakistani)

- Participants and workshop groups:
    - Blind and visually impaired
    - Deaf and hearing impaired
    - People with brain injuries
    - People with mental health conditions
    - Young disabled people
    - Older people with long term health conditions
    - People with mobility conditions
    - Carers
    - people with multiple impairments
    - People with learning disabilites

Workshop Partners

AgeUK East London

Create

Headway

Beyond Sight Loss

Vibrance

Carers Centre

Queen Mary University

Mile End Community Project

Local Voices

deafPLUS