

Health Messaging for All

Insight Report - Local Voices

May



About the participants

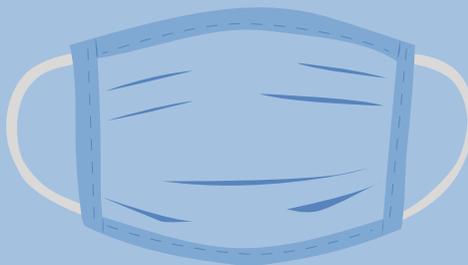
Number of participants/interviewees: **9**

This participants of this workshop comprised a pan-disability group. Some of the impairments identified included autism spectrum disorder, long term health conditions, mobility difficulties and blind. The group live in the London Borough of Tower Hamlets and are members of the Local Voices Network – a network of local disabled people who help to shape services and policy in the Borough. There were 3 Real staff members present.

The language used in the workshop was English, although this was at least one person whose native language wasn't English.

Participation was 50% male and 50% female and the average age was somewhere between 40 and 60 years of age. This was a mixed ethnicity group.

This report also includes extracts from interviews with 4 Local Voices Steering Group Members.



We played a game of word association with the participants asking them what came to mind when we said.....



VARIANT

Mutation

Acceleration

Very dangerous

Nervous

Scared

Doom

Worried

Cautious

VACCINE

Hope

Relief

I feel safe

Moving around

Joyful

Happy

Overwhelmed

LOCKDOWN EASING

Relief

Social interaction

Phobia in back of mind

Not free

Unhappy

Covid

Afraid

Scared

SHIELDING

Home

Safety

Mask

Virus

Danger

Protection

Hands



Health Messaging

Insights

Is there anything still not clear about Covid?

Should be a booklet with pictures in it. If there is another lockdown, there should be a booklet with the places that they can go to. For people with Learning disabilities (LD) there is nothing, especially at the beginning about how it would affect people. She has a friend at a youth club who has LD and they didn't have a clue at the beginning what was happening, and people were laughing in his face. He didn't understand why we were in lockdown. She felt she couldn't explain anything to him because it was hard to understand what it would be. Information wasn't clear - there was no pictures. For people with LD it is hard, there was nothing. Platform with number to help people would be useful, e.g. Real, Tower Project, Create, Core Projects. Her friend has severe LD. He likes sports. He goes to club in Balance Road. Didn't know anything at all. The people running the club were laughing at him. What do you say to that person? How do you explain it in a way they can understand? Especially when everything was so new.

Confusion over 2nd dose. Went onto GPs webpage, and it said book your Covid vaccine, but then there was a link to book at a national centre. Place was too far away. They didn't know they would contact them to book the 2nd one, so he booked at national centre and then had to cancel.

Ambiguity about how long the vaccine lasts for your immunity

WHAT NEW MESSAGES NEED TO BE TOLD?



Getting assistance at train station, people would still be reluctant to lend their elbow to get in/out of train. Concerning issues health from public at large. Walking on road, people would always ask if he needs help, but now there is reluctance to help him cross roads, or help him if he tumbles in the road. People are not willing to lend their arm to help blind people like him. It's a very serious dent in future life.



Make a badge - if they don't want to be a hugged - read what it says. People don't want to feel pressured in to it.



Be aware of others when you are out and about. If you don't want to be hugged, it's up to them, but if they don't, don't pressure them. She is not ready for hugging - maybe for selected friends, but not a stranger. Not ready for that person.



It's become a consent issue. Before we would hug people without thinking, but now you need to make sure there is consent on both sides.

WHAT NEW MESSAGES NEED TO BE TOLD?



Strangers - don't laugh in their faces. We don't understand, and we are trying to learn this too. Tell the public, that our experience is different and we (people with LD) need more time.



Was shielding and throughout kept up to date by government, but since shielding finished, heard nothing from government, and council, nothing from NHS and on all shielding lists, nothing from housing association. A lot of people would not be ok with that, and it feels like you are your own, and if you have an issue, you have to be proactive and do it on your own.



Brace yourself cause you might be in crowds. If you feel anxious, and if you live on your own, be yourself. If someone bumps into you, say "I have wings, I can stand up to you". This is my area, that's your bubble. Space around them, is there. That's your space, that's my space



Taking public transport after shielding, what guidance is there for people with disabilities?

WHAT NEW MESSAGES NEED TO BE TOLD?



Social bubbles - can we expand messaging to discuss about keeping distance. His concern is, as we move out of lockdown a lot of people seeing new freedoms and are forgetting social distance model. In reality, we understand some things will compromise social distance, but still need maintain it when we can.



Touching does not spread Covid, it only spreads love (message after Covid).



"Butt out of my bubble"



How we deal with coming out of lockdown - positive steps coming out to the world.

We asked our participants to tell us if there is anything else they would like to share



1

Key worker really important. Best key worker and been so tremendous. Looks after 30 clients.

2

Staying safe on buses. People with disabilities getting onto buses. Bus drivers. Disability on buses. Some buses don't have ramp. Bus drivers are moody and just drive on.

3

Miss going to a building to see her friends. She doesn't know how they are. 2 years ago since saw her friends from Tower Project. She doesn't even know what they look like now. Need to say thanks to everyone.

4

People with disabilities (mobility) - it is difficult but we need to be extra careful. Everyone need to stay safe. Bus drivers - they can't wait as they don't have the time. They move before people we are seated. It's not safe. Training for bus drivers about disabilities. Used bus and landed badly on seat as driver drove off before she was seated. They need patience.

We also interviewed 4 of the Local Voices Steering Group members asking the question:

"What has been your experience of accessing and understanding Covid-19 health information, and is anything still not clear to you?"



Personal
Experiences
around
Covid-19

TESTIMONY

Leaflets delivered, contacted doctor, booked appointment for injections. Followed instructions on face mask, wash hands – don't have an issue with that. Wife going to work, boy going to school, doing tests twice weekly. Fully aware of what's going on and happy enough with knowing what to do. Know that some people will refuse the injection but they can be persuaded, such as his wife being persuaded by her sister.

TESTIMONY

It's been very confusing but because I have got some amount of capacity I am able to work my way through it. For someone with lesser capacity it would be more of a challenge, ie. Booking appointments, understanding variants, understanding different jabs, single dose, double dose – to mask or not to mask, to distance or not to distance, compliance issues, efficacy issues.

Obviously I think the government and to a lesser degree the council have been inept at supporting people, with the messaging and stuff – had it not been for the covid champion sessions on every Friday, I wouldn't have been able to get a council perspective on what is going on, what surge testing is, and any issues I have with testing centres and the rest of it. Again, if I was in the Real world and Hannah told me to go to these covid champion sessions, I wouldn't have been in a position to do so, depending on where they were – but because they're online, everything is centralised.

Scary thing to get the new contract by default – what about all these other orgs to help us? How far can you stretch the concept of coproduction?

Personal Experiences around Covid-19

TESTIMONY

Mixed view of that - because outside local authority and local voices experience I think it's been quite clear - but there has been a bit of a delay - a lag - so certainly at the beginning the support, the projects to support disabled people felt like they were a few steps behind. Now that the disabled people I know have adapted to the new normal. it feels behind again - a bit of a lag . You have to expect that, but there have been times where you have to think this would be good three or four weeks ago.

But outside LV, I don't really personally have much contact with the council tbh - probably the wrong person to ask

The messaging from BBC news has been leading edge, then there's an echo relating to what the council has done - that echo has been quite distant, the thunderclap and the rumble afterwards. Haven't really needed it - perhaps because of my level of education and sheer bloody mindedness - watch the news and carry on

Uncertainty in March 2020, but quickly got into a routine - put the mask on, follow the rules - never felt the need for it. It is a particular feature of covid-19 that has created that perception of a lag, because the media have been all over it - all that has to happen is that Boris Johnson has to fart and they're analysing it - in a normal health situation that is a little less dramatic that wouldn't happen. So the Local Authority response would be the one I'm relying on, but Laura Kuunssberg, or the health guy.

Boredom and isolation. Being in an open prison . Not much social activity, not much to do . For most of 2020 things shut down . Not had perfect mental health through. Difficulty now - becoming uninstitutionalised.

TESTIMONY

No, not really - quite sick of it. Want to get on with things and work our way out of this rather than concentrating on constant emails about covid-19 and messaging from (health bodies and the council). I know they have a purpose and reach out to communities but if you don't know about it now then where have you been all year?