

COVID-19 Community Involvement Zoom Call 30.04.20: Insight Report: Guidance for people who are clinically extremely vulnerable from COVID-19

Background

As part of the COVID-19 pandemic response, the Patient Experience Research Centre (PERC) is carrying out a [community involvement initiative](#) to rapidly capture the opinions, experiences, preferences and unmet needs of communities in the UK during this pandemic, in an attempt to:

- Guide COVID-19 research at Imperial College London across areas of (1) mathematical modelling, (2) health and biomedical research, (3) engineering and innovation, and (4) socio-behavioural research;
- Inform the UK's pandemic response more broadly
- Highlight key unmet needs amongst diverse communities; and
- Inspire new ways to rapidly engage and involve communities remotely during a public health emergency.



Guidance for people who are clinically extremely vulnerable from COVID-19

Various guidance has been produced for the public with regard to COVID-19 including guidance for people defined as clinically extremely vulnerable to COVID-19.

Call overview and agenda

On Thursday 30th April 2020, we facilitated a video call via Zoom (5:30-6:30pm), with 16 members of the public from across the UK (see **Appendix 1** for demographics) that were recruited via direct email contact. Attendees were asked to meet the following criteria in order to take part in the call:

- Following [guidance on shielding and protecting people who are clinically extremely vulnerable from COVID-19](#) (referred to from now on as “the Guidance”); or
- Caring for/have a family member/friend who is following or was advised to follow this Guidance.

Attendees were invited to review the [online Guidance](#) before the call so that they could share their views on shielding Guidance in general and provide feedback on its clarity, what information they felt was missing and suggested improvements.

The agenda for the call included (1) Introduction to the Health Protection Research Unit (HPRU) in Modelling and Health Economics; (2) Introduction to the Guidance discussions; (3) Anonymous poll; (4) Small group discussions; (5) Next steps; (6) Questions.

Attendee recruitment

Due to the rapid nature of the call and to ensure diversity, we invited approximately 40 individuals by email via existing channels, including people who had joined a previous Zoom call with us and those who were part of the VOICE Community COVID-19 Engagement Support Group. See **Appendix 2** for further details on recruitment, event registration and technical requirements of the Zoom call.

Key Insights Summary

The following insights summarise the key messages that came through in our small group discussions, which are expanded on in the next section.

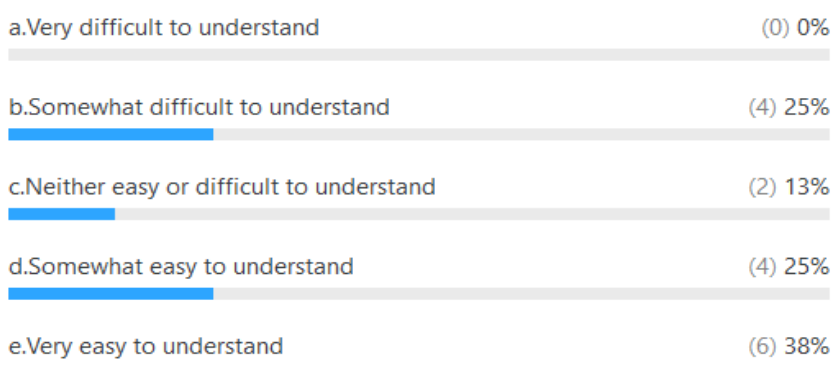
- **Overall, attendees considered the Guidance to be clear, but views were mixed on how easy it is to understand and/or follow.**
 - In our online poll, 10 attendees reported the guidance to be somewhat or very easy to understand, while 4 felt the guidance was somewhat difficult to understand.
 - This was reflected in the breakout room discussions: *“I think the guidance was pretty clear to be honest and my medication... [was] is specifically listed, so I knew that I was included in that demographic even though I didn’t receive a text or letter until last week”*; *“Well-structured but text based”*; *“Very easy to understand but not so easy to follow”*.
- **Attendees felt the Guidance doesn’t address individuals’ different levels of ability to adhere.**
 - It was determined that adherence can mean different things to different people and people’s ability to follow the Guidance depended on their personal circumstances.
 - Certain situations were seen to make shielding more difficult, e.g. living in confined spaces and/or alone; inability to access home deliveries for groceries; inability to access support for healthcare needs
 - A number of attendees shared the view that ‘household shielding’ guidance was easier to manage than ‘living with others’ guidance
- **Many felt the negative impact that following the Guidance may have on people’s health, well-being and quality of life should be more acknowledged and better supported.**
 - Discussions revealed conflicts between the need to adhere to guidance designed to protect individuals from coronavirus infection and the need to continue medical treatment and maintain their health and well-being
 - Attendees felt that recognising these competing factors, in particular in the tone and language used within the guidance, would be welcomed
- **Key information that was felt to be missing included:**
 - Information and tips to promote health and well-being, e.g. nutrition and exercise while shielding; impact of Ramadan and fasting
 - Information and guidance to relieve the negative impact of shielding, e.g. dealing with loneliness, how to access food deliveries telephone or video consultations with clinicians
 - Empowering guidance and activities to mitigate shielded people from feeling like “vulnerable” people, e.g. ways to support the pandemic response from home.
 - More information and clarity for carers and family members, e.g. what should happen if the carer gets sick
 - More information about less known/common symptoms of COVID-19 to be aware of given that many cases are mild and some people may be infectious before or without symptoms
 - Guidance on what they should expect and what they need to know once restrictions are lifted, e.g. information about virus and antibody testing and what they/others can and cannot do
- **Attendees suggested several improvements that could be considered for future guidance:**

- Clarity around what individuals MUST follow and what they can CHOOSE to follow depending on their circumstances
- Improving how understandable the content is, e.g. including example case studies and/or key definitions or glossary of terms
- Improving people’s awareness of the Guidance, and any updates, using multiple channels
- Improving the accessibility and usability of the Guidance, e.g. including the ability to personalise the content and/or navigate to the parts that are relevant to the reader; signposting to translations; including text-to-speech functionality
- Using more positive language and empowering tone of voice
- A suggestion was made to involve the public in the creation of the Guidance so that it met their needs

Poll: Ease of Understanding

All attendees (n=16) took part in the anonymous poll that asked people to respond to the following:

I found the Guidance on shielding and protecting clinically extremely vulnerable persons from COVID-19:



Small Group Discussion Themes

We performed a very top-line analysis of the key themes that came through during the small group discussions (and from comments received by email from one person after the call) and summarised them below.

Improving accessibility and understanding of the Guidance

Understandability and clarity

While most attendees in the session thought the language of the Guidance was clear, views were mixed on how understandable and/or easy it was to follow. This was reflected in the breakout room discussions: *“I think the guidance was pretty clear to be honest and my medication... [was] is specifically listed, so I knew that I was included in that demographic even though I didn’t receive a text or letter until last week”*; *“Well-structured but text based”*; *“Very easy to understand but not so easy to follow”*.

Attendees welcomed clarity as to what individuals can and cannot do or what they MUST follow and what they can choose to follow depending on their circumstances.

“Given that the Guidance cannot be followed to the letter by most people, I think it probably makes it quite likely that people will do as I have done and pick and choose the bits that feel achievable rather than sticking rigidly to every rule...”

Areas in need of clarity and or more information included:

- Whether people can go into their garden, attend urgent medical treatment appointments (e.g. chemotherapy), whether they need to stay two metres away from others in their home if the whole household is shielding
- Information for carers and family members who live with someone who is shielding, e.g. what should happen if the carer gets sick. They also felt there should be greater distinction between those living alone and those living with someone who is supporting or caring for them during this time as there is an assumption that all carers are external
- Information about what you should do if you cannot follow the ‘letter’ of the Guidance (or how to follow the Guidance to different degrees) would be welcome along with acknowledgement that personal judgement can and must play a role
- More information about less known/common symptoms of COVID-19 to be aware of given that many cases are mild and some people may be infectious before or without symptoms
- Guidance on what they should expect and what they need to know once restrictions are lifted, e.g. information about virus and antibody testing and what they/others can and cannot do

Suggested improvements included:

- Case studies would clarify situations which people are struggling to navigate, e.g. the distinction between those living alone and those living with someone (carer)
- The inclusion of a ‘key definitions’ and a glossary to include, for example, ‘shielding’ and ‘self-isolation’ and other terms not used in everyday life and more plain language generally to ensure people fully understand what the terms mean
- More visual explanations would be helpful too

Awareness of the Guidance and updates

Improving people’s awareness of the guidance, and updates, is key to supporting clinically extremely vulnerable persons. In one group, most attendees couldn’t remember when they last read the Guidance and had no reason to believe that there would be more updates, nor did they have a way of finding out that updates had been released.

Attendees called for greater targeted promotion across multiple channels that the Guidance exists, and/or when updates are released, to ensure that everyone in need is aware:

- A highlight box could be included on the website outlining what the updates included and which section of the Guidance the updates relate to
- Social media or other direct lines of communication could target messages at people who are shielding
- Include the option to sign up to an email or text alert that tells them when new updates are available

Accessibility and usability

Accessibility, included the ability to access information that would be helpful to an individual situation, including wide ranging demographic groups. Usability was defined as the ability to navigate the Guidance to gain information relevant to individual situations.

Improved signposting and navigation within the document would mean people could go straight to the information relevant to them and reduce the overall length of the document.

Access to the internet was also noted as a barrier to accessing the Guidance: *"I am 38 and have relatively easy access to the internet so I found the information I needed quite easily but if I had been relying on getting a letter that told me what to do, things would have been quite different."*

Specific recommendations included:

- Improving the order of the content, e.g. moving where someone signs up for support to the top rather than further down the Guidance
- More visual and infographic content
- Signposting to translations
- Including text-to-speech functionality
- Providing printer-friendly versions or pdfs of the Guidance, which could be full-length, shortened and/or personalised – the main Guidance is in html which makes it difficult to share or review on a phone. Having the option to personalise the content would allow people to print and share relevant information with those who cannot access the Internet
- Including a government ID and version number would help people keep track of versions

Tone and empowerment

Although people in the shielding group may be clinically vulnerable to COVID-19, this doesn't mean that they see themselves as "vulnerable." One attendee said: *"I didn't consider myself vulnerable until I received the letter" "shocked when I read that". "Feels heavy handed and less behaviour oriented."*

Attendees felt it would be valuable if the Guidance:

- Used more positive language and a more empowering tone of voice
- Included guidance and activities to prevent those who are shielding from feeling like "vulnerable" people, e.g. ways to support the pandemic response from home such as contact tracing or becoming a remote responder
- Gave people permission to make decisions which are right for them (and their medical circumstances). This could include helping people to better understand their personal risks

Improving the access to support and services offered to those who are shielding

Clarifying who the Guidance applies to

Delay to (or no receipt of) official notification to shield together with reduced access to healthcare providers to obtain bespoke advice contributed to uncertainty as to whether someone fell within the relevant categories and should be shielding.

One person had to rely on a charity to confirm whether they fell within the shielding category, i.e. whether they had "severe asthma" or not was guided by the medication they were taking. One was told by their GP that it was up to them whether they complied or not and that people were just being informed that their condition fell within the shielding category. Another considered that even though her condition (diabetes) wasn't explicitly listed in the "extremely clinically vulnerable" list, she was choosing to shield because she considered that her condition should have been included in this category and believed it had been previously.

Our discussions highlighted that people are having to make decisions for themselves (or contact charities for advice) about whether they should be shielding. This was often in the absence of

guidance from healthcare providers who were often busy with the COVID-19 response. This uncertainty appeared to contribute to variation in how people followed the Guidance, both by those personally affected and by carers and family members, whether intentionally or unintentionally.

Attendees felt it was important to:

- Highlight the uncertainty and negative impact that being told (or having to work out if you should be shielding) has on people's quality of life – particularly where proportions of people within patient groups received a letter and another proportion didn't
- Ensure greater coordination about how and when people are informed about whether they should shield or not, including access to support services to better understand what it means to them

Acknowledging the negative impact of shielding on health and well-being

The requirement to stay inside (and shield) has wide ranging impacts on individual's health and well-being. Several attendees reported that their existing treatment plan directly contradicted the shielding guidance, e.g. if someone needed to exercise in a certain way as part of their care plan, to follow shielding guidance would mean they wouldn't be able to continue their medical care as planned.

Some questioned whether shielding would be worse for their health than the risk of COVID-19. One attendee shared how they felt they had survived cancer because they had stayed active and ate healthily but is now worried it will come back because they are shielding. Several attendees felt their health was suffering because they couldn't take proper care of their condition while facilities were closed and/or medical appointments were postponed.

“Shielding is horrible for people who have limited time [to live] anyway. I'm not staying at home for myself, I am doing what I can to keep others safe, to cause as little worry for my loved ones as possible, and to help the NHS.”

Lack of access to home deliveries was also reported to further impact people's health, due to poor nutrition. Weekly packages were received by one person, but a lot couldn't be eaten due to dietary requirements. *“The service provided is not meeting everyone's needs and needs to rely on mutual aid groups and charities”.*

Attendees felt the Guidance should provide more information and guidance to support people to maintain their health and well-being while shielding. This included:

- Acknowledging that people can/will follow the Guidance to varying levels depending on their personal circumstances and situation
- Information and tips to promote health and well-being, e.g. nutrition and exercise while shielding; impact of Ramadan and fasting
- Information and guidance to relieve the negative impact of shielding, e.g. dealing with loneliness, how to access food deliveries, telephone or video consultations with clinicians

Supporting people to be able to follow the Guidance long-term

Attendees voiced frustration and concern at not being able to follow the Guidance due to personal circumstances, including lack of support, living conditions or services not being effective or accessible. Some noted it was easier for a whole household to shield than for those they live with to follow the 'living with others' guidance as many people aren't prepared to take any chance of putting loved ones at risk. One attendee who lives alone is paying for her son to live away from her because he didn't want to put her at risk and as a result she lives alone.

Several attendees said the services referred to in the Guidance were not accessible, e.g. one person had been told by the shielding service their email would be added to the priority supermarket delivery list but this never happened, and there was no way of re-contacting the shielding service to address this. Therefore, they had to go to the supermarket and put them self at risk. In another case, the Guidance says 'speak to your GP to discuss what this means for you' but then they are not able to reach or get through to their healthcare professional, who may be busy in the COVID-19 response, or their specialist refers them back to the Guidance.

Generally, attendees thought that shielding until the end of June would be feasible although this was not without negative impact to them.

Considering that certain levels of 'shielding' may be needed for quite some time, they felt greater support and services need to be in place to enable people to follow the Guidance long-term:

- Improved access to bespoke healthcare professional guidance and support
- Greater coordination of and access to/control over food deliveries
- Guidance on what they should expect and what they need to know once restrictions are lifted, e.g. information about virus and antibody testing and what they/others can and cannot do
- More information and clarity about what the long-term plans are and how their own freedom and ability to exercise/go out could be supported in a safe way

Post-call feedback from attendees (n=7/16)

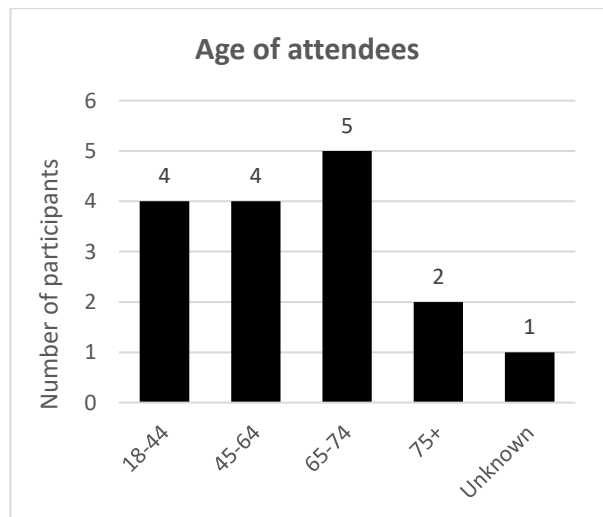
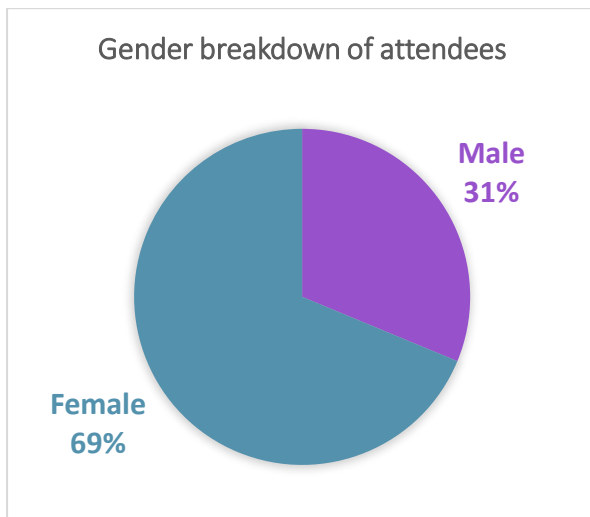
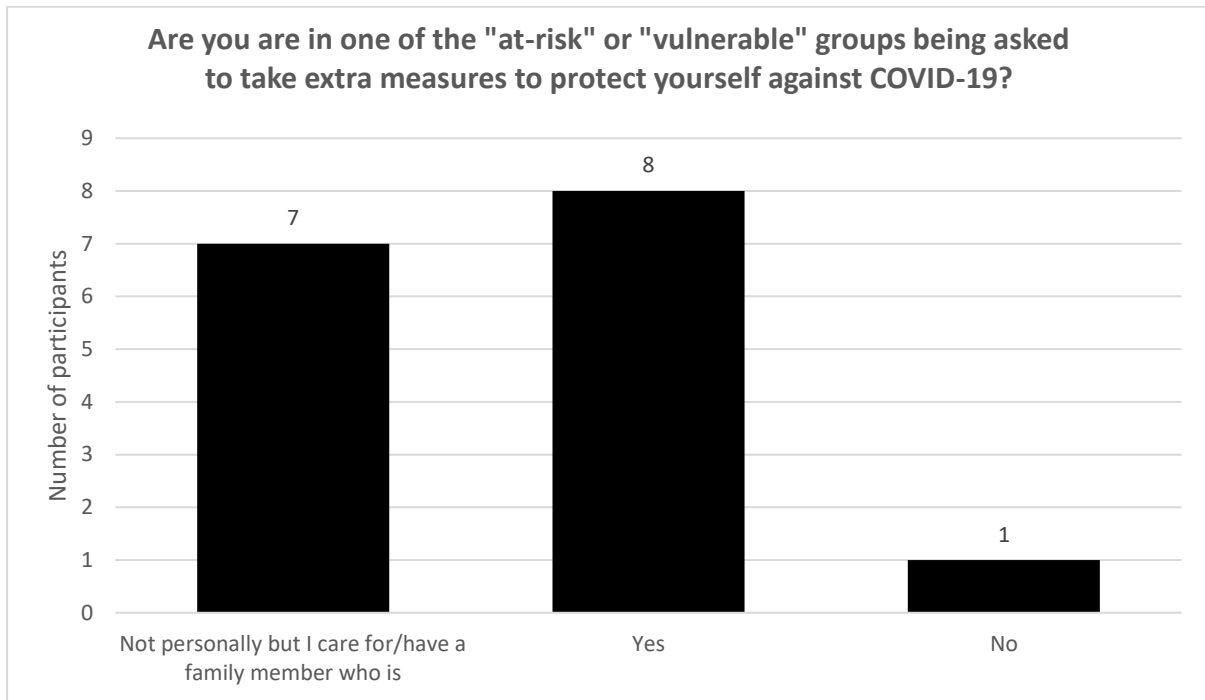
- Attendees rated the call highly, with all respondents rating the call at least 8/10 with the majority (85.7%, n=6) rating the call 8/10, 9/10 or 10/10. One person rated it 4/10
- 85.71% (n=6) of respondents stated they were extremely likely to attend another Zoom call to hear about and discuss important topics relevant to COVID-19, research into COVID 19 and pandemic planning. One person said they were "Somewhat unlikely"
- When asked what they liked most about the call (multiple selection allowed), 53.85% (n=7) said discussions around the Guidance (updated 17.04.20) and 15.38% (n=2) said the Introduction to the Health Protection Unit in Modelling and Health Economics. 23.08% (n=3) said "Other" including the way in which the call was managed ensuring all participants were included and valued, the fact the speakers explained themselves very clearly and competently which made it easy to focus on the main issues about which comments were invited, being able to see the people they were talking to, "discussions were good with input from the majority if not everyone in the group". One person gave their reason as they felt that "participants focused too much on their concerns about their liking of the measures rather than on the method and clarity of the communication" which "may have needed a more specific introduction to encourage the right focus - or a tighter control to discourage deviating from the theme?"
- 87.5% (n=7) respondents (or those they care for) received official information about being in an extremely clinically vulnerable group and 12.5% (n=1) did not
- 60% (n=3) of those who received official information about being in an extremely clinically vulnerable group received any kind of follow up or follow up information from an official source. 40% (n=2) did not receive any kind of follow up
- Of those who received follow up (multiple selection allowed), 40% (n=2) received it from the NHS, 20% (n=1) from PHE, 20% (n=1) from GPs, and 20% (n=1) from the Council
- Those contacted by official sources were contacted by the following methods (multiple selection allowed), 33.3% (n=2) by phone, 33.3% (n=2) by email, 16.7% (n=1) by text and 16.7% (n=1) by Twitter

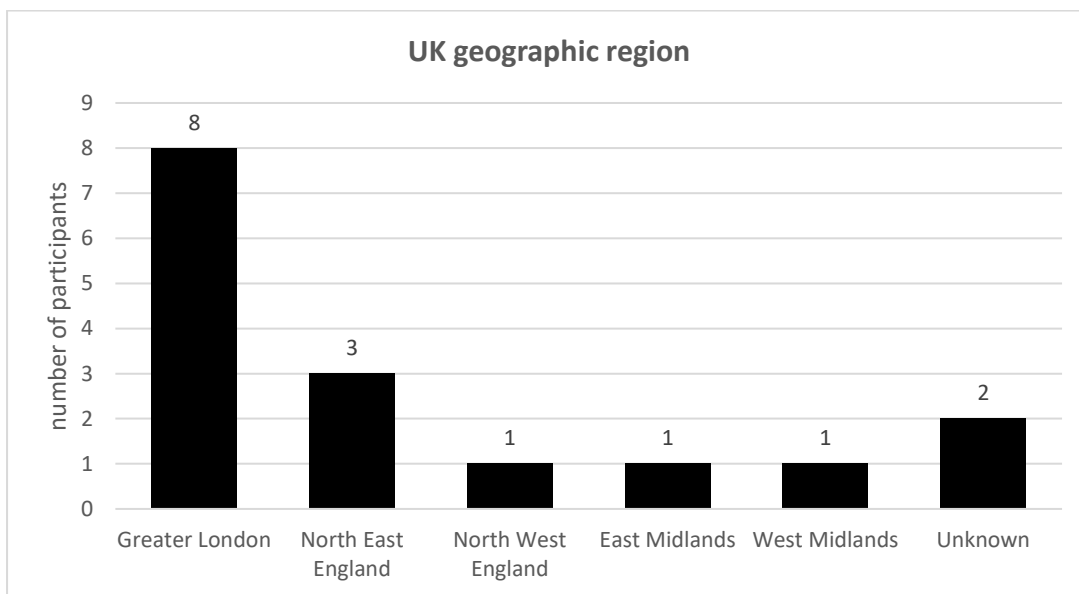
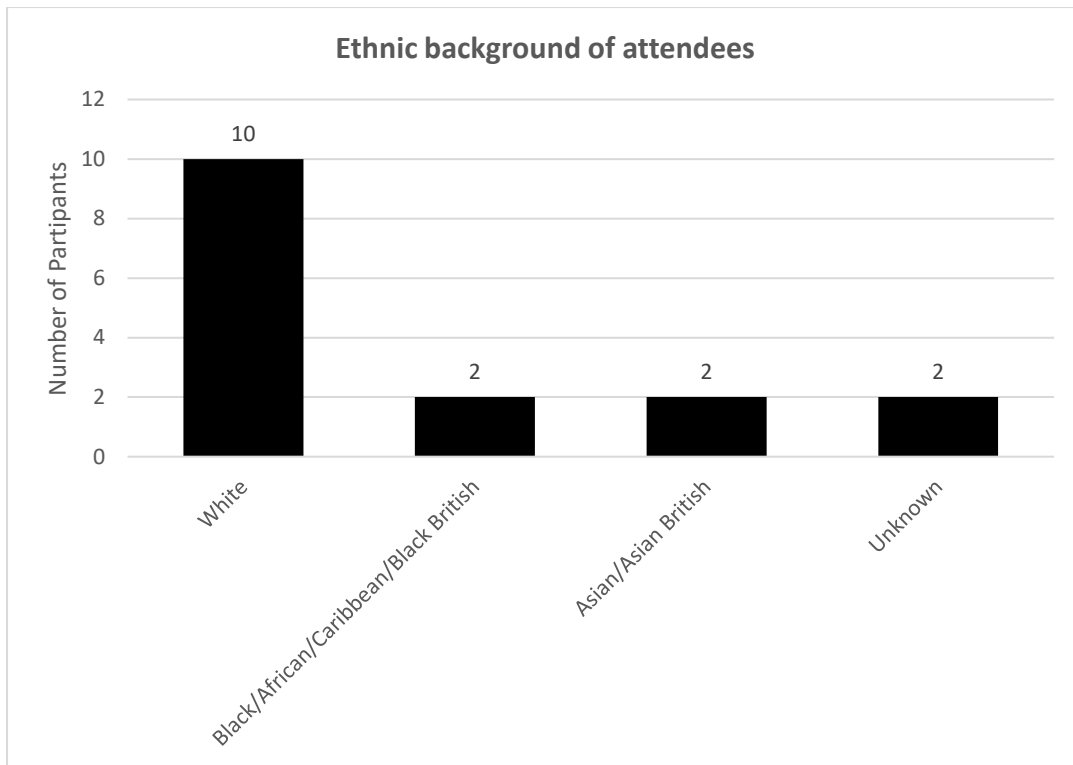
- Half of respondents provided feedback on how the calls could be improved including: trying to ensure discussions were kept on topic but acknowledged that care is needed to avoid appearing to be dismissive of ideas offered. Instructions on using Zoom for an iPad would have assisted. One person noted that it would have been useful to have: “recourse to the considerable resources of behavioural insights available and used widely in the public and private sector” which may be worth exploring in the current situation.

See **Appendix 3** for full table of feedback responses.

Appendix 1: Demographic of public attendees

Table 1: Demographic details provided during event registration (n=15/16; data not available for 1 attendee)





Appendix 2: Event registration and Zoom call set-up

Attendee recruitment

Due to the rapid nature of the call and to ensure relevance of attendees in terms of fulfilling the criteria to be within the shielding category or be caring for someone who is, attendees were invited to the call through a number of existing channels.

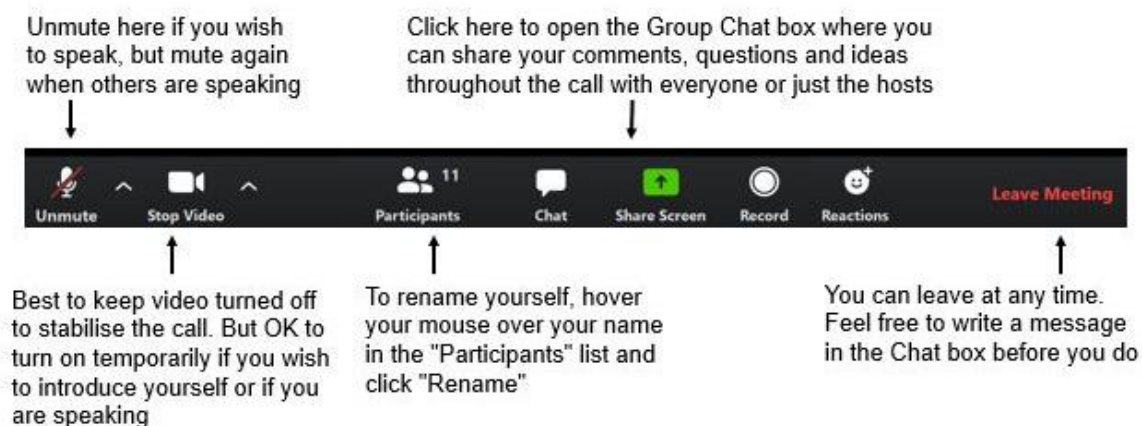
Specifically, an email invite was sent out to individuals who had joined a previous Zoom call with us and those who were part of the VOICE Community Engagement Support Group. The call was limited to 20 places to ensure that the small group discussions would be manageable and productive in a one-hour call.

Event registration

Attendees were asked to register for the call via Eventbrite, which included providing some basic demographic details. Twenty individuals registered for the call via Eventbrite of which 16 joined on the day (see **Appendix 1** for demographic of attendees).

Zoom call technical requirements and troubleshooting

Zoom is a relatively easy platform to use, both from the attendee and facilitator perspective. Attendees may not have had much experience with Zoom, so supporting troubleshooting, where the team can, is a key component to ensuring that participants can join the call and feel included in the work. The team followed best practice by dialing into the call 15 minutes before the session began and shared a holding slide that provide attendees with tips on how to navigate and use Zoom.



The team also did a quick run through of these once the meeting began.

The team set all facilitators up as co-hosts, which supported attendee management as well as troubleshooting.

Co-hosts were able to record breakout rooms to their computers and share the notes and audio recordings after the call. This is useful to provide a record of what was discussed and supports rapid collation of the key insights, comments and questions.

Appendix 3: Post-call feedback

Table 2: Responses to post-call online feedback form

Characteristic	n (%)
On a scale of 1–10, how would you rate the call?	
<7	1 (14.3)
8	1 (14.3)
9	2 (28.6)
10	3 (42.9)
How likely are you to join another Zoom call like it?	
Extremely likely	6 (85.7)
Somewhat likely	0 (0.0)
Neither likely nor unlikely	0 (0.0)
Somewhat unlikely	1 (14.3)
Extremely unlikely	0 (0.0)
What did you like most? (multiple select allowed)	
Introduction to HPRU Modelling and Health Economics	2 (15.4)
Discussions about the Guidance	7 (53.9)
None of it	0 (0.0)
Other	3 (23.1)
Did you, or the person that you care for, receive official information about being in an extremely clinically vulnerable group?	
Yes	7 (87.5)
No	1 (12.5)
I don't know	0 (0.0)
After receiving the official notification, have you received any kind of follow-up or follow-up information from an official source?	
Yes	3 (60.0)
No	2 (40.0)
If you have received follow up, who have you received follow-up from (you can choose more than one)?	
PHE	1 (20.0)
NHS	2 (40.0)
GP	1(20.0)
Other healthcare provider	0 (0.0)
Council	1 (20.0)
Other	0 (0.0)
By what methods have you been contacted by official sources? (you can choose more than one)	
Text	1 (16.7)
Phone	2 (33.3)
Phone	2 (33.3)
Email	1 (16.7)
Other	0(0.0)