

COVID-19 Community Involvement Zoom Call 16.04.20

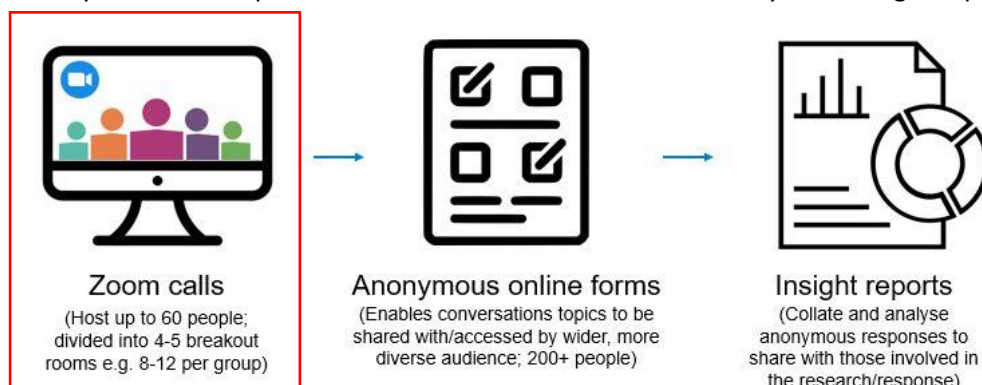
Insight Report: How the outbreak is being communicated to the public

Background

As part of the COVID-19 outbreak 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 outbreak, 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 outbreak response more broadly
- Highlight key unmet needs amongst diverse communities
- Inspire new ways to rapidly engage and involve communities remotely during a public health emergency

Following some early online community involvement at the start of March (see [Imperial College London COVID-19 Response Team Report 14](#)), PERC are now looking to optimise and expand the process of community involvement in COVID-19 research and response planning, to ensure the voices, experiences and concerns of those who may be most affected by the outbreak are heard. This includes establishing a regular series of activity that enables rapid input from members of the public into key discussion topics that can be shared in the form of anonymous insight reports.



Call overview and agenda

On Thursday 16th April 2020, we held our first pilot of the community involvement zoom call (4:30–6pm), which was attended by 24 members of the public from across the UK. The majority were relatively experienced with public involvement in research, but some were new to this concept.

The agenda for the call included (1) An introduction to PERC and our work; (2) An overview of COVID-19 research at Imperial College London; (3) Recap of PERC's community involvement initiative; (4) Pre-Discussion Polls; (5) Breakout room discussions (4 rooms; 6-8 people per room) on two discussion topics: (i) Digital Contact Tracing (e.g. via mobile phone apps); and (ii) How the COVID-19 outbreak is being communicated to the public; (6) Next Steps and Questions.

This report summarises conversations captured on **How the outbreak is being communicated to the public** only. A report on the second topic 'Contact Tracing Apps' is [available online](#).

Key Insights Summary

Research shows that where people get their information, the reliability of this information, and whether it meets their needs have strong links to risk and preventative behaviours during public health emergencies. During PERC's earlier online involvement activity (6–15 March 2020), a number of key concerns, information gaps and unmet needs were raised (see [full online report](#)). Some of these have now been superseded by current lockdown measures, but we were interested to explore with this group which, if any, remained ongoing issues. Throughout the discussions many of the same points were raised that had been raised in our [online community involvement report](#) in March (which captured views from 420 people) suggesting that the views of this small group likely reflect those of the wider population and that much more still needs to be done to improve how information and guidance is shared with and communicated to the public and specific groups.

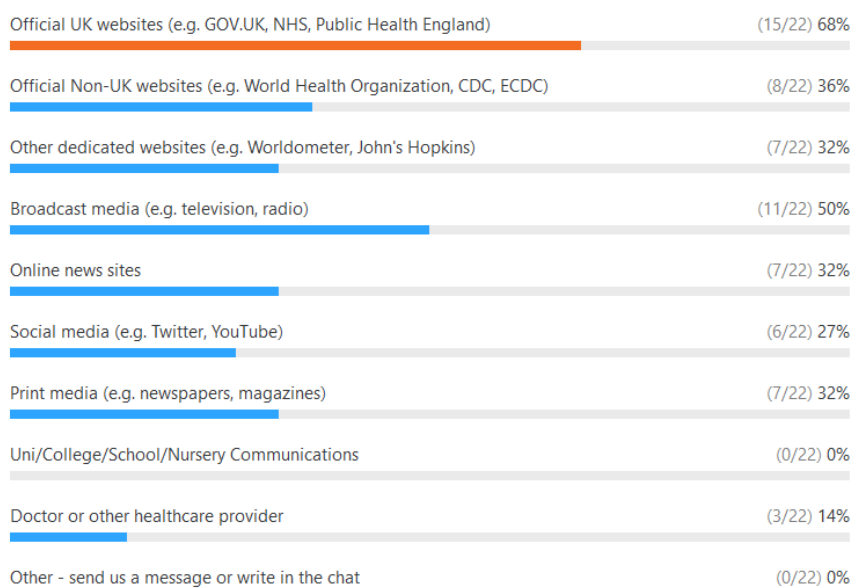
- **Information gaps:**
 - Detailed information for at risk groups (selected by 86%; n=19). At-risk groups were less talked about in group discussions, but some attendees noted that the letters for at-risk groups seemed to less organized, leaving some uncertain if they were at risk.
 - More information on the latest research explaining what we know about the virus and the outbreak (68%; n=15)
 - More insight into what the options are for the UK's exit strategy and how they would be decided
 - More clarity around where the UK is in its phase of the outbreak, compared to other countries
- **Ongoing mistrust in the government and their response to the outbreak**
 - There was a feeling that the government can no longer be trusted due to recent actions and conflicting messages. Lack of transparency also breeds distrust.
- **Ongoing need for clear, consistent and relatable information:**
 - Ensuring information is trusted, transparent, up to date, balanced and evidence-based was selected as an ongoing issue by 68% of respondents in our poll (n=15)
- **As a note, our respondents were primarily accessing information from official sources and the media but much information still missing.**
 - Official UK websites were ranked the most useful, with 68% of respondents picking this as one of their top choices (n=22), followed by broadcast media (50%; n=11).

Polls: How COVID-19 is being communicated to the public

Respondents also took part in some polls relating to how COVID-19 is being communicated to the public. During PERC's earlier online involvement activity (6–15 March 2020), a number of key concerns, information gaps and unmet needs were raised (see [full online report](#)). Some of these have now been superseded by current lockdown measures, but we were interested to understand which, if any, were considered ongoing issue. We also asked which sources people use to access information as this would help us interpret any information gaps or concerns raised. (N=20).

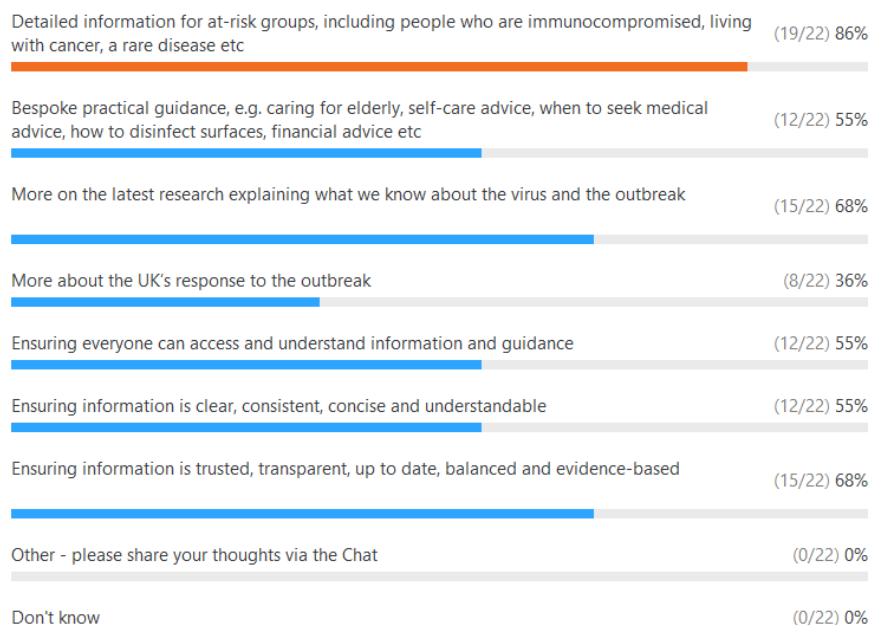
1. Which sources do you find most useful for getting information and guidance about the COVID-19 outbreak?

[Select top three] (Multiple choice)



2. Here are the key information and communication needs raised by respondents during our previous online involvement exercise [6-15 March].

Please select all that you believe are still relevant ongoing issues and share other comments with us via the Chat. (Multiple choice)



Breakout Room Discussion Themes

We have performed a very top-line rapid analysis of the key themes that came through during the breakout room discussions and summarised below the main points that were raised. For transparency, we have also included the original discussion notes at the end of this report, see **Appendix 1**. Full discussion notes from small group discussions on how COVID-19 is being communicated, which informed the rapid analysis of key themes.

Mistrust in the government and the response

Discussions brought up a mistrust in the government response and their response, particularly stemming from changes in the messaging, as well as lack of trust in politicians and their key spokespeople. There was also a sense that there's "a rule for everyone but themselves". Some attendees shared agreement that everyone was learning as they were going along, but that lack of transparency breeds mistrust. Some also noted they felt bad for some of the leading scientists and public health professionals.

Exit strategy and future implications

Discussions had a strong focus on what was next. Attendees had questions about what the next steps were, and how they would be decided. This linked to the overwhelming number of resources available, and a lack of good synthesis about what was important and actionable. It was noted that many people have heard to just watch other countries to see where the UK will be in the coming weeks. The overall consensus is that attendees would like more information about where the outbreak is now, and what is likely to come next.

International versus domestic versus local response efforts and information

Discussions noted that many countries were not taking similar approaches to combating COVID-19. There were discussions about whether it is better to have messaging communicated from the local level, and whether there would be capacity to do this, or whether it was better to look to the international messaging. Some notes were made that it is difficult to use WHO information at this stage, as it is less regularly updated. Further, there were discussions about how the efforts in different countries related to the science, and how that confused what should be done in the UK. One group discussed this as it relates to masks.

Need for clear, relatable, and consistent information

The overarching messages from discussions was that there was a need for clear, relatable, and consistent information, even if the situation was changing. This included all aspects of messaging from bespoke practical guidance, to research being conducted and how to get involved. Some groups noted that the overwhelming amount of information caused fear, which was causing social unrest and negative wellbeing outcomes. It also was overwhelming to know where to go. Some discussions noted that at risk, vulnerable, and seldom hear voices may not access the typical information, and this needed to be taken into consideration. One suggestion was to have large signs with brief updated information at supermarkets. Note: This nicely links back to the points about contact tracing and what members of the public would need to know to support a contact tracing app.

Next steps and recommendations

Rapid and early engagement with the public is an essential part of outbreak response. The insights shared within this report highlight just some of the concerns and questions the public have around contact tracing apps. Ongoing engagement and involvement with the public is essential to improve the understanding, acceptance, adoption and appropriate use of these apps in the UK once lockdown is lifted.

While the numbers are relatively small, this pilot call has already provided relatively rich insight into people's current understanding and knowledge around contact tracing apps. It's also highlight the kind of questions and concerns that would need to be clarified in order to improve acceptance and adoption by the general public.

PERC would be open to facilitating further sessions like this with the public, alongside key researchers working in this field. These could allow more in-depth conversations around specific aspects, and/or broader input from key groups of interest, such as young people or over 70s. We have also drafted an online form that covers many of the same questions but would enable a wider, more diverse audience to input their perspectives on this topic.

Finally, while we have performed a very rapid thematic analysis of the responses, we highly recommend that you read **Appendix 1** of this document (p6–14) to see the detail of the discussions that were had and gain greater insight into people's specific concerns.

Appendix 1: Full discussion notes on Topic 2 – “How the COVID-19 outbreak is being communicated to the public”

Breakout room 1

This came up in general discussion at the start (during introductions) but also during topic 1.

- Doubts raised regarding government response. Several people had now stopped watching the daily press conferences although one person felt these had improved recently.
- People discussed the loss of credibility of public health professionals/scientists who are involved in the UK govt response due to working with politicians who people have little trust/confidence in. Large focus of discussion was around mistrust of politicians but trust in scientists and this “tainted association”.
- One person suggested daily updates from PHE only (i.e. independent or not side-by-side with politicians) and weekly update from politicians suggesting a dissociation of PHE as an agency of the Department of Health and Social Care
- Discussions around lack of investment in NHS and ‘political’ nature of COVID-19 public health response.
- There were also discussions around “who is an expert?” as we have not seen COVID-19 before
- Overall, **clear** messaging was the main comment raised by all people involved in discussions

Breakout Room 2

- During war time there was only really radio and newspapers so everyone got the same information and it reached everyone. Now there are too many channels - not all the same information reaches everyone hence conflicting messaging and information overload
- Not clear what's available and what's reliable
- Many mentioned that they'd recently received the government letter but then said "and so what" it was old news/everything they'd already been told and was too late as by that point they were in lockdown - should have been sent the moment social distancing guidance was released/advised
- Some mentioned watching the 5pm daily briefing
- Some felt information needs to be as local as possible although there was debate around whether it should be kept localised completely or have some central coordination and then adapted by local authorities who people felt understand and know their communities better. Some were worried about this fuelling inequalities though where some boroughs/areas have more money than others
- Poll result highlighted that people want to know more about research. When asked about this, one lady said she thinks researchers need to be applauded for the hard work they are doing. Astonished by the speed of our response - rapid calls/ethics process etc. She believes the public know about the frontline NHS staff but don't really know about all the research and hard work going on behind the scenes. Maybe we need to do more to communicate our research and the science
- There was priority for consistency of messaging, also felt that better communication about the science/research going on might help patient recruitment/sign-up into the clinical trials (improve acceptable and understanding etc), which Helen then noted that in fact that's another area needing public/patient input - also about how to work with people who are not eligible for these trials

Breakout Room 3

Note: Less time was spent on this topic

- International v domestic response
 - A view that there is not a coordinate response was voiced – ie what will happen once lock down ends, advice is look to Spain
 - It feels clear that their isn't great science, but this transparency is not being communicated, so there are confusions
 - Group discussed masks as a prime example of this confusion
 - Take home – it would be good to address some of the bigger global issues as part of the domestic message because it causes confusion
- Big question around what will happen after lockdown
 - When will we know that lockdown should end; Will we need to go back into quarantine later etc
 - Desire for the government to start to share information around future plans and likely outcomes
 - Group understood terms, but generally not what they meant moving forward
- Method of communication – easy access to information
 - Not everyone reads the newspaper, watches the news, accesses the internet either by choice or due to access – most people go to the supermarket – it would be nice to have posters in public places (like the supermarket) which are regularly updated and provide brief and useful information
- General concern that the media provides the wrong kind of information for their own ratings/motives – focuses on the negative/death numbers etc causing more fear

Breakout Room 4

- Information from government has often been confused, muddled and contradictory so don't know where one is. Have relied on Government and 4pm broadcast and read a lot in newspapers and online about it e.g. If you have a runny nose it not COVID 19 but then some people get a runny nose with COVID 19
- Go out of UK for information as don't trust it so go to WHO which gives clear indications of what we should be doing early on and other countries took their advice and we didn't and arrogance that we knew better and we were following the modelling rather than the virologists. Feel less than assured about scientists Government are using the science at the broadcasts but they are choosing the scientists they are following as you can choose from stats as well. I don't' trust what they are doing. Would rather see what other countries are doing to lead us out of this.
- Uses NHS or Government site and if wants further information looks further on NHS site or looks at WHO but other than that doesn't listen to any other news as doesn't want to know as trying to keep as positive as possible and not be worried about symptoms like sneezing.
- Before lockdown looked at WHO but now looks at Worldometers to see numbers and then keeps up to date with news (not every day), MSN comes up and has a quick read and will look into it more if wants to. In first week of lock down kept up to date but now part of you doesn't want to hear about it all the time and a lot it is quite samey so switch off a little bit.
- Trust is being lost slowly due to contradictions and bombarding with information. Have too much information, wants to know about research e.g. vaccines, medication etc. Not aware of this.

- Bamboozled with big numbers which are not compared day to day. Government gives numbers but no percentages. Concerned that being told we can't ask when we are coming out of this, what the thoughts on the exit strategy is. Resent that.
- Everyone is learning as going along even experts so feel a bit sorry for them.
- Given total number of deaths but don't go on percentage of population of countries and have to look somewhere else for this information. Perhaps population per square km can be added into figures.
- What percentage of age demographics have died? Some people who are not old or with underlying conditions have died.
- Whether data includes those people who died outside hospital have been included in the data?
- Deaths per case appear higher because of lack of testing
- Why are they not testing more? We are being told we have the capacity.
- Theory that there is a part of the Government which still believes in herd immunity approach and this has impacted the decision to stop testing. Apparently, there was a simulation exercise on herd immunity (23 March) even after Hancock said they weren't investigating this. Believes this simulation is still ongoing.