COVID-19 Community Involvement Zoom Call 01.05.20

Insight Report: Antibody testing & REACT Study

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

REACT study (REal-time Assessment of Community Transmission)

Commissioned by the Department of Health and Social Care, the REACT study is a complex research programme looking at community transmission of SARS-COV-2 – the virus that causes COVID-19. The second arm of the study, REACT2, will assess the usability, acceptability, validity and feasibility of widespread home self-testing for SARS-COV-2 antibodies using a finger-prick lateral flow test (which looks and works much like a pregnancy test).

PERC are supporting this study by carrying out community involvement to gain early insight on people's thoughts about antibody testing, as well as their questions, concerns and suggestions to inform piloting of the self-testing kits in the community.

Call overview and agenda

On Friday 1st May 2020, we held a community involvement zoom call (5–6.30pm), which was attended by 37 members of the public from across the UK (see **Appendix 1** for demographics). The majority were relatively experienced with public involvement in research, but for some this was their first time engaging with us in this way.

The agenda for the call included (1) Context for the call and an introduction to the project team; (2) A quick introduction to antibody testing and immunity; (3) Our plans for the REACT studies and community involvement; (4) Q&A (see **Appendix 2** for questions asked by attendees) and Pre-Discussion Poll; (5) Breakout room discussions (4 rooms; 9–10 members of the public per room) covering broad topics including (i) Understanding/Concerns/Acceptability (ii) Logistics (iii) Public material; and (6) Next Steps and Further Questions.

Attendee recruitment

Due to the rapid nature of the call and to ensure diversity, an email invite was sent to approximately 50 individuals through existing channels including those who were part of the VOICE Community Engagement Support Group, the Imperial BRC Public Advisory Panel, the Young People's Advisory Group Network and known community leaders. See **Appendix 3** for further details on recruitment, event registration and technical requirements of the Zoom call.

Key Insights Summary

Overall the REACT study was well received, and the at-home antibody test was viewed to be appropriate. However, some felt an alternative approach to testing (beyond just at-home/self-testing) would be needed for certain groups who might struggle with the test in its current form due to perceived usability/accessibility challenges. Comments raised during the breakout room discussions have been themed and summarized below with further detail of these can be found in the next section

Overall support for the at-home antibody test with most feeling they would want to take part.

- 97% (n=34) of respondents to our anonymous poll said they would be likely or very likely to take an at-home antibody test based on what they had heard during the call
- Participants also suggested they would be happy for the test to be available to their family members with some attendees also feeling that it would acceptable and desirable to test children with parental consent although this needs to be explored further with specific groups.

Perceived usability challenges of the test may exclude certain members of the population.

- In general, the test was seen to present usability/accessibility challenges for those with physical or mental impairments, or those for whom English is not their first language.
- Several parts of the testing kit were viewed as being difficult to use or needing improvement. For example, people found the pipette difficult to use or did not understand where to deposit the blood on the cassette.

Instruction video and booklet considered to be clear and well designed

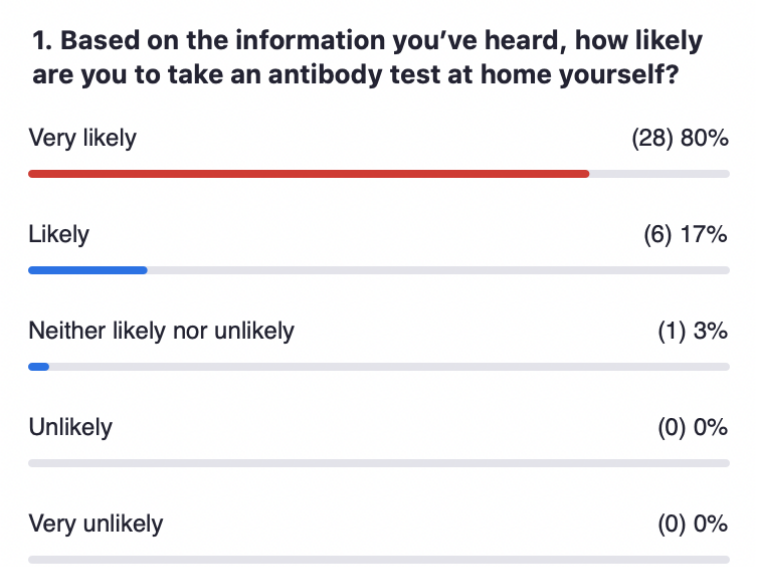
- The sharing of testing instructions via a combination of video and instruction booklet was received positively, with both parts thought to be well designed.
- Some changes were suggested to improve their comprehensibility. For example, making the video shorter or in two parts and adding more detail to the booklet.
- Although call participants understood the REACT2 study is focused on the usability of the test (and that individual results could not be relied on as an indicator of immunity), there were still a number of comments regarding the accuracy of the results, including:
    - Concern around how people might interpret and feel about their test results and whether it would cause people to change their behaviour.
    - Suggestions around how the accuracy of the test and purpose of study could be conveyed more clearly in the information booklet and what the limitations would mean for people's perceptions of the test.

Attendees identified several ways that the REACT2 study could be improved, including:

- Clear data sharing agreements
- Strong and consistent messaging and external/public communication about the study
- Recruitment that ensures representation from the BAME communities who might be most affected be SARS-COV-2 and/or the coronavirus outbreak in general

Poll: Likelihood to take an antibody test

In total 35 of the 37 call participants took part in the anonymous snap poll. 80% (n=28) said they would be very likely to take an at home antibody test based on the information they heard in the Zoom presentation and 17% (n=6) said they would be likely to do so.



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.

Appropriateness of an at home test

Overall the test is appropriate, but consideration of alternatives is needed for certain groups

When reflecting on the appropriateness of an at home self-administered finger prick test for SARS-COV-2 antibody testing, there was a general consensus that a home test was an acceptable solution.

Participants in one breakout group reported a preference for a blood spot test over a swab test because they preferred the accuracy and immediacy it offered. In another group it was agreed that it would be acceptable and desirable to test children with parental consent. These participants were happy for the test to be available to their family members.

Accessibility concerns of the test

In general, the test presents usability/accessibility challenges for those with physical or mental impairments, or those for whom English is not their first language.

While the home test was deemed acceptable, it was not viewed as ideal for all. One breakout group instead suggested mobile testing vans for those that can't perform the test at home or would rather not go to a testing centre – this was seen as particularly suitable in areas with higher levels of deprivation.

Regarding the usability of the test from an accessibility perspective, there were concerns about exclusion for those with a physical or mental impairment. There was a view that the pipette would be

fiddly making it challenging for someone with dexterity issues, arthritis or for those who were visually impaired.

There was a question as to whether a person can be helped to do the test, for example by a carer, if so, this should be made clear in accompanying information. Another suggestion was to establish a helpline to support those doing the test at home or have a bank of volunteers who'd be able to support or apply the test.

Other accessibility concerns of the study included:

- Assumed access to computers or the internet (there was a question as to whether the usability testing and feedback could be done offline)
- Language barriers – As BAME communities appear to be disproportionately affected by Sars-Cov-2, it was felt that the information needed to be translated into other languages or visualised pictorially to ensure greater accessibility for more diverse members of society. An easy read version was suggested as another way to improve the accessibility of the information.

Usability

Several parts of the testing kit were viewed as being difficult to use or needing improvement.

Some participants had carried out the test themselves while others had only seen the video/instructions.

There was a feeling that the pipette would be difficult for most people to use as 'even really good pipettes are quite hard to use'. Participants asked whether the test could perform without the pipette. Some particpants expressed uncertainty around how to use the fingerprick test device (lancet) as it seemed unclear from the guidance, while others reported that it was not clear where to put the blood. One suggestion was that the wells on the test casette could be colour coded as currenrly it was not clear which was for the blood and which was for the buffer solution. Simialrly an explanation or labeling of what the test and control lines are for was important as some people might have fear of 'doing it wrong' if they are unsure what to look for.

This was supported by further comments that the test must be simple, otherwise people will be less likely to use it. It also needs to be well tested to ensure it works as it would be disheartening to not be able to complete the test.

Those who had carried out the test as part of the early pilot gave examples of issues faced in carrying out the test: one received a kit that did not have a pipette inside. They also suggested a need to clarify that you have to remove the red cap from the buffer solution as some people had opened the full buffer cap.

Accompanying information

The combination of video and booklet were received positively with both parts thought to be well designed. Some changes were suggested to improve their comprehensibility.

One participant stated that the test itself is fairly simple but there may be a fear factor involved as people might not feel confident doing this kind of test. The information provided with the test is crucial for alleviating these fears and ensuring people feel able to perform the test correctly.
There was a consensus in one breakout group that although the video and booklet instructions are clear, having more detailed steps of what to do before the test would be useful, for example being

told whether they should watch the video or read the booklet first. When watching the video first, one participant reported that she then briefly skimmed the pdf booklet as she knew what she was doing. Mapping out all the steps is important for ensuring people know what to do and when. Having both a booklet and a video was seen as positive as some people might not be able to use one format, but they could use the other.

Video

For some, the video was viewed as very human and very clear. In one breakout group it was felt that while the video helpful, it was too long (8 mins). The majority of this group felt a shorter version, with just practicalities of doing the test, would be better. However, it was agreed that the background information about antibody testing could be included as part of a second video.

The format of the video presenting a doctor:patient style conversation had mixed reviews. Some liked this format. While others felt the two-way consultation contradicted the proposed approach of the test, which is to be done at home in the absence of a healthcare professional, and created an additional element to understand when trying to follow the instructions.

Related to the earlier theme of accessibility, it was felt that subtitles were needed for those with other languages and hearing impairments.

Booklet

Call participants found the information booklet well laid out, easy to read, with a good step-by-step and visual lay out.

For some there was a feeling that the names used for the items in the kit were too scientific, i.e. lancet and pipette. An alternative suggestion was to use an alphabetic key for the pictures and not names.

There was a feeling that the booklet needed to contain more precise information on timings: for example when using the alcohol swab there was a question as to whether the timing was important (one person said that when they give blood they clean the area for 10-15 seconds). Additionally, for step 6, after adding the buffer to start the test, it should say that it is important/essential to note the time and perhaps use an alarm or phone for accuracy. Feedback from one participant after the call suggested that the need for a phone with camera and timer should be stated at the beginning of the instructions, to be seen before you start the test.

Interpreting the test at an individual level

Among call participants there was a feeling of concern about how people might interpret their tests results and change their behaviour.

Many felt that even if this is only an epidemiological surveillance test, people will treat the test like it is an accurate measure for themselves, as though it were for clinical individual use. This would matter differently for this sort of large-scale epidemic relative to normal testing scenarios because individual behaviour change is key to response to the pandemic. Some call participants stated that they might feel more relaxed once they got their result but would not personally change their behaviour.

Participants thought the accompanying information must make it very clear that the test should not be used to make health decisions, as a positive result does not necessarily equate to immunity. The suggested message was ‘whatever your test is, still follow the guidelines’. It was noted that this is currently at the end of the information booklet where people might miss it. This information should be shared up front.

Accuracy of the test

Although call participants understood the study is focused on the usability of the test and that individual results could not be relied on as an indicator of immunity, there were still a number of comments regarding the accuracy of the test. Specifically, participants suggested ways in which test accuracy could be conveyed in the information booklet, what the limitations would mean for people's perceptions of the test/study and voiced concerns about how people would feel or behave after reading their result.

Limitations of result

Some call participants thought the information booklet should contain statistics on the accuracy of the test to ensure those taking it understood the limitations of their results. One participant felt that if the information contained these limitations it might discourage people from taking part in the study. Another participant suggested that even if the test only reported 70% accuracy, people might still read into their result and change their behaviour.

The message about immunity (that a positive result does not guarantee that people are immune and not able to catch it again) needs to be made very clearly. It should also be separated from messaging around the accuracy of the test to ensure that if messaging around the accuracy of the test is communicated (whether now or later in the study), that those who took part or are taking part understand that this only gives information about past infection, not any information about future protection. For this reason, people should not change their behaviour based on the result and current guidance must still be followed, even if the test is later found to be accurate.

Trust

There was a feeling that the accuracy of the test matters, as transparency is important. People are desperate for testing; however it was felt that the test should not be rolled out in advance of it being useful and safe. If researchers roll out a test that is perceived to be inaccurate, it could damage people's trust.

Concerns

There were some concerns regarding people who are living alone (or those who are shielding) who might receive a positive test and not have any support. Ther was a feeling that the accompanying information was key to stopping panic in response to results. It was felt that something should be added into the information booklet about what to do if you get a postive result. One person was concerned that it might accidently give a positive result for another disease, and this was seen as a privacy concern.

Considerations for study

Participants offered their reflections on how the REACT2 study might be improved: through clear data sharing agreements; strong messaging and external comms; and recruitment that ensures representation from the BAME communities who might be worst affected be SARS-COV-2.

Data sharing

A number of call participants stated they were happy to share their data with Ipsos Mori but felt they wanted to know who IPSOS MORI share this with, and the time limit on storage of this data. For this they felt a short simple privacy notice would be good. Others felt that data sharing could be on a 'needs must' basis as the study is so important and there is a need to do the testing quickly.

Recuitment

Call participants pointed out that the current test kit and materials assume that people have access to emails, smartphones etc. If recruitment will be done using a random sample, there may be people who are unable to complete the test. In the feedback on participant suggested that recruitment

could be supported by community leaders who could be brought on board both to verify the process and to spread the word that this is happening in order to bring a more representative sample into the testing cohort. Some participants suggested they would be able to help recruitment by sharing the study information within their networks.

Communications

Particpants reflected on the plans for the wider communication for the study. On the one hand it was felt an antibody testing study could send a positive message about the increasing chances of easing lockdown restrictions. It was felt that people could be encouraged to take part by building on their feelings of community spirit in response to efforts against the virus. On the other hand there was concern about how the wider media might share infromation about the study that focuses on the indvidual result rather than the process of doing the test, as intended. It was seen as important that wider communications and messaging about the study is clear about the objectives. Finally, it was suggested that although Ipsos Mori were fine for the research study, the test should come from Public Health England for the wider roll out.

Post-call feedback from attendees (n=20/37)

- Attendees rated the call highly, with all respondents rating the call at least 7/10 with the majority (80.0%, n=16) rating the call 9/10 or 10/10
- 95% of respondents stated they were extremely likely to attend another Zoom call to discuss important COVID-19 research (1 respondent stated they were somewhat likely)
- When asked they liked most about the call (multiple selection allowed), 35.3% (n=12) said the introduction to the REACT study and 26.5% (n=9) said the explanation of the antibody testing and 20.6% (n=7) said the breakout room discussions. Respondents also provided their own highlights, which included hearing the questions from other members of the public and the first-hand accounts of the strengths and weaknesses of those who had already taken the test.
- 100% respondents found the call either Informative or Extremely Informative; and the information about the antibody test either Clear or Very clear
- The information about coronavirus antibody testing was new to 30.4% of respondents (n=7), while those that already knew about antibody testing (from the news and media, online courses or from doing the test), still found hearing it reiterated by experts useful and valuable. The level of detail provided (i.e. details about immunity) was also was new to some. Some had never heard of IgG and IgM, which some felt were important complexities for them to realise
- Feedback on how the calls could be improved included: seeing if the speakers could be presented on the screen alongside the slide deck, ensuring breakout discussions stay on topic, shorter/clearer Event notifications and invite emails sent once, and importantly ensuring a greater diversity of people are invited to the calls and/or involved in the study to ensure a more representative sample of society help to share the project going forwards.

See **Appendix 4** for full table of feedback responses.

Appendix 1: Demographic of public attendees

Table 1: Demographic details provided during event registration (n=31/37; data not available for 6 attendees)

Characteristic	n (%)
Age (in years)	
Mean (range)	52.6 (19–80)
Approx. age group	
18–24	3 (9.7)
25–34	2 (6.5)
35–44	7 (22.6)
45–54	3 (9.7)
55–64	2 (9.7)
65–74	12 (38.7)
75–84	2 (6.5)
Sex	
Female	22 (71.0)
Male	9 (29.0)
Ethnicity	
White	28 (90.3)
Mixed / Multiple ethnic groups	0 (0.0)
Asian / Asian British	1 (3.2)
Black / African / Caribbean / Black British	1 (3.2)
Other ethnic group	1 (3.2)
Prefer not to say	0 (0.0)
Location	
North East England	10 (32.3)
North West England	0 (0.0)
Yorkshire and the Humber	3 (9.7)
East Midlands	0 (0.0)
West Midlands	1 (3.2)
East of England	0 (0.0)
Greater London	10 (32.3)
North London	*4 (40.0)*
East London	*0 (0.00)*
South London	*2 (20.0)*
West London	*4 (40.0)*
South East England	3 (9.7)
South West England	1 (3.2)
Scotland	3 (9.7)
Northern Ireland	0 (0.0)
Wales	0 (0.0)
At-risk vulnerable group	
Yes	8 (25.8)
No	21 (67.7)
Prefer not to say	1 (3.2)
Don’t know	1 (3.2)

Appendix 2: Questions asked by call participants using the chat function in Zoom

Answered during call

1. How do people report results of test back to Imperial
2. If the antibodies are likely to stay in the blood for only a couple of months and we are in the middle of the pandemic currently- do we not need to send antibody tests out as soon as possible otherwise we might miss the window if the antibody test are sent out late this year?
3. What additional data about the people taking the test would be collected (e.g., hospital visits/recency of symptoms, demographics...?)
4. Will there be periodic follow up tests with the same individuals, to establish how long the antibodies are present for?
5. Let's not forget supermarket staff as key workers
6. Will you retest after a period to see if people who test positive still have antibodies?
7. If we do the tests, would you like our household to test too?
8. How does the antibody test relate to asymptomatic carriers?
9. How long will the whole process/all the stages take? (Sorry if mentioned before)

Unanswered

1. Time frame for the studies?
2. Will you test people who have not been tested but have had symptoms and self-isolated?
3. Is the questionnaire after the test been online or in the post?
4. Do you know when the first tests will start?
5. Are studies like this being done worldwide and will there be a co-ordination between countries and how will the general public be given access to results.
6. Is it possible to get a positive antibody test result and still be infectious? I think Helen mentioned antibodies can begin to appear around 14 days of having the virus.
7. Is this a one-off test? does antibody test pick up other problems? if the antibody is negative could it be upsetting for the person? can one leave the study if decide to?
8. After the present crisis, will there be ongoing review of those tested e.g. over a wider timeframe... a couple of years?
9. Would you want us to recruit around us?
10. What percentage of correct test results would be acceptable for a particular test to be rolled out nationally?
11. I think co research and co design are more commonly used phrases rather than public involvement
12. Are you only involving people who have access to a computer even for study 3,4,5?
13. It doesn't need to be a dialogue between two people. Requires and additional layer of thought. It would be easier to understand if it showed one person, demoing the test
14. The test seems quite complicated; do you think the wider community i.e. study 3,4,5 will manage to do it?
15. Will these tests be specific enough to indicate if it the 'early stage' antibodies, or the later occurring antibodies?

Appendix 3: Event registration and Zoom call set-up

Attendee recruitment

Due to the rapid nature of the call and to ensure diversity of attendees in terms of age, ethnicity, geographic location, and experience, attendees were invited to the call through a number of existing channels.

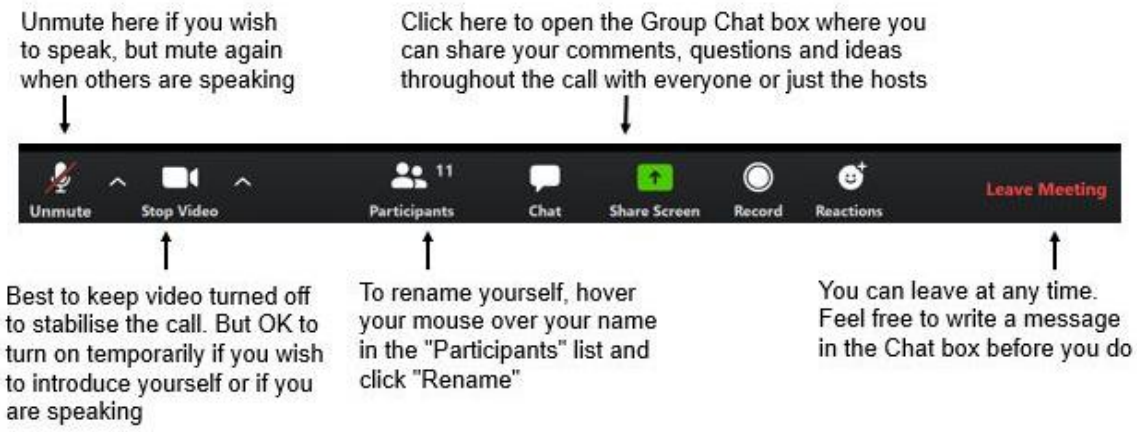
Specifically, an email invite was sent out to individuals who had joined a previous Zoom call with us and those who were part of the VOICE Community Engagement Support Group, the Imperial BRC Public Advisory Panel and the Young People's Advisory Group Network. We also worked with Public Involvement and Community Engagement Leads at Imperial to extend the invite to a couple of known community leaders within the White City Area and elsewhere in the UK. In total roughly 50 individuals were contacted.

Event registration

Attendees were asked to register for the call via Eventbrite, which included providing some basic demographic details. Thirty-three individuals registered for the call via Eventbrite of which 31 joined on the day. A further 6 were given direct access to the Zoom call either by PERC or by an invited attendee (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. Each breakout room had a second co-host who was not facilitating the discussion but helped support set up of breakout rooms and manage attendees who might be struggling.

Co-hosts were able to record breakout rooms to their computers and share the notes and audio recordings via Box 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 4: 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?	
<6	0 (0.0)
7	1 (5.0)
8	3 (15.0)
9	11 (55.0)
10	5 (25.0)
How likely are you to join another Zoom call like it?	
Extremely likely	19 (95.0)
Somewhat likely	1 (5.3)
Neither likely nor unlikely	0 (0.0)
Somewhat unlikely	0 (0.0)
Extremely unlikely	0 (0.0)
What did you like most? (multiple select allowed)	
Explanation about antibody testing	9 (26.5)
Introduction to the REACT study	12 (35.3)
Breakout room discussions	7 (20.6)
None of it	0 (0.0)
Other: • Hear early literature and video about antibody testing - reading an explanation and a human voice, with all its qualifications and stresses, so yes, that was good • Good to feel involved, opportunity to feedback – breaking up into smaller groups helped the process • Hearing the questions from other members of the public • Hearing first-hand account of those who've already used the test • REACT study/ instructions well-explained in lay person's language	6 (17.6)
How informative was the call?	
Extremely	11 (55.0)
Very	9 (45.0)
Moderately	0 (0.0)
Slightly	0 (0.0)
Not at all	0 (0.0)
Was the information about antibody testing new?	
Yes	7 (30.4)
No	11 (47.8)
Other: • Heard about it on TV/via daily news/media/via online course but as with all new things need several explanations for it to sink in • Never heard of IgG and IgM – Important for us to realise	5 (21.7)
Was the information about antibody testing clear?	
Very clear	9 (45.0)
Quite clear	11 (55.0)
Neither clear or unclear	0 (0.0)
Quite unclear	0 (0.0)
Very unclear	0 (0.0)
Other	0 (0.0)