

REACT Public Involvement Sprint: Online Survey

Insight Report: Antibody testing on children and young people

REACT (REal-time Assessment of Community Transmission) study background

The REACT study is a major programme of home testing for COVID-19 to track the progress of the infection across England. It was commissioned by the Department of Health and Social Care and is being carried out by Imperial College London in partnership with Imperial College Healthcare NHS Trust and IpsosMORI. The Patient Experience Research Centre (PERC) are supporting the antibody testing usability studies as part of this programme of work and leading the public involvement activity that is informing its design and management.

An important aim of this programme is to estimate how many people in England have already been infected with the virus that causes COVID-19. This involves getting people to do a finger-prick antibody test at home to check for antibodies in their blood. The presence of antibodies (i.e. a positive test result) would suggest someone had already had COVID-19 in the past. However, our studies to date have only explored how easy it is for adults (aged 18+) to use these finger-prick antibody tests correctly at home. Few studies have explored the usability and acceptability of performing finger-prick testing on children. Enabling these tests to be performed on children would give researchers a much greater understanding of how the virus is spreading through the population.

We felt further research is needed to understand the acceptability and usability of performing antibody testing on children, particularly a finger-prick antibody test, therefore we turned to parents, carers and young people to get their thoughts and guide any plans going forwards.

Survey overview

Between 18-21 June 2020, we carried out an online public involvement survey to capture the views of parents, carers and young people across England on the acceptability, feasibility and usability of antibody testing on children and received 4,290 responses: 4,180 parents/carers (of children aged 5–17) and 110 young people (aged 16–17). Of the parents/carers, 23.7% had children aged under 5 (n=1,480), 56.0% had children aged 5–11 years old (n=3,500), 16.2% had children aged 12–15 years old (n=1,010) and 4.2% had children aged 16–17 years old (n=262). See [Appendix 1](#) for respondent demographics.

Broadly, the questions aimed to gather their views on:

- The acceptability of testing children to see if they'd already had COVID-19
- The acceptability of performing antibody tests on children as part of research
- The acceptability of performing a finger-prick antibody test on children
- Where the test should be carried out and by who
- Whether the instructions and material already developed were suitable for children, and if not, what should be improved or is missing

The survey invite was shared with relevant audiences via email, WhatsApp, Instagram, Twitter and Facebook using a mix of a new and existing networks. See [Appendix 2](#) for further details on the dissemination strategy.

Quick Links

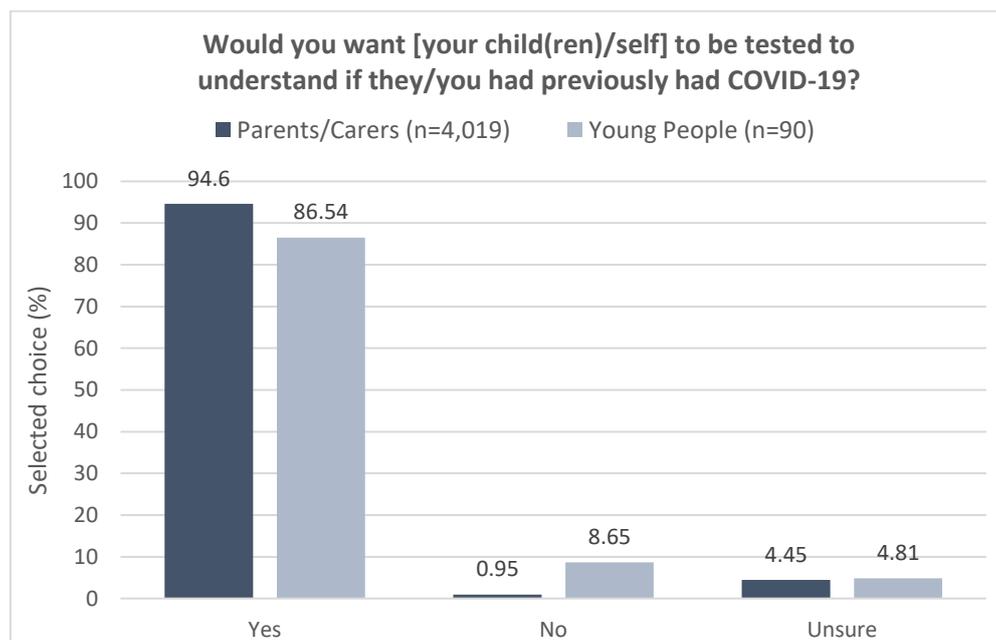
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Report Findings

Willingness to perform antibody testing on children

Among parents and carers who responded to the survey, 94.6% stated they would want their child to be tested to understand if they previously had COVID-19. Less than 1% answered 'No' and 4.45% answered that they were 'Not sure'. Reasons given by parents are summarized below.

This compared to 86.5% of young people being willing to do the test, with a greater number saying they would not want to do the test (8.6% compared to less than 1% of parents) and 4.8% who were unsure. Young people were not asked to provide a reason for their response.



The reasons given by parents for their response included the following:

- Wanting clarification about whether some past symptoms seen in their child(ren) over the last 6 months had in fact been COVID-19. People described these as cold or flu-like symptoms, strange symptoms, or those typically reported as COVID-19 symptoms, e.g. fever, cough, respiratory symptoms and fatigue. Symptoms were reported as having varying degrees of severity, in some cases they required a visit to A&E or hospitalization.
 - There were several examples of the different types of cough observed – dry coughs, barking coughs, bad coughs that lead parents to question if their child had the virus.
 - There were several mentions of different types of viral infection experiences over previous months, ranging from chest infections to suspected or non-specific infections as well as other infection sites such as skin or kidneys.
 - Chest symptoms were frequently mentioned (and discussed in relation to infections) but also referred to pain and tightness which matched some of the Covid-19 symptoms.
- On the other hand some parents were curious as to whether their children had been asymptomatic carriers at any point, or may yet be a carrier if they have not had the virus.
- Understanding if/when their child could return to school. Some parents were more focused on the child's safety, not wanting them to go back until it was safe, while others were more focused on whether they would be *allowed* back to school if they were found to already have had the virus)

- Helping to relieve anxiety in their child, e.g. about going outside or just about catching the virus in general. Equally it would give the parents ‘peace of mind’. Parents would feel more comfortable allowing the child to mix with others, e.g. playing with friends
- If the child was high risk due to particular existing conditions e.g. asthma the parent was concerned to know if they had already had the virus
- Understanding what risk their child posed to other more vulnerable members of the household such as a grandparent or relative with underlying health issues, with some wanting to make sure their child wasn’t going to potentially pass on the virus as a carrier. There was a view by many parents that getting the result would help them make informed decisions about allowing the child to do different things such as socialising, visiting grandparents, or going back to school
- In several cases parents were key workers so wanted to know if their child had been exposed (through them).
- There was also a feeling that the test would be a helpful contribution to the broader understanding of the virus and that they would be happy to contribute to the research

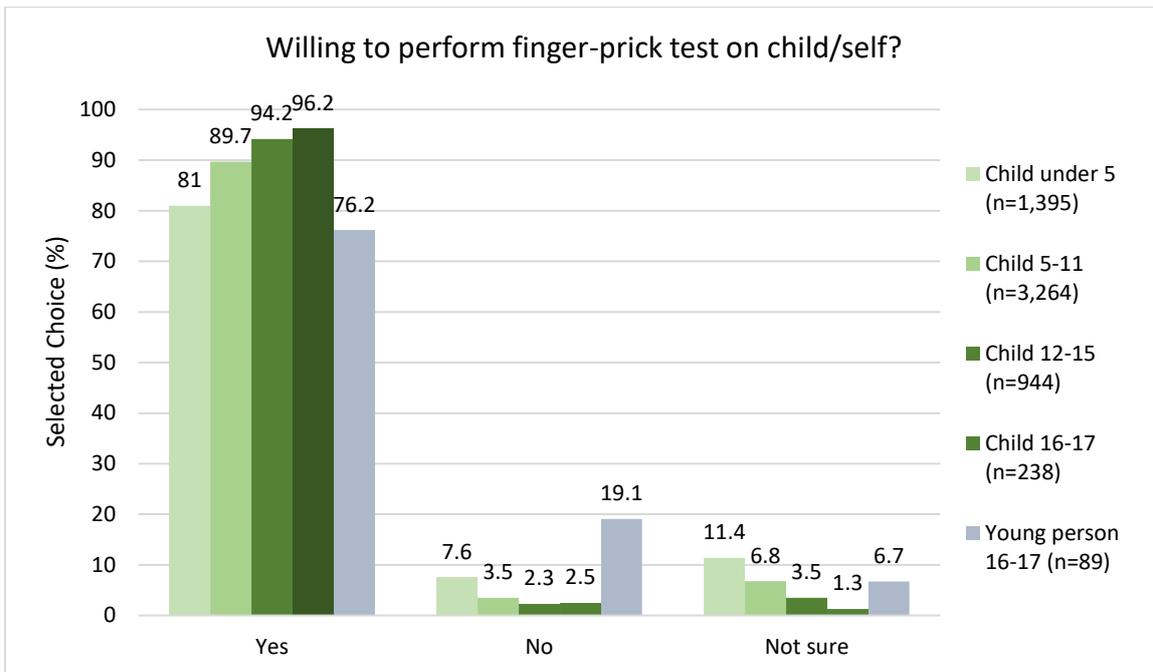
In some cases, feasibility of performing the test was included as part of their motivation:

- Many described the test as looking “simple and straightforward” and for this reason felt they could perform it on their child.
- Others shared that they were confident to perform the test and/or that their child would be fine because the parent was a healthcare professional and therefore used to performing tests, or because their child was used to having finger-prick tests or medical tests performed on them due to diabetes or another health condition
- In contrast, those who did not want to do the test themselves reported having concerns about their ability to do the test on a child. There seemed some confusion as to whether it was a finger-prick blood test or an intravenous blood test.
- Many felt it should be carried out by a medical professional due to fear of hurting the child or if it required blood to be taken intravenously
- Although a minority, some parents were opposed to performing a blood test or finger-prick blood test for “research purposes only” saying that they wouldn’t want to put their child through the test if it didn’t give them a reliable answer (suggesting they would allow the test to be done if blood was being taken for an accurate test result)

Respondent’s views on the feasibility of antibody testing on children is expanded on later in this report – see p11, [Perceived feasibility and usability of finger-prick antibody testing](#).

Acceptability of performing a finger-prick antibody testing on children

Survey respondents were shown the instruction booklet and asked to watch a short video explaining how to perform the finger-prick antibody self-test. Although the information shared did not demonstrate the test being performed on children, respondents were able to see what the test would involve. Based on what they had seen they were then asked whether they would be willing to perform the test on their children. Responses were collected for parents of children in each age group.



Children aged under 5

81% of parents who responded said they would be willing to perform the test on their child, 7.6% answered No and 11.4% were unsure. Parents were again asked to give the reason for their response. Reasons given by those who responded 'Yes' included:

- The test seemed quick and simple
- Many felt that on seeing the test it looked as though it would not be painful
- Those who have experience doing blood glucose tests or other medical procedures on children or had other family members or friends who do similar kinds of tests expressed they would be willing or able to carry out the test. Several commented on its similarity to the newborn heel-prick test
- There was a feeling among some that the test could be difficult but worthwhile to get the results (for themselves/ their child but also as part of the efforts to learn about the spread of the virus)

Reasons given by those who responded 'No' included:

- Concerns about inflicting pain, causing the child to be frightened or making them cry
- Emotional stress of situation, the child being upset, and parents fear of doing the test were suggested as things that might cause them to do it wrong/make a mistake/not do it properly (and possibly hurt the child)
- Parents reported a willingness for their child to be tested but not for them to do it themselves. Many felt it would be better done by a professional such as their GP or nurse, and that the child would be more accepting of this.
- There were also physical challenges, for example parents would struggle to keep small child still or would find their little fingers too small to prick with the lancet
- Parents would rather comfort their child and have somebody else do the test

Reasons given by those who responded 'Not sure' echoed those who answered 'No' but were less strong in their sentiment; while some parents shared the concerns around inflicting pain or doing the test wrong, they felt they would still be able to do the test if required. For many, their ability to do the test would depend on their child's willingness/compliance. They would not want to do the test if there was a struggle.

Children aged 5-11

89.7% of parents who responded said they were willing to do the test on their child, 3.5% stated they were not willing and 6.8% were unsure. For this group, the reasons given were similar to those given by parents of under 5s for 'Yes', 'No' and 'Not Sure'. However, there were also some notable differences:

- There were some comments about the child resisting or having a fear of the test or this type of test in this age group
- Some felt they would have to convince or persuade their child
- There was a feeling for some parents that children of this age would be more agreeable if another adult such as a nurse or GP performed the test
- There was a suggestion that helping the child understand and feel like it was part of a science experiment would help them do the test
- The parents of children in this age talked more about explaining the test to their child to encourage them than parents of under 5s

Children aged 12-15

89.2% of parents who responded said they were willing to perform the test, 2.3% were not be willing and 3.5% were unsure. Again, the reasons provided were similar to those given by parents of younger children, e.g. the simple and straight forward nature of the test made them think it could be done quickly and easily. There were some responses that were more specific to this age group:

- The level of the understanding of older children was reported by some as a facilitator for being able to do the test, it was felt that this age group were 'old enough' to understand the importance
- Respondents also reported more consideration of the child's views in this group – parents would be happy to do the test with the child's agreement. A small number of parents felt their teenager would rather a professional do the test
- Fear of needles was a reason parents thought their 12 to 15-year-old would not do the test
- There were also suggestions around the difficulty of persuading a teenager to do things. It was felt it would be their decision, not the parent's
- Some parents of older children cited learning difficulties or disabilities as a reason why they would not carry out the test

Children aged 16-17

96.2% of parents who responded said they would be willing for their children to have the test, 2.5 were not willing and 1.3% were unsure. There was a feeling among these parents that the teenager would be able to do the test themselves but that it would be straightforward for them to do.

Young people (aged 16-17)

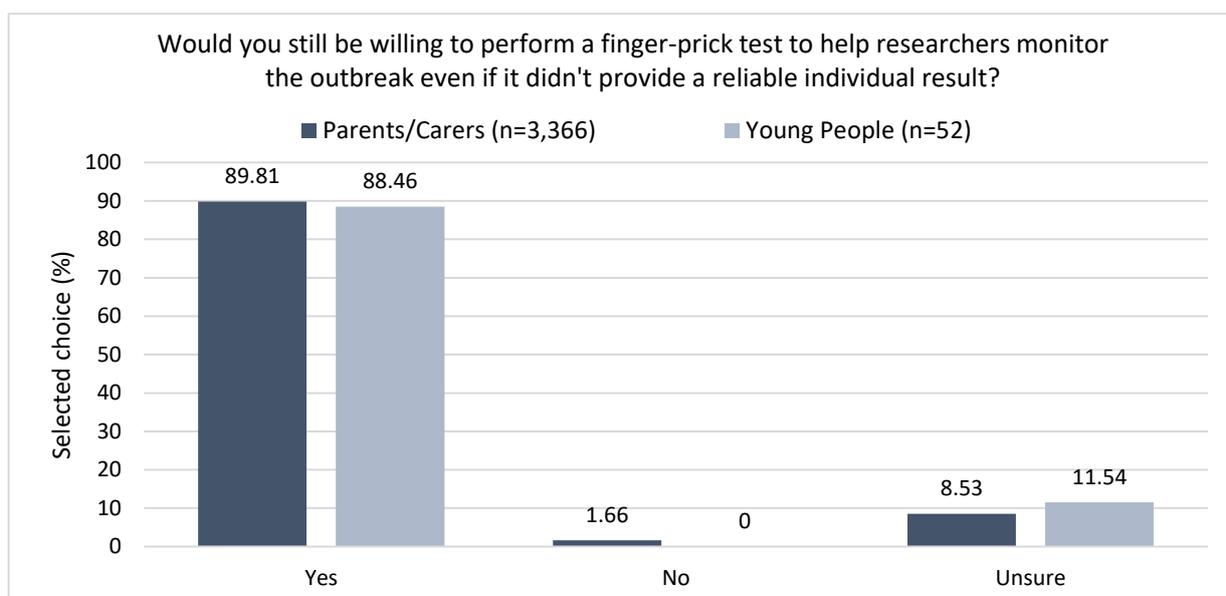
74.2% of young people who responded said 'Yes' they would be happy to perform the test on themselves based on what they had seen. Those who gave a reason generally said that it looked straightforward. For some it seemed akin to a science experiment or something they might have done in a biology class. Others mentioned working up the courage to inflict the pain on themselves would be the only challenge. 19.1% young people who responded to the survey answered 'No' and 6.4% said 'Not sure'. Of these only a very small number gave any reasons, these included having a fear of needles and/or blood or a feeling they would want a professional to do it to make sure they had done it correctly.

Of those that said 'No' to performing a finger-prick antibody test on their child

Just over half (55.6%; n=100) of parents said being able to carry out the test on themselves first would influence their willingness to do the test on their child. This was primarily based on being able to see how painful the finger-prick was and to gain some practice, so they felt more confident and able to do it properly on their child. Over a quarter (28.9%; n=52) however still said 'No', which was primarily based on not wanting to cause any pain to their child, knowing that their child would never let them do a test like this on them or not wanting to put their child through something that they didn't think would be beneficial. A final 15.6% (n=28) said 'Unsure'. One respondent also raised the point about informed consent saying, "no means no" and that they "shouldn't be coerced against their will". A few parents of older children commented in other sections that they would ask their child if they wanted to do. However, it should be made clear to all that the test should not be performed if the child doesn't want to do it, is resisting or becoming very anxious.

Acceptability of performing a finger-prick antibody test on children as part of research

When asked whether they would be willing to perform the test as part of a research study only (i.e. not to provide a reliable individual result), 89.8% of parents and 88.5% of young people answered 'Yes'.

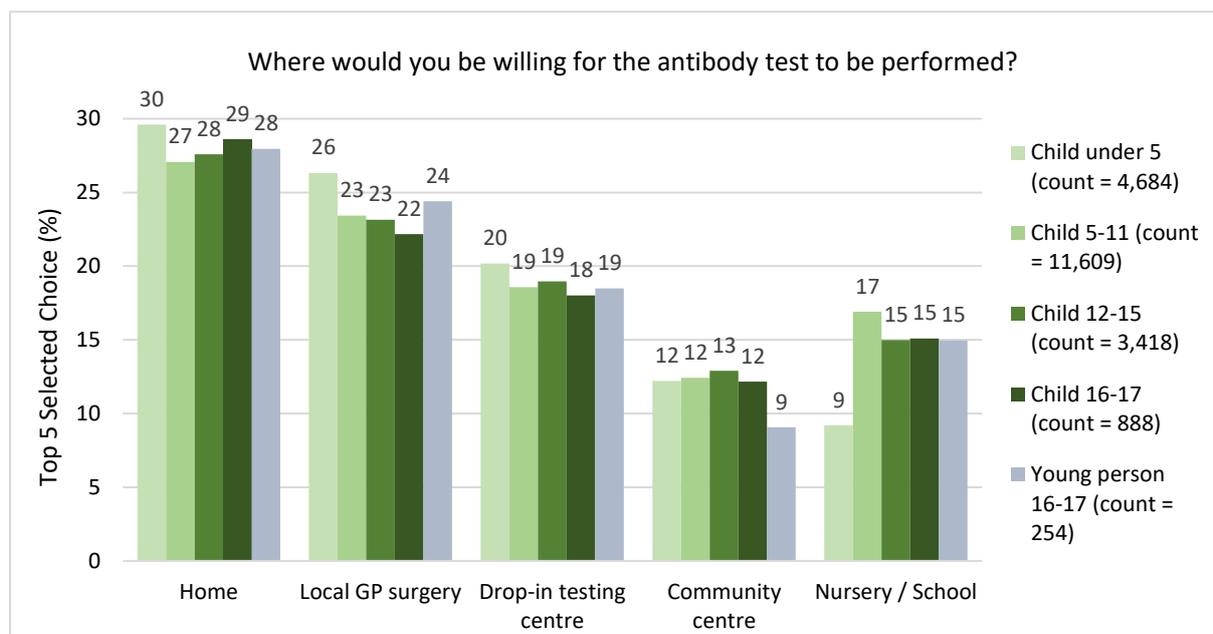


When asked the reason for their answer:

- Of those that would 'still' want to do the test even if the results were not reliable, there was a feeling that the test was important for understanding and finding out about COVID-19 and how it has spread throughout the country. Contributing to research was seen as a way people could help
- Several responses indicated a personal 'interest' in the topic, the research or related science
- In contrast, those that were not in agreement felt there was 'no point' doing the test if it was not accurate. They felt it was not worth putting a child through the potential discomfort of the test when there is no direct benefit to them. Some parents felt they should prioritise their child's mental health and avoid adding to their anxiety over doing the test 'just for research'
- Others wanted clarification on how the test had any value at a population level if it was not accurate or reliable at an individual level

Preferences on where the test should be carried out

Respondents were asked where they would be willing for the test to be performed on their child (or themselves for young people). It should be noted that this was asked prior to showing further details of the finger-prick testing kit. 27–29% selected ‘At home’, 22–26% selected ‘Local GP surgery’ and 18–20% selected ‘Drop-in testing centre’. There was little difference in selection across the parent groups or among young people, apart from parents of under 5s who showed less willingness to test their child at nursery. According to the comments, this appeared to be linked to a wish to prevent negative associations with these places of care.



Further analysis of the 280 free text comments provided showed a consensus across the age groups. If testing wasn't carried out at home, people were generally happy with "anywhere" providing the following key requirements or considerations were met (listed here with the most frequent first):

1. A parent must be able to join throughout

This was the most clearly indicated requirement by respondents. It appeared to be linked to the fact that blood was being taken but also likely due to the unique circumstances of the epidemic. Based on other comments shared, parents wanted the reassurance of being there to comfort their child and confirm that appropriate precautions were taken to limit any infection risk.

2. It must be safe and well-managed

Respondents wanted clear reassurance and communication about the precautions that were taken to keep the site safe and limit the risk of infection. They would want bookable appointments with strictly timed windows so that there was no waiting or queuing. They would want strict social distancing to be possible and for enclosed or crowded places to be avoided. Some felt that going to testing locations beyond the home was only OK if community transmission in the area was low. This was particularly true for those who shared that someone in their household was shielding.

3. It must be local, convenient and easy to access

Several respondents who had a car were prepared to drive anywhere, even up 45 minutes, in order to reach a testing site. While others, especially those without a car or unable to drive/travel easily said it had to be walkable, cyclable or easy to access. This included being able to bring multiple children in their care, even if not all were being tested.

4. It should be child-friendly and preferably somewhere that they are already visiting
- A suitable “child-friendly” location was somewhere that put children at ease and allowed parents to bring children of any age. Several parents also suggested “nowhere new” or somewhere “already visiting”. This was mentioned in relation to both its convenience and potential safety benefits as people felt this limited any additional risks to infection by being within their “bubble”. Going somewhere known to the child was considered to be less stressful, although as a note, parents felt that the person performing the test should not to be known to the child, unless they were part of the child’s routine care.

Suggested locations included: school, community centre, village hall, pharmacy, testing centre, research centre, hospital clinic as part of child’s routine care, parent’s workplace if a healthcare professional.

Schools were selected as a possible testing location by around 15% for each of the age groups, which was reinforced in the comments due to it being a site parents already visit, and a location known to the children. However, some issues or caveats were raised in the comments, even by respondents who selected this as an option:

- Parents are currently not allowed within schools due to COVID-19 restrictions
- Many schools are still closed
- Some children are home-educated and are therefore not affiliated to a school. There would need to be the option to have children tested at any school or a sibling’s school
- It would be too much additional work to put on teachers and school staff
- One respondent noted that kids can make each other nervous and therefore performing the test at school could amplify worries among kids

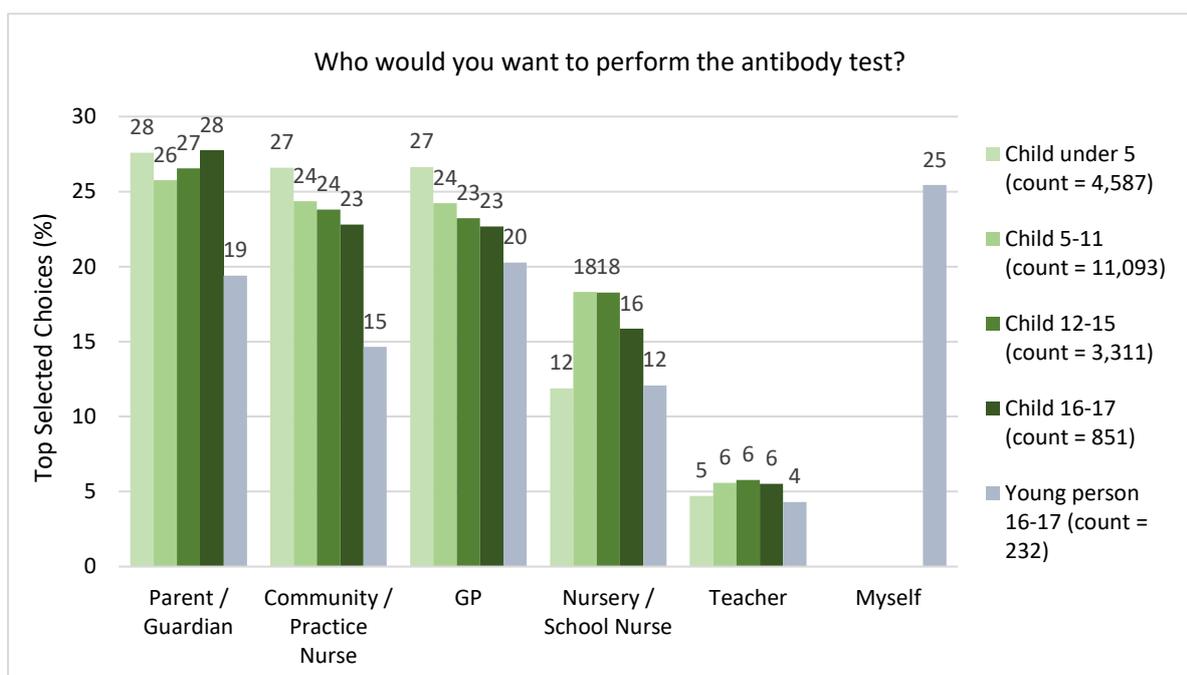
Although GPs were selected as an appropriate location by 22–26% of respondents, several people commented that they would not want to go to their GP practice specifically due to:

- Social distancing being difficult
- The feeling that they may be exposed to other illnesses
- It being difficult to get an appointment at their practice and/or not wanting to add to the burden

Only a small number expanded on why they preferred to perform the test at home, with reasons including convenience, ease of test and wanting to limit contact with others due to either personal choice or because they themselves, their child or a member of their household was shielding due to a clinical vulnerability. Those who felt confident in being able to communicate to their child and perform the test felt that being at home would also be less stressful than going to an alternative testing site. While those who were less confident or knew their child may behave better or be more accepting of the test being performed by a medical profession felt going to a dedicated site would be better.

Preferences on who should carry out the test on children

Overall preference among parents was for the parent/guardian to perform the test themselves on their child. Several said it depended on what was involved. Only a very small number thought that the blood sample was taken from a vein and that in this case it should only be performed by a trained healthcare professional or paediatric phlebotomist. Young people had a greater preference to perform the test themselves, but a parent/guardian was preferred over any other alternative.



While there were numerical differences in who people selected to perform the test for the different age groups, the 318 free text entries showed little variation in the comments provided.

If the parent wasn't to perform the test, preference was for it to be carried out by a medical professional. However, most seemed happy to accept "anyone" providing the person was:

- Adequately trained to do the test correctly and safely
- DBS-checked
- Used to dealing with children
- Ideally not known to the child (unless they were the child's routine healthcare staff)

Suggested people included: medical professionals (e.g. nurse, healthcare assistant, health visitor, pharmacist, secondary care staff, medically-trained friends and colleagues); trained professionals (e.g. testing centre staff, volunteers, soldiers); the parent (particularly those that are medically trained); the child themselves (if 12 or older and with parental supervision).

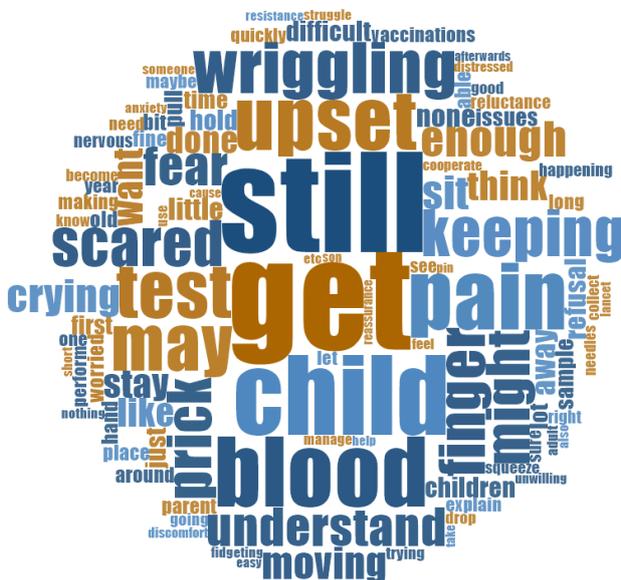
This was further supported by the small selection of parents who specifically said "No" to performing the finger-prick antibody test on their child themselves. 60.3% (n=111) said it should be performed by a community or practice nurse, followed by 14.7% who said GP (n=27).

Across all the comments provided, primary reasons for wanting the test done by someone else included: parent feeling uncomfortable or unable to do it themselves; wanting the certainty that it was done correctly and wouldn't need to be repeated; because blood was involved; not wanting to hurt the child or damage their trust or relationship; expectation that their child would behave better; feeling that it would be quicker and less stressful for the child.

The majority of respondents felt teachers should not be asked or expected to perform the test though because: it would be unfair, beyond their responsibility, add to an already heavy workload and could damage their relationship with the child.

Perceived usability and feasibility of home-based finger-prick antibody testing on children

After seeing instructions and a video showing what is involved with the finger-prick test, many stated that it looked simple and straightforward, although not as simple as a pregnancy test. Despite the perceived simplicity, depending on the age and character of their child, some issues were anticipated, as summarized below:



A. Expected issues with children under 5



B. Expected issues with children aged 5-11



C. Expected issues with children aged 12-15



D. Expected issues with children aged 16-17

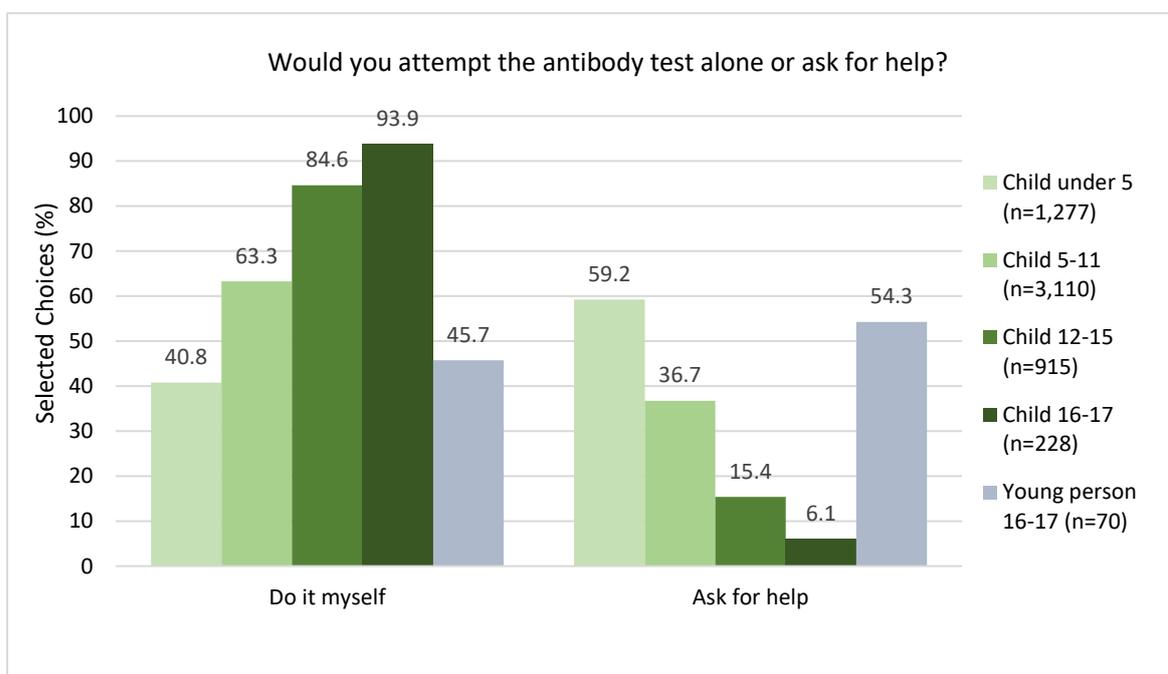
For children under 5, the most common expected issues (of 1,094 comments) were the child wriggling or moving; not getting enough blood or difficulties transferring the blood to the testing stick; fear of hurting the child or causing pain; the child getting upset or resisting after the finger-prick; and the inability to explain the test or get informed consent, especially with under 3s.

For children aged 5-11, the most common expected issues (of 2,307 comments) were concern about hurting the child, causing pain or the child being scared; not getting enough blood, sight of the blood or difficulties transferring the blood to the testing stick; none expected; the child getting upset or resisting after the finger-prick; and having to explain the reason and rationale for doing the test.

For children aged 12-15, the most common response (of 532 comments) was that there would be no issues. However, issues that were reported included the child’s fear of the finger-prick and feeling pain; not getting enough blood, sight of the blood or difficulties transferring the blood to the testing stick; the child’s fear of needles; and having to explain the reason and rationale for doing the test.

For children aged 16-15, the most common response (of 133 comments) was that there would be no issues. However, issues that were reported included explaining the reason and rationale for doing the test; the child’s fear of the finger-prick and feeling pain; the sight of blood upsetting the child; and the child’s fear of needles.

Finally, most young people who responded also expected no issues. However, those that were reported included not getting enough blood, sight of the blood or difficulties transferring the blood to the testing stick; worries about doing the test correctly; fear of doing the finger-prick on themselves and feeling pain; and doing the test one-handed.

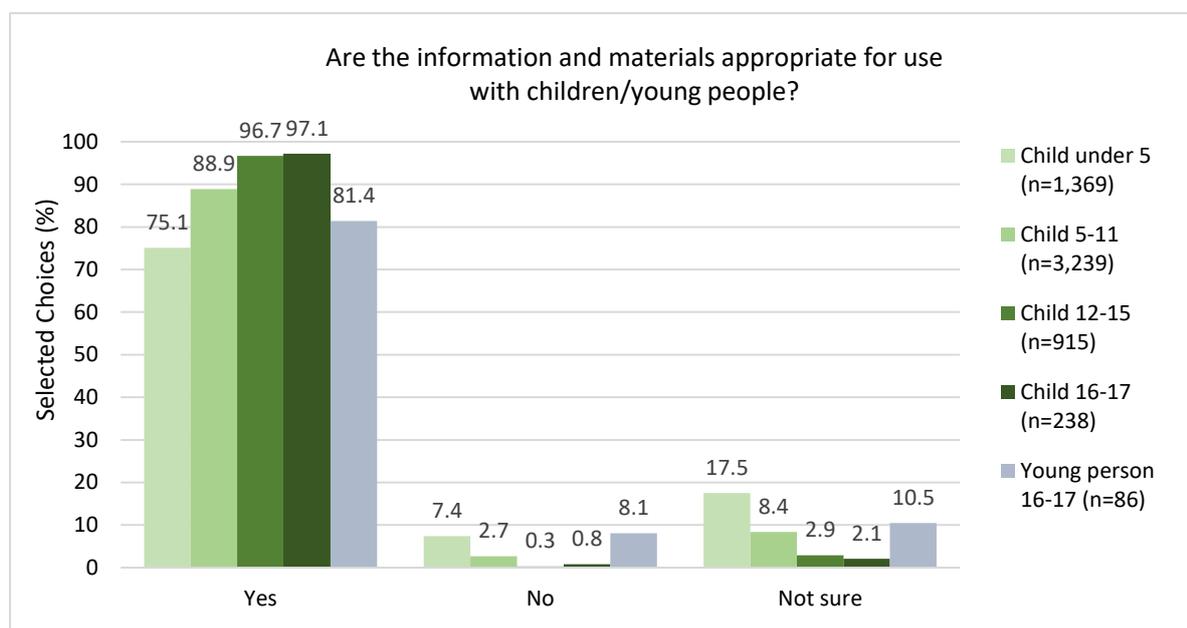


These perceived issues align with the findings that parents/carers of children aged under 5 and young people themselves were most likely to ask for help or support from someone else in their household. The primary reason among parents was to have someone to distract and comfort the child while the other read the instructions and performed the test. While young people were keen to have someone there to support, most commonly the mum, to help them do the test and interpret the result correctly, and to overcome barriers foreseen by doing the test one-handed.

In contrast, parents of children over the age of 12 started to suggest that their child could or would want to do the test themselves, with their supervision.

Appropriateness of material and further information needed

Overall, the materials were seen to be appropriate for all age groups. However, many felt it was more likely that the parent would use them rather than the child directly, especially under 5s.



Suggested improvements to make the instructions and testing kit easier to use, especially with younger children, were framed around three objectives:

- Making the test easier to explain and engage with, e.g. why the test is needed and how it helps; less words, more pictures; brighter images; storyboard style including a cartoon hero or well-recognised character; Makaton symbols; more child-friendly language and images; videos clips of children explaining what it's like and why they think it's important; kit parts labelled; signpost to where information is available in other languages; include links on where people can find reputable sources of information on COVID-19 and/or testing
- Making the test easier to perform, e.g. providing a distraction for the child such as a video, something online, a second member of household; simplify the instructions onto one larger page to make it easier for parents performing the test by themselves. Some suggested taking guidance from the wording and process adopted by Diabetes UK for blood glucose monitoring. One stated that teenagers were not good at following instructions due to lack of concentration therefore it needed to be simple, stepwise and short
- Making the experience more 'rewarding', e.g. a sticker, "ideally as sparkly as possible", or including a known cartoon character or superhero. Some suggested including a child-friendly (cartoon) plaster too and perhaps something to colour in afterwards

Further comments on the kit itself included:

- Suggesting that there should be a bigger area to drop the blood onto
- Suggestions that a smaller or appropriately sized lancet was supplied for use on children
- Questions about whether a numbing gel could be provided and used to ease the pain. Some did query whether use of a numbing gel would interfere with the results

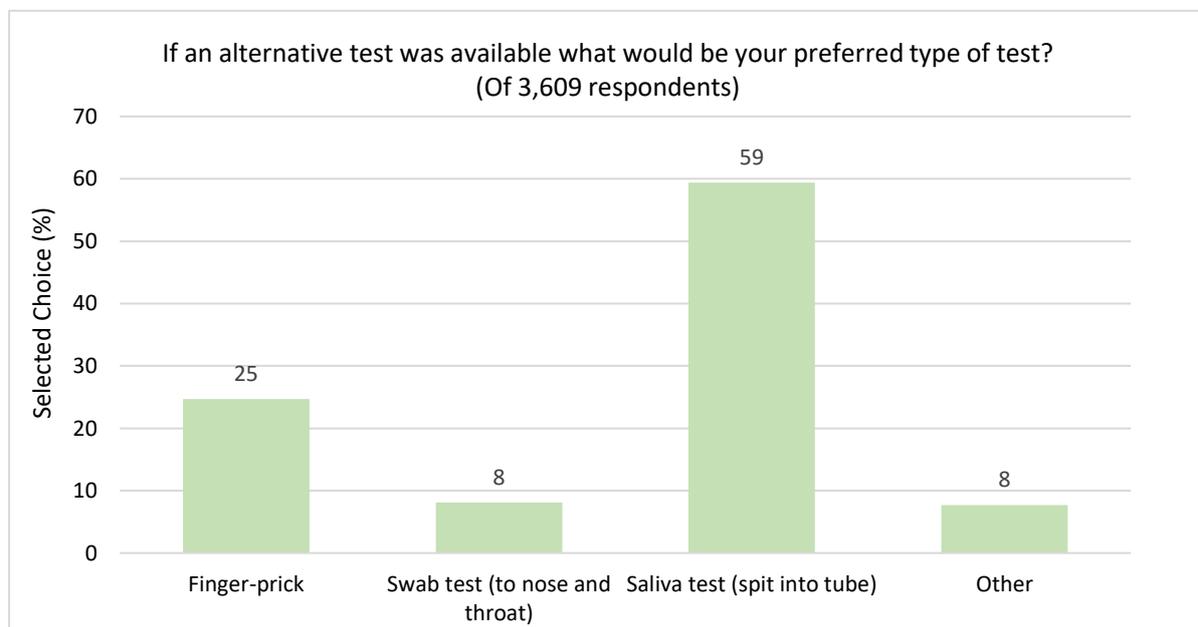
Minimum age of testing

From a research perspective, our assumption was that the minimum age for inclusion would be 5 years old. However, as part of this survey, we decided to capture the opinions of parents who had children under 5 to see if the acceptability and usability declined. It was, as expected, perceived to be more difficult to carry out the test on this age group, but there appeared to be no limit on the age that parents felt was acceptable to be tested. Many felt they would manage and/or that their child would cope, it was more a discussion of where it should happen and by who. The overall conclusion was that the option should be there for a child of any age to be tested, but that it would be up to the parent to decide, and where possible the child too.

The mean age that parents felt children could perform the test by themselves was 7 (with a standard deviation of 2.9; n=3,603). However, further comments highlighted that whether it was appropriate and/or possible was highly dependent on the child themselves, not on their age. Some parents of very young children felt confident they would be able to do the test because their child was very communicative or was used to similar tests, among other reasons. In contrast, parents of some older kids predicted they would have great difficulties due to their child's fear of needles or blood, or because of sensory issues.

Preferred testing approach

When asked their preference of testing approach, 59.4% of respondents (n=2,145) selected a saliva test, which was referenced as "spit into tube". A quarter (n=892) selected the finger-prick test that was presented in the survey. 8.2% (n=2,145) selected swab test and 7.7% (n=279) selected 'Other'.



Of those who selected 'Other', some respondents mentioned a preference for a 'blood test' in relation to an intravenous blood test as this meant it would be done by a professional and was believed by some to give more accurate results. However, other participants had a strong preference against any test that drew blood from their children.

The view on the "best test" for different age groups differed. Although some parents preferred a saliva test for younger children as it was seen to be less invasive, others pointed out that getting a small child

to spit is quite difficult. It was also noted that spitting is generally discouraged in children therefore they were not keen to now encourage that for this test in case children mimicked it later. There was a view that a swab or saliva test could be a good non-invasive alternative compared to taking blood. However, there was an awareness among some that a swab test resulted in some discomfort.

Accuracy was a concern for many respondents with some stating a particular testing approach based on their perceptions of its accuracy. Others stated they would want whichever test was most accurate although acknowledged that this would need to be balanced with the ease and experience of the test.

Final questions and comments

The survey closed by asking respondents if there were any other questions or comments they wanted to share. These broadly fell into five categories:

- **Accuracy**
The majority of questions were surrounding the accuracy of the antibody tests with some querying how the accuracy of a finger-prick test compared to other tests such as an intravenous blood test or saliva test. Some said they would be happy with 85% accuracy, others said it would need to be >95%. Linked to this was how likely you were to get a false positive or false negative. One respondent also wanted to better understand why the test may not be accurate.
- **Purpose and expected benefit**
Secondly people queried how it's possible to get meaningful data about the spread of the virus if the antibody test itself isn't accurate at an individual level. People felt this needed further explanation, so they had reassurances that performing this test on their child was going to be worthwhile and confirmation that it was necessary. This linked to questions around how the Government and researchers use this widespread testing to inform decision-making and "what's the benefit to me or my child".
- **Study design and results**
Thinking more about the specifics of the research if it went ahead, some respondents wanted to know what data would be collected, how it would be stored and whether it would be anonymous. Others stated that they would want the whole household tested, feeling that this could provide greater validation for them. Respondents also wanted to know how people were selected to the study and questioned why we don't select people who think they may have had COVID-19 in the past. The final thing raised here was about the findings with several comments asking whether participants will be kept informed about the findings or followed up afterwards, and what the expected timeline is for the study. One wanted to know if the data was comparable to ONS data.
- **Support**
Several people just said to "get it done" reinforcing a view by many that this work is important and necessary. If testing was to go ahead, two respondents felt older children and young people were more likely to contribute to the spread and therefore should be prioritized. It should be noted that some comments highlighted "an urgency for one that's accurate" reiterating the hope and importance that people are putting on antibody tests. While researchers reiterate the message that people shouldn't change their behavior based on the results because they may not be reliable and/or antibodies may not last, it should be remembered that some people simply want an accurate test for the reassurance of knowing what COVID-19 was actually like if their test is positive. Therefore, we need to be considerate of the circumstances and factors that are driving people's hopes for an antibody test and the emotions that may be linked to these.

- Instructions, testing process and kit

The remaining comments related to the process and things to consider with the instructions, much of which had been raised earlier. However, a couple of new comments included stating that the finger-prick test was not as simple as a pregnancy test as it required more steps. Several people also shared that they would be unlikely to repeat the test if they failed first time but might infer the results by testing the rest of the household. Others questioned the health and safety of the kit e.g. sterility and tamper-proof features and felt these should be highlighted in the instructions.

A full outline of questions asked by the respondents can be found in [Appendix 3](#) and the full tabulated set of survey data is available in [Appendix 4](#).

Conclusion

The positive response we received to this survey was so over-whelming. We did not anticipate such a rapid and wide uptake. However, this further reinforces what we have been seeing throughout our work on the REACT testing programme that there is high public interest and engagement in testing. This likely stems from people's desire to get answers about whether they have had COVID-19 and whether they might get it again. Therefore, as researchers, we have to be very careful to use this engagement appropriately and ensure that people are fully informed about the purpose and benefits of widespread antibody testing, before getting them to consent to take part. We were pleasantly surprised to see little drop in the acceptability of antibody testing on children for research purposes. However, it was clear from people's free text comments that many may still consciously or unconsciously make validations about their antibody status based on the result of this test, and in turn use this to influence their behavioural choices.

Overall a home-based antibody testing kit such as a finger-prick test was seen as something that would be acceptable and possible to use by most, albeit with some possible barriers among younger children. However, there was no strong feeling that these barriers were so significant to stop the majority of people being willing to try it at home, and some ways to make it easier were suggested. An appropriate alternative testing site should still be made available though for parents who do not feel comfortable testing their child themselves and/or want the reassurance of having it performed correctly first time by a trained professional.

Related material and further reading:

- Read the [Antibody Testing on Children & Young People Insight Report - Executive Summary](#)
- Download a copy of the [Antibody Testing on Children Infographic Summary](#)
- Visit [our website](#) where additional updates and material will be published
- For related findings, read our [Antibody Testing Insight Report](#) from 1 May 2020, which captured people's early views on the REACT study and antibody testing on adults
- Visit [Imperial's REACT study webpage](#) for further details about the wider testing programme

Appendix 1: Demographic and background of survey respondents

Characteristic	N (%)
Perspective (eligibility screener)	
Parent/carer of at least one child aged 5-17	4,180 (95.2)
Young person (aged 16-17)	110 (2.5)
Neither	102 (2.3)
Age of parent/carer's child/ren	
Under 5	1,480 (26.7)
5–11 years old	3,500 (56.0)
12–15 years old	1,010 (16.2)
16–17 years old	262 (4.2)
Approx. age group	
Under 18	69 (1.9)
18–24	9 (0.25)
25–34	794 (21.9)
35–44	2,156 (59.5)
45–54	551 (15.2)
55–64	27 (0.75)
65–74	2 (0.06)
75–84	0 (0.0)
85 or older	0 (0.0)
Prefer not to say	0.39 (14)
Sex	
Female	96.5 (3,491)
Male	2.9 (106)
Transgender female	0.03 (1)
Transgender male	0 (0.0)
Gender variant/Non-conforming	1 (0.03)
Not listed	4 (0.11)
Prefer not to say	13 (0.36)
Ethnicity	
White / Any other white background	3,373 (95.2)
Mixed / Multiple ethnic background	71 (2.0)
Asian / Asian British	71 (2.0)
Black / African / Caribbean / Black British	5 (0.1)
Other ethnic group / Arab	13 (0.4)
Prefer not to say	9 (0.3)
Location	
North East England	132 (3.7)
North West England	367 (10.1)
Yorkshire and the Humber	268 (7.4)
East Midlands	293 (8.1)
West Midlands	176 (4.9)
East of England	365 (10.1)
Greater London	404 (11.2)
South East England	1,121 (30.1)
South West England	430 (11.9)
Scotland	21 (0.6)
Northern Ireland	2 (0.1)
Wales	25 (0.7)

Highest education qualification achieved	
No formal qualifications	47 (1.3)
GCSEs/National 5s/Scottish Standard Grade or equivalent	454 (12.6)
AS and A levels/ Scottish Highers and Advanced Highers or equivalent	469 (13.0)
Higher National Certificate/Higher National Diploma or equivalent	490 (13.6)
Foundation degree	111 (3.1)
Bachelor's degree	1,071 (29.6)
Master's degree	365 (10.1)
Professional degree beyond bachelor's degree	368 (10.2)
Doctorate degree	96 (2.7)
Other	51 (1.4)
Prefer not to say	95 (2.7)
Current employment status	
Employed full time (30 or more hours per week)	1,114 (30.8)
Employed part time (8-29 hours per week)	1,255 (36.6)
Employed part time (Less than 8 hours per week)	65 (1.8)
Unemployed and currently looking for work	37 (1.0)
Unemployed and not currently looking for work	38 (1.1)
Student	106 (2.9)
Retired	8 (0.22)
Homemaker	514 (14.2)
Self-employed	340 (9.4)
Unable to work	44 (1.2)
Other	65 (1.8)
Prefer not to say	37 (1.0)

Appendix 2: Dissemination strategy

We targeted relevant audiences through a number of new and existing channels / contacts and asked that the information was shared with anyone who might be interested in taking part. This included the following:

Channel	Target audience	Examples of groups approached
Email	<ul style="list-style-type: none"> Parents/carers (of children aged 5-17) 	<ul style="list-style-type: none"> 50+ public members of the VOICE COVID-19 Engagement Support Group Public involvement and engagement leads
	<ul style="list-style-type: none"> Young people (aged 16-17) 	<ul style="list-style-type: none"> 30+ public members of the Imperial Young People's Advisory Panel (aged 17-25)
WhatsApp	<ul style="list-style-type: none"> Parents/carers (of children aged 5-17) 	<ul style="list-style-type: none"> Sent to friends, family and public partners with the request to pass on to people with children of relevant ages ask on children to share amongst friends
	<ul style="list-style-type: none"> Young people (aged 16-17) 	<ul style="list-style-type: none"> Known contacts, family and friends, e.g. Liverpool's 'Fightin Thru' group
Twitter	<ul style="list-style-type: none"> Parents/carers (of children aged 5-17) 	<ul style="list-style-type: none"> First tweet posted by @Imperial_PERC on 17 June and tagged @Imperial_IGHI @ImperialMed @ImperialNHS @NIHRinvolvement @profhelenward @ImperialSPH Direct message to @NNPCF @SickleCellUK Retweeted to @BMEHealthEM @BMEHAW @TheAbbeyCentre @Charecroft Direct promotion by Imperial (@ImperialSpark) and White City Community (@InventionRooms) Societal Engagement teams Tagged >10 x groups, including Research in Practice, Contact, Coram Voice, Mumsnet, Fatherhood Institute, the National Autistic Society and Scope
	<ul style="list-style-type: none"> Young people (aged 16-17) 	<ul style="list-style-type: none"> Direct promotion by Imperial Outreach teams (@icoutreach) Retweeted to @UKYP @LondonYouth Tagged 16 x youth groups, including: Access UK, British Youth Council, Generation R, Healthwatch Youth, Leaders Unlocked and NHS England Youth Forum
Facebook	<ul style="list-style-type: none"> Parents/carers (of children aged 5-17) 	<ul style="list-style-type: none"> Direct message to Parents1st Post on 'Family Lockdown Tips & Ideas' with permission from group Admin/Owner
Instagram	<ul style="list-style-type: none"> Young people (aged 16-17) 	<ul style="list-style-type: none"> 'Story' posted from a personal account on 17 June 2020 for 24 hours Tagged 19 x youth groups, including Youth Voice UK, Youth Brent Foundation, Young Minds, the Mind Map, and the Teenage Cancer Trust

A promotional image or 'card' was used to increase engagement with the posts via WhatsApp, Twitter and Facebook:

Share your views, questions and concerns about antibody testing on children and young people.
These are tests that check if they've already had COVID-19.



Closes 21 June 11pm

The online public involvement survey is open to anyone in England who is aged 16-17 or a parent/carer of a child aged 5-17.

Share your views, questions and concerns about antibody testing on children and young people.
This is part of work to help us understand how many people in the population have already had COVID-19.



Closes 21 June 11pm

The online public involvement survey is open to anyone in England who is aged 16-17 or a parent/carer of a child aged 5-17.

Appendix 3: Final comments and questions from the public

Accuracy

- How accurate are the results?
 - How likely to get a false positive or false negative?
 - How accurate are finger-prick tests compared with intravenous blood tests, saliva tests or swab tests?
 - Why might the test not be accurate?
 - Would a test pick up an infection from December?
 - Needs greater accuracy before use on children under 16

Purpose and expected benefit

- Purpose
 - How will it help?
 - How will the Government use the information to inform decision-making?
 - How can you estimate the spread of the virus based on a test result that's not reliable or accurate?
 - What's the benefit to the child?
 - Need reassurances as to why it's necessary

Study design and results

- Data handling
 - What data is collected and how is it stored?
 - Is data confidential and anonymous?
- How are the results collected/recorded?
 - Do you have to send the kit or sample back?
 - What do you do with the sample/kit afterwards?
- What's the meaning and impact of the result?
 - Some concern about how young people may interpret the results
 - Do you require a follow-up test to confirm the result?
 - How long do antibodies last and what are the chances of reinfection?
 - Will there be an online chat system for support, feedback or counselling?
 - What if one person in the family tests positive?
 - What do the G and the M lines mean?
 - What would happen in the long-term?
 - Would a positive result affect my eligibility when a vaccine comes available?
 - Would a positive test affect my insurance policy or access to mortgages?
 - Will the results only be used for research purposes?
- How do I hear about the study findings?
 - Where can I find the population level result data?
 - Is it comparable to ONS data?
 - Will I be kept informed about the study?
 - What's the timeline for the study?
- Who is being tested and how?
 - Allow testing of whole household

- Supervision is needed – concern about kids doing it on themselves
- Need to make sure there's an option for it to be carried out by a medical professional
- Whether a child can be tested depends on the child, not their age
- Why cut-off minimum age at 6? Children younger than 6 could perform it themselves
- Parents will know best if their child is able to do it or will be able to cope
- Informed consent is a major barrier with this. Children shouldn't be coerced into doing it – “no means no”

Support

- Just get it done
 - If results benefit the population
 - Prioritise older children first
 - Whatever is needed, parents will do
 - Worth doing, even on small children
 - Worth doing, even if tricky
- Urgently need an antibody test that's accurate and at individual level
- Efficient approach
 - Looks like an efficient test approach
 - Looks simple and straightforward
 - Like being able to do it at home

Instructions and process

- The finger-prick testing process
 - If failed, probably wouldn't repeat the test but might infer results by results of other family members
 - Does it have to be the finger?
 - How easy and safe is it to carry out?
 - Why are the lancets different colours?
 - Include spare kits
 - An appropriately sized lancet should be used for children
 - Normal for diabetics – learn from what Diabetes UK does
 - Lancets are tricky to use – need one with a good design
 - Are there ways to do it incorrectly
 - Is adding too much buffer an issue
 - Would using a numbing gel affect the results?
 - It's not as simple as a pregnancy test – more complex and with more steps, not an appropriate comparison
 - Could it encourage self-harm behavior or for children to dismantle it?
- The instructions
 - Make the health and safety very clear e.g. keeping lancet away from kids and not to dismantle it
 - Teens not good at following instructions
 - Make sure kit parts are labelled
 - Include links to content in other languages
 - Include links on where people can find reputable sources of information on COVID-19 and/or testing
 - How to dispose of the lancet and kit safely
 - Highlight health and safety features e.g. seal not tampered with, sterilization and hygiene

- The kit
 - Make the health and safety very clear
 - Are the testing pieces sterile?
 - Are there any safety features on the lancet to prevent young children from tampering with it?
 - Will the kit come in a sealed package to ensure it's not been tampered with?

Appendix 4: Tabulated involvement survey data

Would you want [your child(ren)] to be tested to understand if they/you had previously had COVID-19 (i.e. test for antibodies, which are produced by the body to fight infection)?

Answer (Selected choice)	Parent/Carer (% , N)		Young Person, YP (% , N)	
	Yes	94.60	3,802	86.54
No	0.95	38	8.65	9
Unsure	4.45	179	4.81	5
Total	100	4,019	100	104

Would you still be willing to perform this finger-prick test on your child(ren) as part of this research study, i.e. to help researchers understand the spread of coronavirus even though it might not to provide you with an accurate individual result?

Answer (Selected choice)	Parent/Carer (% , N)		Young Person (% , N)	
	Yes	89.81	3023	88.46
No	1.66	56	0.00	0
Unsure	8.53	287	11.54	6
Total	100	3366	100	52

Based on what you have just seen, would you be willing to perform this finger-prick antibody test on your child(ren) / yourself (young people only, YP-Self)?

Answer (% selected choice)	Under 5 (n=1,395)	5-11 (n=3,264)	12-15 (n=944)	16-17 (n=238)	YP-Self (n=89)
Yes	81.00	89.71	94.17	96.22	74.16
No	7.60	3.49	2.33	2.52	19.10
Unsure	11.40	6.80	3.50	1.26	6.74
Total	100	100	100	100	100

Where would you be willing for the test to be performed?

Answer (% selected choice)	Under 5 (count=4,684)	5-11 (count=11,609)	12-15 (count=3,418)	16-17 (count=888)	YP-Self (count=254)
Home	29.61	27.07	27.59	28.60	27.95
My local GP surgery	26.32	23.43	23.14	22.18	24.41
Drop-in testing centre	20.18	18.57	18.96	18.02	18.50
Community centre	12.21	12.42	12.90	12.16	9.06
Child's nursery / school / college	9.20	16.91	14.98	15.09	14.96
Work	-	-	-	-	3.54
Other	2.07	1.54	2.11	3.27	1.18
Nowhere	0.41	0.05	0.32	0.68	0.39
Total	100	100	100	100	100

*Other locations suggested: Pharmacy; children's centre; community centre; testing centre; village hall; established healthcare setting e.g. hospital clinic as part of child's routine care, parent's workplace; sibling's school/any school for children who are home-educated; research centre; sports centres.

Who would you want to perform the antibody test on your child(ren) / you (YP)?

Answer (% selected choice)	Under 5 (count=4,587)	5-11 (count=11,093)	12-15 (count=3,311)	16-17 (count=851)	YP-Self (count=232)
Myself (YP only)	-	-	-	-	25.43
Parent/Guardian	27.58	25.76	26.55	27.73	19.40
GP	26.64	24.22	23.23	22.68	20.26
Community or Practice nurse	26.58	24.35	23.80	22.80	14.66
Nursery/School nurse	11.88	18.30	18.27	15.86	12.07
Teacher	4.71	5.59	5.77	5.52	4.31
Social worker	-	-	-	-	2.16
Other*	2.18	1.71	2.11	4.70	1.29
Nowhere	0.44	0.06	0.27	0.71	0.43
Total	100	100	100	100	100

*Other people suggested: nurse, healthcare assistant, health visitor, pharmacist, medically qualified friends, routine secondary care staff, testing centre staff, volunteers, soldiers

How easy or difficult do you think it would be to perform a finger-prick antibody test like this at home on your child(ren) and young people?

Answer (% selected choice)	Under 5 (n=1,286)	5-11 (n=3,136)	12-15 (n=920)	16-17 (232)	YP-Self (n=71)
Very easy	14.07	25.51	49.02	59.48	29.58
Moderately easy	27.53	30.48	25.43	21.98	47.89
Slightly easy	10.89	11.22	8.91	6.90	12.68
Neither easy nor difficult	9.95	9.50	5.98	7.76	8.45
Slightly difficult	24.81	17.54	7.93	2.16	1.41
Moderately difficult	11.12	4.85	2.39	0.86	0.00
Extremely difficult	1.63	0.89	0.33	0.86	0.00
Total	100	100	100	100	100

What issues do you think might come up when performing the test on your child(ren)/yourself?

Freq.	Under 5	5-11	12-15	16-17	Young person
1	Child moving and fidgeting	Hurting child, fear of finger- prick	None	None	None
2	Blood: Getting enough, sight of, transferring	Blood: Getting enough, sight of, transferring	Fear of finger- prick/pain	Explaining test	Blood: Getting enough, sight of, transferring
3	Hurting child, causing pain	None	Blood: Getting enough, sight of, transferring	Fear of finger- prick/pain	Doing test correctly
4	Getting upset, resisting	Getting upset, refusing, moving	Fear of needles	Sight of blood	Fear of finger- prick/pain
5	Explaining test/ informed consent	Explaining test	Explaining test	Fear of needles	Doing it one- handed

Would you attempt the antibody test alone or would you ask for help/support from someone in your household?

Answer (% selected choice)	Under 5 (n=1,277)	5-11 (n=3,110)	12-15 (n=915)	16-17 (n=228)	YP (n=70)
Do it myself	40.8	63.3	84.6	93.9	45.7
Ask for/seek help/support	59.2	36.7	15.4	6.1	54.3
Total	100	100	100	100	100

After seeing the materials, please indicate what is the minimum age you think a child or young person could do the test by themselves (with minimal supervision)

Answer (selected choice)	%	Count
6	5.2	187
7	1.4	50
8	4.6	167
9	1.9	70
10	14.5	522
11	5.9	212
12	16.9	608
13	10.5	379
14	11.2	403
15	8.1	291
16	17.1	616
17	2.7	98
Total	100	3603

Mean age	Std Deviation	Variance	Count
7.42	2.88	8.29	3603

From what we have shown, do you think the test information and materials are appropriate for use with children/young people?

Answer (% selected choice)	Under 5 (n=1,369)	5-11 (n=3,239)	12-15 (n=915)	16-17 (n=238)	YP (n=86)
Yes	75.1	88.9	96.7	97.1	81.4
No	7.4	2.7	0.3	0.8	8.1
Not sure	17.5	8.4	3.0	2.1	10.5
Total	100	100	100	100	100

If an alternative test was available what would be your preferred type of test?

Answer (selected choice)	%	Count
Finger-prick (as shown previously)	24.7	892
Swab test (to nose and throat)	8.1	293
Saliva test (spit into tube)	59.4	2145
Other	7.7	279
Total	100	3,609
