

Testing Times: An ethical framework and practical recommendations for COVID-19 testing for NHS workers



Contents

3 Recommendations

5 Executive summary

8 Background, scope, and methods

8 Scope

8 Methods

10 Results

11 Goals of the testing programme

12 Access to testing

14 Properties of the test

15 How testing is used in practice

16 Choices about testing

19 Privacy, confidentiality, and data protection

21 Trustworthiness and legitimacy

22 Communication and information about testing

24 Conclusions

25 Report contributors

25 Members of Expert Group

25 Members of the consultation team

26 Appendix 1: Details of Expert Group

29 Appendix 2: Terms of reference for the Expert Group

31 References

The Healthcare Improvement Studies Institute aims to strengthen the evidence base for improving the quality and safety of healthcare.
www.thisinstitute.cam.ac.uk

Published by: The Healthcare Improvement Studies Institute, 2020

© The Healthcare Improvement Studies Institute

ISBN 978-1-9996539-5-8

This is published under a Creative Commons licence called **CC-BY-NC-ND 4.0**. It means that you're free to reuse this work. In fact, we encourage it.

We just ask that you acknowledge The Healthcare Improvement Studies Institute (THIS Institute) as the creator, you don't distribute a modified version without our permission, and you don't sell it or use it for any activity that generates revenue without our permission.

Ultimately, we want our work to have impact. So if you've got a use in mind but you're not sure it's allowed, just ask us at enquiries@thisinstitute.cam.ac.uk

Recommendations

Table 1. Ethical framework and recommendations

Ethical consideration	Recommendations
Goals of the programme	<p>Nationally: Communicate the policy goals clearly and consistently. Explain the scientific rationale supporting the programme and acknowledge the strengths and limitations of the test.</p> <p>Nationally: Show how the policy goals seek to protect both individuals and public health.</p> <p>Nationally and locally: Do not emphasise targets. Ensure that delivery of testing and prioritisation are both driven by health benefits. Acknowledge possible competing objectives and risks and how they are being resolved. Explain the individual and collective benefits of the programme.</p>
Access to testing	<p>Nationally: Avoid unwarranted variation in access. Ensure that how testing is provided does not discriminate against particular groups, including the more socio-economically disadvantaged (where BAME staff may be over-represented). Ensure that the infrastructure for testing is fit for purpose and does not impose logistical burden.</p> <p>Nationally: Ensure clarity about eligibility and prioritisation for testing. Explain the values that have informed those principles.</p> <p>Locally: Ensure clear, consistent communication about access to testing and ensure sound operational systems that facilitate equitable and fair access.</p> <p>Locally: Ensure that specific groups are not inappropriately or inadvertently de-prioritised for testing. Any deviation from nationally agreed criteria should be explicitly acknowledged, and explained to staff and other local stakeholders.</p>
Properties of the test	<p>Nationally and locally: Acknowledge explicitly and manage the implications of the strengths and limitations of the current RT-PCR test, including the relatively high rate of false negatives reported in the scientific literature. Exercise appropriate caution about use of negative test results for decision-making, for example about whether people are fit for work or where they should be allocated for work.</p>
How the test is used in practice	<p>Nationally and locally: Monitor uses of the test and its results in practice. Identify any unintended consequences, including potential for inequalities and for inadvertent or indirect discrimination.</p> <p>Nationally: Provide national guidance about how test results may be used to make decisions both about return to work and allocation of work area/roles, and be explicit about the principles used to make these decisions.</p> <p>Nationally: Offer clarity in guidance about under what circumstances a negative test result is sufficient basis for requiring people to work, while acknowledging the tensions in seeking to ensure safe staffing levels.</p> <p>Locally: Ensure transparency and clear communication about how the test is used in practice, for what purposes, and on what basis. Assess potential for inequity of risk distribution associated with these decisions.</p> <p>Locally: Where external contractors employ staff who work in NHS organisations, ensure that their practices in relation to testing, sick pay, and other policies support the goals of the testing programme.</p>

Table 1. Ethical framework and recommendations Continued

Ethical consideration	Recommendations
Choices about testing	<p>Nationally: Provide guidance about the degree and nature of requirements for staff to engage in testing. Develop clear and explicit principles to help to inform decisions about when individuals can insist on or decline testing, recognising that what is intended to be a voluntary choice may not appear that way to those on the ground.</p> <p>Nationally and locally: Agree on criteria for regularity and frequency of testing and priorities for testing, taking into account the potential for discrimination or disadvantage either through over-testing or under-testing of particular groups.</p> <p>Locally: Consider the impact of any organisational policies in terms of choices about testing (including degree of voluntariness) and the extent to which they may be experienced differently or have different consequences for different groups, including those not directly employed by the NHS, people who are lower down in organisational hierarchies, or people who are more exposed to discrimination. Be clear and explicit about HR procedures or other consequences in response to choices about testing.</p>
Privacy, confidentiality and data protection	<p>Nationally: Provide clarity about how personal information arising from testing will be handled, including which individuals and bodies it may legitimately be shared with. Where appropriate distinguish the different data flows relevant to different Pillars of testing.</p> <p>Nationally: Provide explicit reassurances about the purposes for which information may not be used and bodies with whom it may not be shared. Consider preparing templates on data flows that can be customised locally to provide clarity.</p> <p>Locally: Undertake an Impact Assessment (and associated equality assessment) according to Information Commissioner guidance.</p> <p>Locally: Publish the workflows that explain how information about whether individuals have had tests, and the results of those tests, may be shared. Provide clarity on how and when disclosures about tests may be made. Where appropriate, distinguish between the different Pillars of testing.</p>
Trustworthiness and legitimacy	<p>Nationally: Recognise the potential for mistrust and loss of legitimacy associated with communications that do not appear trustworthy or founded in good evidence. Address the risks through clear, consistent, and honest communications and commit to improvement.</p> <p>Nationally and locally: Create a national template that can be customised locally that identifies risk assessment processes, workflows, and principles for decision-making.</p> <p>Locally: Ensure psychological safety, so that staff can be sure that if they voice concerns they will be heard. Be aware that staff may vary in their ability to exercise voice, especially those lower in organisational hierarchies and those from BAME groups.</p>
Communication and information about testing	<p>Nationally and locally: Ensure that information is comprehensive, clear, accessible, up to date, and compliant with equalities legislation. Acknowledge uncertainties explicitly. Declare when changes are made and explain why they are made. Provide up-to-date information on the test, including eligibility criteria, frequency of testing, properties of the test, action to be taken in response to test results, possible uses to which test results might be put, practices in relation to data sharing, interfaces with Test and Trace, and any possible negative consequences of having the test. Address the needs of specific communities, including those less economically advantaged and BAME populations, in the selection of communication methods and channels.</p>

Executive summary

This report uses the deliberations of an Expert Group and the results of a consultation exercise to identify ethical considerations relevant to swab testing of NHS workers for current infection (not antibodies) with COVID-19. Though it is focused on those who work in the National Health Service (NHS) in England, the broad principles and recommendations are likely to be transferable to other keyworkers and to the rest of the UK.

An Expert Group, with diverse expertise across academic disciplines and across the NHS, met regularly over six weeks and worked collaboratively on documents. An online consultation exercise was held between 27 May and 8 June 2020 to identify the range and diversity of views on this topic. The 93 participants in the consultation included NHS workers in clinical and non-clinical roles, NHS senior leaders and system-level stewards, policy-makers, and relevant experts. The Expert Group's deliberations together with the findings of the consultation identified eight ethical considerations relevant to the COVID-19 swab testing programme for NHS workers. These considerations are likely to remain of enduring relevance as the programme evolves, providing a systematic framework for continuous improvement and monitoring of progress.

The remainder of this section summarises the results of our analysis, from which we synthesised the **Recommendations** provided in the previous section. The analysis is especially attentive to the increasing evidence that COVID-19 does not affect all population groups equally. It considers how features of the testing programme may affect people who face socio-economic disadvantage and/or who are members of Black, Asian or Minority Ethnic (BAME) communities (while also recognising the problematic nature of the "BAME" term).

Goals of the testing programme

The Department of Health and Social Care five-pillar testing strategy, at the time the work was conducted May-June 2020, focused primarily on large-scale testing of critical keyworkers who were symptomatic or in household isolation. Its goals included enabling staff to stay in work if they test negative and to keep themselves and others safe if they test positive. Regular testing was recommended to keep workers safe and ensure they did not spread the virus.

Participants in the consultation felt there was lack of coherence and clarity about the goals and implementation of the testing programme, and that the underlying scientific rationale was not always sufficiently explicit or sound. They criticised the political focus on the number of tests carried out in particular.

Recommendations focus on showing how the policy goals seek to protect both individuals and public health, the scientific rationale for the programme, the strengths and limitations of the test, and avoiding over-emphasis on targets.

Access to testing

Access to an efficient and effective quality-assured testing programme is a key feature of an ethically sound approach. The capacity for testing of keyworkers was an issue at the start of the pandemic. Participants in the consultation indicated that access for NHS workers has since improved, but raised outstanding issues:

- Variation in quality and equity of access. Logistical barriers (e.g. some individuals expected to travel to testing sites by car), may be particularly limiting for BAME staff who are known to be more likely to hold lower paid and less flexible roles;
- Lack of clarity over responsibility for testing, especially for locum or agency staff with multiple employers;
- A need for clarity over who qualifies for testing, including who counts as a keyworker, whether testing (currently intended for those who are symptomatic) should be extended to asymptomatic healthcare workers, and whether to prioritise at-risk groups (such as BAME colleagues) for testing;
- Some concern over the validity, reliability, and usability of home testing kits.

Recommendations focus on ensuring ease of access, clarity about eligibility and prioritisation, and sensitivity to the differential impacts of access arrangements for different groups.

Properties of the test

The scientific literature indicates concern about the sensitivity of swab testing, including a relatively high rate of false-negative results (up to 30% by some estimates). Because of this issue, which is a feature of the test inherent in the nature of medical diagnosis, participants were not always convinced that the results of tests were a secure basis for decision-making (e.g. about whether individuals were fit for work or where they should be allocated for work).

Recommendations call for explicit acknowledgement of the limitations of the current test and appropriate caution about using results for decision-making is warranted.

How testing is used in practice

Uses of the test in practice in NHS organisations were the focus of some concern, relating to:

- Variations in how test results affected decisions about fitness for work, especially regarding whether staff with negative results (or those who have not had a test) should be expected to work when they have symptoms;
- Decision-making about return to work being influenced by the need to maintain staffing levels;
- Lack of clarity, consistency, and explicit information over the use of test results by managers to assign staff to work in areas that are either “hot” areas of COVID-19 infection or “cold” areas thought to be COVID-19 free, including concern around the potential for inequity in risk distribution (such as possible disproportionate redeployment of BAME staff into hot areas);
- Perceptions about requirements for testing to determine entitlement to benefit payments such as death-in-service or disability benefits.

Recommendations focus on providing clarity and guidance to facilitate consistency, and assessing any potential for inequitable risk distribution or discrimination.

Choices about testing

Testing for COVID-19 must consider the ethical principles of informed choice and autonomy alongside the broader responsibilities to protect public health. Individuals might wish to decline tests for a range of reasons, including fear of physical discomfort, anxiety about the financial, social, and emotional consequences that might follow a positive test, and the impact of disability, illness, or religious and ethnic affiliations. Considerations include:

- The need to strike a balance between duty of care to patients, colleagues, and broader public health, and the personal freedom of workers to decline tests;
- Lack of clarity about the extent to which various forms of compulsion, coercion, or encouragement for testing might be ethically acceptable;
- Pressure to participate in testing may vary according to occupational group and have unequal effects;
- Ability to exercise choice over testing may be variably distributed, and limits on choice may disproportionately affect more socio-economically disadvantaged people and BAME staff;
- Lack of clarity about the acceptable frequency of testing, including whether it should vary for different groups, and whether or not more frequent tests should be prioritised for at-risk groups including BAME staff.

Recommendations call for improved guidance on degree and nature of requirements to engage in testing, using explicit principles, and considering the impact of organisational policies in terms of different experiences of choice across different groups.

Privacy, confidentiality and data protection

Privacy, confidentiality, information governance and data protection were key concerns in the context of the swab testing programme. The consultation identified:

- Lack of clarity, and variable practice, over how and with whom test results may be shared and the uses to which the information from the tests might be put;
- Some scepticism regarding the quality of data protection practices;
- Lack of clarity about whether colleagues are entitled to know who has been tested and the outcomes of testing;
- Concerns that data might be shared across other government agencies such as the Home Office, causing anxieties that may disproportionately affect BAME staff.

Recommendations focus on providing improved clarity about how personal information relating to testing will be handled and providing explicit reassurances about the purposes for which it may not be used or shared.

Trustworthiness and legitimacy

Trustworthiness and legitimacy is essential for safe, effective, and efficient operation of the testing programme. According to participants it could be compromised by:

- Perceptions of policy mishandling early in the pandemic;
- Perceived lack of transparency in the Government’s approach, with information about testing seen as inadequate or political rather than evidence-based;
- Perceived problems with the underlying scientific evidence;
- Concern that the pandemic might be used as an excuse to drive through other changes;
- Risk of unintended consequences when local organisations exercise discretion in the interpretation and application of rules;
- Risk that the staff voice will not be heard and their concerns will not be addressed.

Recommendations focus on addressing the potential for mistrust that may arise through communications that do not appear founded in good evidence or are untrustworthy.

Communication and information about testing

Individuals should be provided with full, accurate, and up-to-date information about testing, including the nature of the test, the implications of a positive test, and the uncertainties associated with testing. The data flows and interface of NHS staff testing with the Test and Trace programme requires clarity. Participants emphasised the importance of a comprehensive communication strategy based on research and evidence, reporting the following concerns:

- A perception that national communication can be complex, chaotic, and difficult to understand, with the risk that misunderstandings will cause staff (especially those in at-risk groups) to forego testing;
- An apparent lack of clearly communicated scientific rationale underpinning the testing approach;
- Possibility of confusion arising from availability of multiple testing options (though the associated flexibility was welcomed);
- Mismatch between national communications and the professional and experience-based knowledge of staff (for example over the issue of false negatives), with implications for trust and legitimacy;
- Variability in addressing the needs of groups who may have distinctive needs for communication, including those with accessibility requirements, those for whom formal methods (e.g. through corporate email) is not appropriate, and BAME groups who may have distinctive language needs or be more comfortable with community-led forms of communication.

Recommendations focus on ensuring high quality communications and information that addresses the needs of specific communities and acknowledges uncertainties.

Offering a set of practical and actionable recommendations for improvement, the analysis illustrates the value of explicit, systematic and consultative consideration of the ethical issues. It is likely to have relevance to many other areas of practice and policy in response to the pandemic. Though some of the issues may already have been identified and addressed since the consultation was conducted, the recommendations are likely to have enduring value as a resource for continuous improving, helping to sensitise stakeholders to the range of ethical issues and take appropriate action in response.

Background, scope, and methods

Systematic identification of ethical issues is valuable in implementing policies and programmes. In a public health emergency such as the current COVID-19 pandemic, the need for clarity about ethical issues is particularly pressing.¹ We report here the deliberations of an Expert Group and the results of a consultation exercise to characterise ethical considerations relevant to swab testing of NHS workers for current infection with COVID-19. The aim is to inform practical decisions about improvement, while recognising the tensions between different values and goals in such a complex area of policy and practice.

Scope

The analysis focuses on:

- Issues relevant to those who work in the National Health Service (NHS) in England, though we expect that our analysis will have broad transferability, at the level of principle, to other keyworkers, and to the rest of the UK;
- Swab-based polymerase chain reaction (PCR) testing for SARS CoV-2, not antibody testing.

Methods

This report is based on a) contributions and deliberations from an Expert Group and b) a consultation exercise. It was led by The Healthcare Improvement Studies (THIS) Institute at the University of Cambridge, a research centre funded by the Health Foundation with a mission to improve the evidence-base for improving quality and safety of care in the UK.

Expert Group

A group of experts with diverse expertise across a broad range of academic disciplines and experience of working in the NHS and with multiple communities (Appendix 1) was assembled. Chaired by Mary Dixon-Woods, Director of THIS Institute, the group met five times (remotely) and contributed to documents and idea development outside of meetings.

Consultation

A rapid consultation was conducted between 27 May and 8 June 2020, using remote methods with 93 purposively selected participants from relevant stakeholder groups. These groups included: NHS workers in various clinical and non-clinical roles from different kinds of organisation, including acute, community, and primary care; NHS senior leaders and system-level stewards (including those in executive/board positions and regulatory bodies); policy makers; and relevant experts. The aim of the sampling was not to achieve representativeness, but rather to identify the widest possible range of views.

Participants were recruited through networks of the Expert Group and the networks of THIS Institute, including The Point of Care Foundation, an independent charity with a mission to humanise care. Participants were invited to take part using emails that linked to information about the project, and a request to register on Thiscovery (THIS Institute's secure citizen science platform). Given the methods of recruitment, it is not possible to calculate precisely the number of individuals who were invited to take part, but we estimate around 300 to 350.

Following registration on Thiscovery, participants had the option to take part in an online semi-structured interview with an experienced interviewer, or to complete responses to a series of open-ended questions through a survey. The interviews (20 in total) were transcribed verbatim by a specialist company, and the qualitative survey responses (73) were extracted into tables. All contributions were fully anonymised and subject to qualitative analysis using the Framework method.²

No claim is made for the representativeness of the sample included in the consultation (Table 2); rather, as noted above, the aim was to explore the diversity of views and experiences.

Governance and ethical approval

All members of the Expert Group agreed to the Terms of Reference for the project (Appendix 2). All members participated pro bono. All members declared any relevant conflicts of interest at the outset of the project and before each meeting.

It was determined, following the use of the Health Research Authority's (HRA) decision tool and associated guidance, that the consultation did not meet its criteria for research. However, to provide additional ethical assurance for the project, an application was made for ethics committee approval to the University of Cambridge. This was obtained on 18 May 2020. All participants in the consultation were provided with information and gave consent.

The project was conducted under the sponsorship of the Department of Health and Social Care and is supported for engagement and dissemination purposes by the Wellcome Trust and the Academy of Medical Sciences.

This project was independently funded by THIS Institute's grant from the Health Foundation. All subcontractors (including RAND Europe) contributed to the project under agreements through the same funding.

Table 2: Participants in the consultation

Job role	Interview (n=20)	Qualitative survey (n=73)
Working clinically in the NHS	16	48
Working in the NHS in a non-clinical role	2	6
In a senior leadership position (e.g. board, director, or executive level) in an NHS trust, Clinical Commissioning Group or other local/regional NHS organisation, or have a position on a national body	2	9
Other (including educators and academics, retired clinicians, and participants who had previously worked in the NHS but currently work in other organisations)	0	10

Results

Our analysis, based on the deliberations of the Expert Group and the findings of the consultation, identified eight ethical considerations that are likely to be particularly important to the COVID-19 swab testing programme for NHS workers, including the importance of:

- clarity about goals;
- ensuring access, effectiveness, and efficiency;
- recognising the limitations of the properties of the test;
- understanding how the test is used in practice and the implications of these uses;
- choices about testing;
- data protection and confidentiality;
- trustworthiness and legitimacy;
- information and communication about testing.

We report the views of the Expert Group and those engaged in the consultation together. We recognise throughout that policies and programmes often involve competing goals and tensions. In the context of testing NHS workers for current infection with COVID-19, it is likely that some tensions arise because testing has many of the characteristics of clinical care and the duties owed to individual workers as patients, but it also has many of the features of a public health intervention, with implications beyond individuals. It is important not to overplay the distinction between the autonomy of individuals and the collective good, or between public health ethics and clinical ethics. But explicit recognition of possible tensions is nonetheless useful.³

Our **Recommendations** acknowledge that no easy answers exist in resolving these tensions, but seek to provide practical suggestions about how best the programme could be optimised from an ethical perspective. We also note that the consultation was conducted at a particular point in time during a fast-moving pandemic situation, and it is likely that some issues have already been identified and addressed at national or local level. Nonetheless, the recommendations are likely to be of enduring value in sensitising stakeholders to the range of relevant ethical considerations in testing programmes for staff and in monitoring further progress.

A key uniting concern in all of these considerations is the increasing evidence that COVID-19 does not affect all population groups equally. This makes it an important ethical responsibility to consider how features of the testing programme may affect people who are members of groups facing wider socio-economic disadvantage, or with protected characteristics as defined in the Equality Act 2010.

The evidence thus far is that older age, deprivation, male sex, and geographical location influence mortality and morbidity from COVID-19. The virus appears to have especially adverse impacts for people who are racialized as “Black, Asian and Minority Ethnic” (BAME).⁴ While we use the BAME category here given its policy currency, including the recent report from Public Health England (PHE),⁵ we recognise its problematic and contested nature. The problems include (but are not limited to) its potential for “othering”, and the grouping together of different ethnicities who do not face the same kinds of public health issues or the same forms of social disadvantage, and who may have different risk profiles.

The PHE report found that people from Black African, Black Caribbean and South Asian ethnic groups are likely to be at highest risk from COVID-19. It further identified that both ethnicity and income inequality are independently associated with COVID-19 mortality. The risks associated with COVID-19 transmission, morbidity, and mortality may be exacerbated by the housing challenges faced by some BAME communities, by access to poor diets, and by factors such as Vitamin D deficiencies. A Health Foundation analysis reported that people from BAME communities are more likely to be exposed to the virus because they are more likely to be keyworkers, tend to live in areas of high population density and in more over-crowded households, and may suffer racial discrimination and economic disadvantage,⁶ creating a large number of aggregated risks. It is very likely that distinctive issues arise in the context of testing of BAME staff that may be relevant to the testing programme, the information and choices available to them, and the impact of the aggregated actions of others.

Goals of the testing programme

The policy for the COVID-19 testing strategy for current infection in NHS workers at the time the project was conducted was laid out in a series of documents, principally including:

- The five pillar strategy policy paper (6 April 2020) <https://www.gov.uk/government/publications/coronavirus-covid-19-scaling-up-testing-programmes>
- Guidance on getting tested (11 June 2020) <https://www.gov.uk/guidance/coronavirus-covid-19-getting-tested>
- Privacy notice on testing (12 June 2020) <https://www.gov.uk/government/publications/coronavirus-covid-19-testing-privacy-information>

The Department of Health and Social Care five-pillar testing strategy⁷ made clear that the large-scale testing programme for keyworkers who are symptomatic or in household isolation had the goals of enabling people to stay in work if they test negative and keeping themselves and others safe if they test positive. The policy also stated that the intention was to test critical keyworkers regularly, to keep them safe and ensure they do not spread the virus.

At face value, these goals had considerable legitimacy, particularly in enabling informed decisions and in keeping healthcare workers safe, which, in the broadest sense, is an ethical obligation at system level to care for workforce health and assure the quality of working conditions. Other goals, which were more or less explicit across the current policy documents, might include the broader public health goals of reducing mortality and morbidity for the population as a whole, protecting more vulnerable groups of workers, maintaining attention to health protection and promotion, and reducing health inequalities.

In the consultation, many participants reported lack of coherence and clarity about the goals of the testing programme and its implementation, including what was happening and the scientific rationale for it. A frequent observation was that policy and policy messaging was too driven by what might be termed “style over substance” — managing appearances rather than systems. The political focus on the number of tests carried out and what was done to try to hit particular targets was especially criticised.

I feel there was too much of a drive to hit target numbers at points. This led to last minute requests at NHS Trusts to support testing which was unreasonable and may have led to some poor outcomes (experience, results).
(S_134_Senior)

A need for clarity about the priority groups for testing was emphasised, with several participants stressing the need to include all NHS workers (not just clinical staff) and to ensure that colleagues in social care also had ready access to testing.

There is emerging evidence that ancillary staff such as housekeepers, are at higher risk of acquiring CV 19 than ICU staff. The testing programmes should prioritise those staff who are actually at higher risk of acquiring CV 19 occupationally, rather than those that are perceived to be at risk. (S_383_Clinical)

Access to testing

Achieving the goals of testing programmes depends critically on providing sufficient access to quality assured testing. The effectiveness, efficiency and legitimacy of any programme may be compromised if it is cumbersome, slow, unresponsive, poorly coordinated, wasteful, or excessively bureaucratic. Frustrations and delays in getting tests, providing test results, or missing test results have ethical consequences, for example in inducing anxiety and increasing the risks of people having to self-isolate unnecessarily and creating pressures on colleagues and households.

Concerns were expressed publicly at the outset of the pandemic about capacity. There was widespread reporting of keyworkers who struggled to get tested, did not get tested at all, or did not have test results returned in a timely way. Delivery of testing has evolved over time as capacity has scaled up and as the means for making testing available has diversified. At the time this report was prepared in mid-June 2020, NHS workers, defined as “essential workers”, were prioritised. They could either self-refer or be referred by employers. Self-referral allowed people to choose a drive-through appointment or a home test kit. Employer referral allowed employers to refer essential workers who are self-isolating because they or members of their household have COVID-19 symptoms. An employer referral portal was available to upload names and contact details of employees, who would then receive a text message with a code to book a test for themselves at a regional testing site.

In addition to regional testing sites, mobile testing units and satellite centres have been established. Many NHS facilities (such as hospitals) provide testing and have their own local policies and procedures. Some organisations, for example, test all staff whether or not they are symptomatic.

In the consultation, participants strongly emphasised the ethical, system-level obligation to ensure access. They indicated that access for NHS workers has improved since the pandemic started, associated with increased capacity and availability of locally organised testing.

I believe if you're asking staff to work in environments that expose them to greater risk, then tests should be available for any NHS worker who wants one. (S_387_Senior)

The current testing that we have available is easy to access with adequate capacity within our hospital to support demand. This situation has however come about far too late, there were many staff in the initial stages of the pandemic who were mildly or overtly symptomatic who were unable to get tested. (S_291_Clinical)

Also critical is ensuring that testing is sufficiently inclusive of the range of staffing groups.

I agree that all NHS workers should be offered the test even if they do not have symptoms. This should be started in front line workers who are in contact with patients with COVID. Naturally this will be in doctors and nurses but should include porters (one of our porters has died from COVID), cleaners and others. (S_230_Clinical)

Who is eligible for testing and how decisions are made about testing are important ethical considerations. There remain some uncertainties about the boundaries around NHS worker, keyworkers, and essential workers. Participants in the consultation also commented that agency, locum, bank, and subcontracted staff may have complex employment arrangements. They may, for example, work in multiple locations and with several organisations. Clarity is therefore needed about their eligibility for testing, who is responsible for ensuring and assuring that their swabs are taken, and who has access to that information.

Access to testing, even when available in principle, may however, be frustrated in several ways. Participants reported that local programmes were variable in quality and equity of access.

We know that each trust's locality is going to be different because of the way the NHS in England is particularly set up. So we know that there are going to be disparities all around the country with deliveries and logistics. (L_305_Clinical)

Logistical barriers (e.g. some individuals being expected to travel to testing sites by car) may have social and ethical consequences, such as structuring access in inequitable ways. The barriers may be much greater for those who lack their own transport, or whose working patterns or familial commitments are not compatible with the available opening times. BAME staff are much more likely to have lower-paid roles, meaning that they are likely to have less flexibility and poorer transport options. They may be disproportionately concerned about loss of income if tested.⁸ Home testing kits do not fully resolve these challenges, given some uncertainty about their validity and reliability and ability for individuals to self-administer effectively.

Improvements already put in place as the programme has evolved include use of Language Line (interpreter service and staff are trained to manage language barriers) by the NHS 119 call centre, provision of translation services at testing sites and sign language interpreters at regional tests sites. Around a dozen new 'walk in' local testing centres have also been opened to make it easier for people without cars to get a test. Where good practice was identified in the consultation, participants emphasised ease of process, rapid access, and low burden.

But it [testing] was certainly there on tap and very available and middle and senior managers were encouraging people to take that up if it was necessary. (L_306_Clinical)

So those people that have required tests seem to have got them fairly quickly; I've certainly not had anybody complaining about not being able to access a test, or [the process being] cumbersome or burdensome within my immediate clinical colleagues. (L_376_Clinical)

Properties of the test

Achieving the goals of the programme depends crucially on the properties of the test itself. This includes its sensitivity (whether it correctly detects people who have the disease) and specificity (whether it correctly classifies people as negative who do not have the disease). Both of these properties of the test have ethical consequences, since test results may be used by organisations as the basis of important decisions about, for example, whether people are considered to be fit for work or where they should be assigned.

The swab test uses PCR to look for the presence of the genetic signature (RNA) of SARS-CoV-2, the virus which causes COVID-19, to identify whether individuals currently have COVID-19. It involves the use of a swab to collect a sample from the nose or throat. The RNA COVID-19 test is very specific (low chance of false positives), but the scientific literature indicates that its sensitivity is problematic, lying somewhere in the range 71%-98% based on repeat testing.⁹ A recent New England Journal of Medicine article suggested that around 70% was a reasonable estimate of the sensitivity in apparently symptomatic people,¹⁰ noting that, "at this sensitivity level, with a pretest probability of 50%, the post-test probability with a negative test would be 23% — far too high to safely assume someone is uninfected."

Some of the reasons for the relatively poor sensitivity of the test lie in challenges relating to the site of the body from which the sample is obtained, operator sampling technique, stage of disease, and degree of viral multiplication or clearance.⁹ Not all of the variation associated with these challenges can be eliminated. For these reasons, it has been suggested that clinical adjudication is likely to be the most pragmatic way of determining whether someone probably does have the disease even if they test negative.⁹

Given the possibility that the test generates a relatively high rate of false negatives in apparently symptomatic people, one ethical consideration is whether those who test negative are entitled to further tests. This is particularly important given the nature of the decisions (return to work, and where to work) that might be based on the results, and what should happen when there is still clinical suspicion that a person does have COVID-19 even when tested negative.

Further uncertainties arise, of course, in the context of testing asymptomatic people. Sensitivity is likely to be lower in a low prevalence context. The scientific literature notes that designing a reference standard for measuring the sensitivity of SARS-CoV-2 tests in asymptomatic people is priority, particularly as test results for contact-tracing or screening purposes become increasingly important.¹⁰

Participants in the consultation repeatedly raised concerns about the properties of the test. They expressed particular anxiety about the use of test results to make decisions about fitness to work and allocation to work areas.

I have concerns about the validity of the testing – and therefore any policy which stands upon it. Policy MUST acknowledge weaknesses of Sensitivity and Specificity. (S_256_Other)

Blind faith in negative swabs meaning no COVID – no apparent understanding of the concept of clinical COVID and negative swab. (S_121_Clinical)

Participants noted that the accuracy of the test was dependent in part on who conducted it. It relies on getting a sufficient sample from an appropriate location in the body, and thus requires robust quality assurance, training of staff, and peer review. Some scepticism about home testing was also evident.

The test is too invasive and uncomfortable hence it is often performed in a suboptimal fashion. Explicit guidance (and perhaps peer review) to all who perform the test as to how to do it well is important. (S_181_Clinical)

I'm not loving the idea of the postal tests. I find it very hard to believe that anyone is going to shove a swab seven centimetres down their own nostril. I wouldn't. I'd have looked at seven centimetres and gone, no, my nose is not that big. (L_128_Clinical)

Improving the properties of the test may rely on technical innovation. For now, the ethical standing of the testing programme requires explicit acknowledgement of the limitations of the current test (alongside its strengths). There is need for appropriate caution about basing decisions on test results (particularly negative tests when individuals are symptomatic) and greater awareness of the possible consequences of those decisions, as we discuss in the next section.

How testing is used in practice

Understanding how testing and its results are used in practice, and the legitimacy of those uses, is important to the ethical standing and effects of the programme. It is possible (as for all policies) that uses in practice may be additional to or instead of the policy goals, or distort those goals. These uses can therefore cause ethical problems of their own, for example by causing avoidable levels of anxiety, by unduly affecting the behaviours of individuals, or by creating, intensifying, or perpetuating inequalities.

One important set of issues centres on the use of test results to determine whether people should be at work. Participants in the consultation reported variable practices by organisations about how decisions were made about fitness for work based on tests, with much concern focused on the problem of false negatives. They worried about whether a negative test was a sufficient basis for requiring people to work. It was suggested that some managers might not be sympathetic to individuals wanting to self-certify in the absence of a test, or self-isolating after a negative test, if those individuals felt they were symptomatic. Some participants expressed the concern that, at least at the time the consultation was undertaken, negative test results might be used to pressure staff to return to work despite symptoms.

I have concerns about the current culture in the NHS especially the manner in which they were forcing staff to return if there is a negative swab regardless if they remain symptomatic. I have many colleagues who are sure that they were positive but were never offered a repeat test. (S_330_Clinical)

Given the false negatives, I would not be happy if anyone tried to use a negative result to decide that someone should be working, as I gather has happened in hospitals. (S_480_Clinical)

Organisational decisions about return to work and allocation to work areas based on negative tests (or no test, but symptoms) were seen as heavily influenced by considerations about maintaining staffing levels. One major ethical dilemma, therefore, was balancing two distinct but interrelated risks: the possibility that patients could be exposed to risk through understaffing, and the possibility that staff might infect colleagues and other patients.

In an ideal world, staff members who believe that they legitimately have symptoms could self-certify for 7 days. The woeful gaps in the NHS workforce has meant that organisations have had to trust that negative result, to ensure they have enough staff to deal safely with the needs of their patients. There is no slack or plan B in this scenario. (S_387_Senior)

I don't think there is any choice at present – we were short on workforce anyway before all this, and if people who test negative do not have to work, operationally this would become impossible to manage. (S_293_Senior)

Particular anxieties may arise in relation to use of tests for organisational decision-making about where staff are allocated. Managers have to make decisions about where staff can work based on the admission pathways that channel patients into red/hot areas of current known COVID-19 infection, or green/cold areas thought to be COVID-19 free. In some organisations, staff who have previously tested positive might be assumed to have immunity (even though the science behind immunity is still unclear), and thus be asked to work on “hot” COVID wards, or alternatively, assigned to “cold” COVID wards on the basis that they are less likely to transmit infection. Similarly, staff may be assigned to cold areas on the basis of negative test results.

These practices in relation to deployment of staff based on test results are likely to benefit from clarity about the principles on which they are based. Transparency, clear communication, and assessment of any potential for inequity of risk distribution are critical. This is especially important given suggestions in the media that BAME staff may have been disproportionately redeployed into hot areas.¹¹

Concerns were also expressed about use of testing and the potential for it to be used to determine entitlements to death-in-service and/or disability benefits. For example some reported perceptions that there might be a need to have had a positive COVID-19 test or need to “prove” where individuals contracted the disease.

Choices about testing

Testing for COVID-19 takes place in the broad context of the pandemic, which entails responsibilities to protect public health, including patients, colleagues, household members, and the wider public. For some diseases it is considered acceptable, to a greater or lesser extent, to make participation in a public health programme a necessary condition of employment for some roles (e.g. tests for tuberculosis or hepatitis), or to strongly encourage participation while not making it strictly mandatory (e.g. flu vaccinations). Similarly, in some occupations outside healthcare (e.g. air traffic controllers, pilots), testing programmes (e.g. for drugs and alcohol) are used on grounds of public safety.¹² It is useful to consider the extent to which it might be ethically acceptable, or even ethically obligatory, for employers to require individuals who work in the NHS to undergo testing (as a condition of their continued employment, for example), whether other options for encouraging people to take tests (e.g. financial incentives, nudges etc.) are more or less legitimate, and whether individuals can be required to participate in testing regularly/frequently, whether or not they are symptomatic. Similarly, whether it is legitimate or reasonable to treat people who have declined to be tested differently (e.g. assigning them to hot or cold areas) and what implications this may have for equity, solidarity, and justice, are key questions.

Reasons to allow individuals to decline testing operate at the level of broad principle (e.g. respect for individual autonomy) and at the level of the specifics of the programme. COVID-19 swab testing does have some elements of a healthcare encounter, where principles such as informed choice, privacy, and autonomy are key ethical considerations, and where, with some exceptions, people can refuse an intervention for any reason. Current policies emphasise that participation in testing is voluntary. [NHSX guidance](#), for example, explicitly states that “tests are entirely voluntary. Staff may be invited by their employer to get tested, but there is no compulsion to be tested.” Many publicly available documents from NHS trusts also emphasise the voluntary nature of participating in testing. But the extent to which choice about testing can be considered truly voluntary in an employer-employee relationship is not clear.

A large number of responses to the consultation indicated specific circumstances that might be considered acceptable reasons to decline testing – for example, when people do not have regular contact with patients or other clinical staff, have had a positive antibody test, have medical conditions that would make swabbing difficult, have a mental health condition that might be exacerbated by testing, or have had

an adverse reaction to previous testing. One reason why people might wish to decline testing is that the swabbing procedure is often uncomfortable; when done properly it should make the person being tested both gag (at the oropharynx) and shed a tear (at the nasopharynx). Our consultation found that being asked to undergo testing might induce undue anxiety in some individuals. Apart from the physical discomfort, some longer-term harm was also thought possible, which might disproportionately affect some groups.

I blew blood out of my nose for some hours afterwards, and what that tells me is that there was some tissue damage and I think if we were really going to say to staff, you need to be tested frequently and regularly, actually there's going to be [injury] there. People are going to start having scarring of tissue in their nasal cavities. We've got an awful lot of BAME workers, I'm worried about keloid scarring there [...]. (L128_Clinical)

Other influences that affect ability and willingness to participate might include religious or ethnic affiliations and beliefs (e.g. relevant to acceptability of touching) and disability/illness. Declining the test might also be linked to anxieties about the outcome of the test or the possible uses and misuses of information arising from it. For instance, some individuals might decline a test out of fear that a negative result might mean allocation to a hot area. For BAME staff, this fear may be heightened by their possible increased vulnerability and poor outcomes of infection.

Possible negative financial, social, and emotional impacts may be key influences on willingness to be tested, perhaps especially for those who are less socio-economically advantaged. Staff on temporary, precarious, or subcontracted arrangements may worry about whether a particular test result (e.g. a positive test requiring self-isolation) might compromise their income or future employability. For instance, though self-isolation pay guarantees based upon the average of recent weeks' pay were available, they were not universal for agency and locum staff who are not included in the sick pay schemes of trusts. For some, the consequences of a positive test in causing other close contacts to have to self-isolate were important. Further, some staff, perhaps especially those on lower incomes, may be less able to implement the public health measures necessary to achieve maximum benefit from testing. One example is restriction on their ability to self-isolate effectively linked to housing conditions, which may be especially relevant to some BAME populations.

I don't think the testing programme will make anything worse but in some situations the benefits may be limited by people's living situation and their ability to self-isolate if they are living in cramped conditions, or with multiple generations in 1 household etc. (S_157_Non-clinical)

It is not clear which reasons for declining the test might be regarded as more legitimate than others, and whether and how the appropriate balances might be struck. In the consultation, some participants proposed that, at the level of broad principle, it would not be ethically justified to compel testing given the limitations of the test. More generally, views on the degree to which testing should be compulsory were varied. While many felt the duty of care to patients and to colleagues and/or the public might generally be more important than personal autonomy where risk was high, others emphasised the importance of individual choice.

Where there is clear evidence that an individual has been exposed to the virus or is displaying symptoms, I believe that compulsion is warranted on the basis of the health and safety of other employees and patients. The requirement that there be 'clear evidence' means that this compulsion would, in my view, be proportionate. (S_424_Other)

No, I do not think that anyone should be compelled to be tested. If a member of staff is showing symptoms they should not be allowed to work for 7-14 days. It has to remain a choice for staff, people cannot be forced to undertake a medical procedure or test if they have the capacity to understand the risks and consequences of their decision. (S_483_Non-Clinical)

Many recognised the ethical consequences of different choices about participation in testing and the dual identity (and duties) of people both as patients and as workers.

Cannot compel anyone to undergo a physically invasive procedure. Patient & colleague safety is paramount so NHS workers who decline to be tested cannot work in situations where there is a risk of them infecting others – they can only work at home. That raises all sorts of issues e.g. equity with colleagues who accept testing, and what to do if their job is impossible to do from home. (S_348_Senior)

I am conflicted by this as it is important for safety of staff and patients but it is a human right to refuse. (S_381_Senior)

I have a general concern about maintaining the autonomy and confidentiality of positive COVID test results for health care workers. The role of the 'patient-centred care' model at the core of the NHS helps cement a culture that (should) protect medical results for a patient, but I worry that an NHS Worker won't be viewed in the same way. (S_297_Clinical)

Relevant here is that some measures to encourage testing might not appear to be compulsory, but have the effect of being coercive or pressurising, e.g. linked to institutional targets, pressures through stigmatisation, economic necessity, consequences for employment, etc. Social pressures are also relevant. For example, those who wish to decline may fear they will be marginalised by colleagues who think they are not fairly sharing in collective responsibility, are undermining fair choices about work allocation, are shirking clinical and other duties of care, or are not displaying the qualities of the "virtuous worker".

Ethical issues also arise if the degree of coercion or pressure varies according to occupational group. Ability to exercise real choice over testing (and the consequences of test results for allocation to work areas) may be distributed differently across and between organisations, making vulnerability to coercion or pressure to have testing inequitable. Some staff are much less able to assert themselves forcefully. For example, those on more precarious contracts, with insecure residency or citizenship rights, or in roles that do not enable strong self-advocacy, may feel less able to refuse testing, or, conversely, to insist upon it. Again, limits over choice may disproportionately affect less advantaged groups and BAME staff, given their over-representation in lower-paid positions. Control over choices about testing have effects beyond individuals. If staff from different professions and different socio-economic groups behave differently in terms of their choices about tests, the potential for widening inequalities between different groups increases.

Choices over frequency of testing

Many of these issues acquire additional potency given the current policy intention to test key workers "regularly". What is meant by "regularly" was not specified during the period the project was undertaken, yet may be important to the effectiveness of the programme and to the ethical issue of stewardship, including the need to ensure that the benefits of testing are maximised with minimal waste of resource. Frequency of testing has implications for acceptability and legitimacy, especially given the range of possible reasons people might wish to decline (outlined above) and possible enhanced risks associated with frequent testing. The extent

to which frequency of testing should be stratified by local infection rates or risk in particular clinical areas, and whether individuals who have specific reasons for more frequent testing (for example living with elderly or at-risk household members) should be able to access more testing is not clear. Who should get to decide, using what criteria, on the appropriate frequency of testing has not been determined.

NHS staff have been able to access asymptomatic testing for some time, subject to local decision making and following clinical guidance on this matter issued by NHS England. A recent [letter from NHS England](#) on 24 June 2020 set out a risk-based approach, including guidance that surplus NHS testing capacity should be used for testing non-symptomatic staff (in addition to all patients and symptomatic staff) working in situations where there is an untoward incident or outbreak or high prevalence. It also explains that the view of the Chief Medical Officer is that periodic staff testing is best done as part of Public Health England's SIREN study, which is seeking to determine where prior infection in healthcare workers confers immunity to re-infection.

In the consultation, which was conducted before the letter was issued, many participants felt that regular testing should be universally available for all, particularly when staff had symptoms or other reasons for seeking a test. Making it a requirement to have frequent tests, particularly when individuals were asymptomatic, was often seen as more problematic, however.

How often should we be tested? Weekly? I don't think I'd want to be tested weekly in perpetuity — not in perpetuity — but on an ongoing basis. It's not a particularly pleasant test [...] I mean it's okay, it's not the end of the world, but it's certainly not something you'd do for fun, it's more uncomfortable than a blood test I'd say. (L_376_Clinical)

I really can't think of any reasons to opt out if the test was offered because you had symptoms or had a significant contact with someone who was a confirmed case. It is different though if you are talking about screening staff for asymptomatic carriage of the virus. In the asymptomatic population, the positive predictive value could be very low due to the low prevalence of the disease in this population group. [...] Personally, I would only want to be screened if there was some other mitigating factor e.g., an unexplained spike in hospital acquired COVID. (S_106_Clinical)

Stewardship of resource is clearly important, especially if frequent testing is scaled up. If a situation where resource is limited (which is not one that applies generally at present), explicit principles would be needed to facilitate prioritisation between different key workers (and possibly those close to them). For example, important questions might arise regarding whether BAME colleagues and other particularly at-risk groups should be prioritised for testing. Such an approach might have some merits, but might also have unintended consequences (e.g. potentially by increasing discrimination and disadvantage), and careful consideration is therefore needed. Some felt that regular and frequent testing should be prioritised for BAME staff or others deemed to be at higher risk of infection or poor outcomes of COVID-19, but others felt that this approach, particularly if mandated in some way, would be less useful or have the potential to discriminate.

Regular testing of BAME staff is imperative as part of the risk management. [...] NHS staff should be tested regularly in the same way that footballers seem to be being tested. Testing should be made available to all NHS staff, including contracted staff i.e. cleaning and facilities management staff. Agency workers should also be tested on a regular basis. (S_170_Other)

Mandatory testing may create feelings of discrimination or sense of being 'profiled', both unhelpful and unwanted. (S_134_Senior)

Privacy, confidentiality, and data protection

Privacy, confidentiality, information governance, and data protection are key concerns in the context of the swab testing programme. The proper limits of privacy and confidentiality are, of course, highly contested, both in general and in the context of public health, and between law and ethics. One clear ethical responsibility is to ensure that personal information arising from the testing programme (including test results and whether people have had tests) is handled safely and responsibly. Perhaps more complicated questions arise in relation to data justice, which includes a concern for equality and social justice outside of more narrow concerns about individual privacy¹² and in particular the boundaries of what might be considered acceptable in the context of a global pandemic. Relevant questions may include, for example, who legitimately should have access to information about individuals' test results (and whether they have had tests) and the range of legitimate uses of that information. These kinds of questions are likely to grow in significance as the Test and Trace programme intensifies.

The Employment Practices Code issued by the Information Commissioner's Office recommends an impact assessment that involves: identifying clearly the purpose(s) for which health information is to be collected and held and the benefits this is likely to deliver; identifying any likely adverse impact of collecting and holding the information; considering alternatives to collecting and holding such information; taking into account the obligations that arise from collecting and holding health information; and judging whether collecting and holding health information is justified. It should include an equality impact assessment. The extent to which employers have undertaken such assessments in relation to the COVID-19 swab testing programme is currently unclear.¹³

NHSX guidance explains that employers can ask staff if they have been tested (and if so the result of the test). Employees do not have to disclose the result, unless it impacts on their working ability (e.g. if they need to self-isolate for 7 days the employer needs to be able to plan to manage their absence). The guidance also explains that accessing results without the knowledge or permission of the staff member is a breach of confidentiality and is illegal under the Data Protection Act (Section 170 – unlawfully obtaining personal data).

The issues around privacy, confidentiality and data protection are complicated by differences between Pillar 1 and Pillar 2 testing, which may not be clear to those on the ground. Pillar 1 involves swab testing in Public Health England labs and NHS hospitals for those with clinical need, including health and care workers. The resulting data is intended to be treated in the same manner as all pathology test results in the NHS. Pillar 2 involves commercial partnerships to deliver testing capacity for the wider population, but health and care workers may access testing through this route and is governed by a privacy policy. People are encouraged to inform their employers if they test positive, but results are not shared by default.

Many participants in the consultation saw the test result as private personal information. They assumed that the consent of the individual is or should be required for disclosing it to others.

So, that's personal information for the individual so they obviously need to get that information first. What we do with other health protection issues is then we have to balance it with the public good in terms of who needs to know, so you always then get the consent of the individual for sharing information further, which is usually routine.
(I_249_Non-clinical)

All test results should remain confidential to the patient, only accessed by other NHS staff and healthcare professionals directly responsible for their care, and anonymised for PHE purposes. Only the employee can consent to sharing their result, positive or negative, with others (especially employers, colleagues and patients).
(S_338_Non-clinical)

However, limits on privacy do exist. Some information on test results may be required to be shared beyond the individual because COVID-19 is a notifiable disease. The Health and Safety Executive also requires that it be notified on incidents of, or deaths from, COVID-19 that arise as a result of occupational exposure (through the person's work).¹⁴ Further, consent to share test results with GPs seems to be assumed as part of the testing procedure for Pillar 2: the government website states that "For English residents, we will link your test result to your GP record, so you do not need to inform your GP of your result".

Notwithstanding the guidance, participants in the consultation were concerned about lack of clarity and apparent variability in data sharing and pathways for referral and notification of test results (or whether a test has been taken). The various interfaces and circulation of data for different purposes were not always clear, and distinctions between Pillar 1 and Pillar 2 were not meaningful on the ground. Participants indicated that how the test result is shared with the employee appears variable – in some cases, for example, the testing team notifies the individual, while in others the occupational health service is notified and then informs the individual. Uncertainties were reported about what gets recorded in people's personnel records/ occupational health records and who gets to know about it and when. In general, participants were unclear about information flows and expressed considerable scepticism about the quality of data protection.

So data is held terribly and handled badly most of the time, so I think the reality of it is that if I was in that position as a healthcare worker [...] I would be testing with a knowledge that my data is probably going to be held somewhere terribly, but I think most people trust the system and will expect other things from it. So I think in reality we're probably breaking all sorts of data protection laws as we go, but the nature of the emergency is letting us to a certain degree – not letting us, but we are just carrying on. (I_479_Senior)

Whether and which colleagues are entitled to know about others' test results (or whether they have been tested) is an important ethical question. It is important that staff are reassured that any disclosure to colleagues, or beyond, is done transparently, fairly, and appropriately. For BAME staff, such reassurance may be particularly salient, especially in light of evidence about the impact of concerns over privacy among those of an ethnic minority background on HIV self-sampling testing.¹⁵

It was not clear to participants in the consultation that all possible uses to which information resulting from tests might be put are legitimate, nor that it would be possible to predict the future use of such information. For example, fears have been raised about the impact of test results on people's access to financial products such as life insurance, income protection policies, and mortgages. DHSC have said that they may use an agency to verify an individual's identity. Though it states that the information will not be used as a credit check, some may feel anxiety in response.

I would also be deeply suspicious they would sell my information to profit making companies who would use it for their own good and not for any public benefit! (S_375_Clinical)

I think that we're all feeling a bit sceptical about it all getting shared with Serco and whoever else, and my information, and not just my test result but potentially my telephone number, my date of birth, confidential information about me getting shared with a private company. (I_201_Clinical)

Important concerns also arose in relation to the possibility that data might be shared across other government agencies. These anxieties and consequences may be felt unevenly across different groups: the government's approach to immigration policy, which includes measures to compel the NHS as employer and healthcare provider to share information with immigration authorities in certain circumstances¹⁶ may have a particularly corrosive effect on trust in some communities. For example, data sharing with the Home Office is a concern that has been explicitly raised by overseas staff, including Filipino nurses, for example.¹⁷

Some of these concerns may be perceptions that are not grounded in actual practice, but the level of anxiety suggests that they need to be addressed through appropriate information, clarity and reassurance. Key to ethical (and legal) practice is ensuring that individuals who take part in testing are made fully aware of how information about test results will be shared, and possible effects of this sharing of information.

Trustworthiness and legitimacy

The safe, effective, and efficient operation of the testing programme is likely to depend to a large extent on its trustworthiness and legitimacy among diverse audiences. Legitimacy can be defined in various ways,¹⁸ but broadly, for purposes of this analysis, can be taken to refer to how far the actions and values of the policy/programme are perceived to be desirable, acceptable, proper, and appropriate.

The consultation suggested that early problems in the response to the pandemic, and ongoing perceptions of policy mishandling, may have challenged trustworthiness and legitimacy of handling issues related to COVID-19 overall and become generalised to testing. The Government's approach was often seen to lack transparency and therefore appeared dishonest, with information about testing either seen as inadequate or coming across as political rather than evidence-based.

The blatant dishonesty about how many people were being tested and all the double counting. Hard to imagine how we could have handled it worse? (S_387_Senior)

The testing process and directives from the government and Public Health England do not appear to be organised and comprehensive. (S_311_Senior)

Perceived problems with the scientific evidence and expertise behind the testing approach made it difficult for some healthcare professionals to trust the programme. They also expressed worries that COVID-19 testing might be used as the thin end of the wedge to drive other changes that could affect staff.

No clear published data on false positive and false negative testing relates, however the media and Government seem to speak as though it is 100% sensitivity and specificity. (S_256_Other)

I'm also mindful of the fact that there are people who have a vested interest in the flu vaccine becoming mandatory for all NHS staff. The pandemic is being used to change and reconfigure services (not necessarily in a bad way- i.e. GPs and hospital doctors using video consultations). Giving the green light for blanket testing here may embolden people to think flu jabs should be mandatory for everyone too. (S_427_Clinical)

The tensions about the goals and uses of testing, and conflict between competing interests, need to be resolved. Local organisations are likely to wield considerable practical power arising from their discretion in the interpretation and application of the rules. These organisations are likely to develop dynamics of their own that require careful scrutiny because of their potential for generating unintended consequences. One possible solution might be a national template (to be customised to local circumstances) that could identify risk assessment processes and guide decision-making about return to work and allocation to work areas. This could help ensure transparency and equitable access to information but nonetheless offer flexibility, thus allowing for regional or organisational variation (e.g. with regard to prevalence). More broadly, organisations need to be open, accountable, reflexive, and responsible in their decision-making. Satisfactory and effective appeal mechanisms are clearly necessary.

Trustworthiness and legitimacy are likely to be further enhanced if staff are confident that any concerns will be heard and addressed. Psychological safety, defined as an interpersonal climate where individuals feel able to take risks without fear of negative consequences is relevant for enabling speaking up — a behaviour in which people voice their observations, questions and concerns, especially to colleagues above them in a hierarchy.¹⁹ Some NHS staff have felt that their raising and voicing of concerns on response to and management of the pandemic has been unwelcome or ignored (e.g. in relation to personal protective equipment) and may even be held against them. Possible power imbalances in the workforce and the differing agency of staff to speak up must be recognised. The evidence that BAME staff may be especially reluctant to raise concerns for fear of reprisal²⁰ means that it is particularly important to ensure that the system operates transparently, fairly, and appropriately.

Communication and information about testing

Communication (national and local) regarding the testing programme is fundamental to its effectiveness, trustworthiness, and legitimacy. Key requirements for ethical conduct are for organisations to be fair and transparent to staff in relation to how they would use the results of tests (e.g. in terms of allocation of place of work), to safeguard their health as far as possible, and to prevent discrimination. It is ethically important that individuals are provided with full and accurate information about testing. Having clear criteria in place for interpretation of the test results and a quality assurance process are likely to be important in securing trustworthiness.

High quality communication and information is key to respecting autonomy, creating shared purpose and engagement, securing legitimacy, accountability and transparency, and achieving the broader goals of the programme, including those relating to public health. Information about testing should be comprehensive, clear and accessible, both nationally and locally, pitched at a level that people are able to understand, and available in formats that are compliant with equalities legislation. Information should detail the degree of choice over having a test, consent procedures, any physical discomfort that might be expected during the test, what a positive test means for quarantine procedures, what help is available to support those required to isolate, clarity about who receives and has access to test results and in what sequence, and what should happen in response to a negative result in someone who has symptoms. The decisions that may be based on test results, the principles that inform them, and any rights of appeal or other mechanisms available to employees should be clear and explicit. How testing of NHS staff interfaces with the NHS Test and Trace programme should also be explained. Changes over time should be highlighted and explained, otherwise consent might become routinised. However, the consultation identified multiple wide-ranging concerns about information and communication.

The main issue with the testing process so far has been lack of information, other than via public media.
(S_158_Clinical)

I think there is a lot of misunderstanding and indeed ignorance of COVID-19 understandably given its complexity of action. So many people now use social media as their only source of information gathering, the importance of achieving the trust of NHS workers is challenging and can only be achieved through education, transparency and by listening to their voices. COVID is here to stay so it is essential that all NHS staff have confidence in the system for the sake of their and their patients and colleagues health and that of their families.
(S_452_Other)

Many participants described how much of the national communication was complex, chaotic, and difficult to understand. They reported receiving, particularly in the early stages of the pandemic, conflicting information from different sources (e.g. from Public Health England versus local organisations), leading to confusion about the process, the availability of testing, and what would happen in response. Some participants found national promotion efforts effective at raising awareness, while others found them “extremely unclear”. Several participants also expressed concerns that misunderstandings or anxiety about COVID-19 and testing, especially amongst members of higher risk groups, might lead them to forego testing.

The testing process to date has been complex to understand and navigate even for NHS professionals [...].
(S_338_Non-clinical)

Procedurally, the availability of multiple options for testing (e.g. through work, through national drive-through centres, through postal testing), while welcomed as providing flexibility, was also seen as potentially confusing.

[The current approach to testing] is confusing and inconsistent with the drive through centres not using the same criteria. NHS staff are confused by the changes to guidance and have sought screening outside of [the] organisation – this then leads to employers not being informed of results. (S_381_Senior)

I guess mixed messages has been difficult to manage, because day by day and sometimes hour by hour the advice we were given locally and nationally conflicted and it was difficult in the midst of everything else you were doing. (L_318_Clinical)

Some participants believed that communication around testing has improved. Those who identified good practice welcomed organisational communication that was clear about process, procedure, and criteria.

What's been really good is really good publicising of how you access the programme and what you need to do if all your family need a COVID test. [...] during the whole process our medical director sends an email every evening with a daily update of what's going on in the organisation and it's divided into subheadings so there's what's going on with COVID, what's going on with re-establishing services, staff wellbeing and staff care. (L_128_Clinical)

There is now clear guidance that if you or a member of your household has symptoms that your line manager can arrange testing at a local site. (S_330_Clinical)

My own Trust has a very clear process and has been clearly communicated. (S_293_Senior)

My own Trust has taken a responsible and well-coordinated approach with what has been made available. (S_354_Senior)

More broadly, the consultation showed that direct frontline experience and professional knowledge has multiple implications for trust and legitimacy in communications about testing. Many NHS workers are well-informed about the disease, having experienced it first-hand in their patients. NHS clinicians are also steeped in evidence-based practice, and as knowledgeable “consumers” they may require particular forms of communication if they are to be convinced of the scientific basis of testing. Participants commented extensively on the seeming lack of scientific rationale underpinning the testing approach, or at least a failure to effectively communicate any such rationale:

The main issue with the testing process so far has been lack of information, other than via public media. The next greatest issue is that information is circulated is often vague, and doesn't seem to contain a logical rationale or scientifically justifiable underpinning. I receive information from two different NHS Trusts as part of my clinical role – both are taking different approaches to testing and neither seem to have been offered a coherent strategy for either sampling or routine testing with a plan for managing the results. (S_158_Clinical)

Many staff were acutely aware of the problem of false negatives in test results, perhaps through having direct experience of patient tests coming back negative on one or two occasions before a subsequent positive test result. Yet, until very recently, official guidance did not acknowledge the extent of false negatives,²⁴ potentially undermining trust. This was something that was repeatedly the focus of comments

in the consultation. Similarly, what counts as symptomatic is continuing to evolve, and staff may be aware of a much wider range of presenting symptoms relevant to COVID-19 than is listed in the official criteria. Participants emphasised the need to have comprehensive communication that is clear and based on research and science. Explicit acknowledgement of uncertainties is needed, including not just the issues of test sensitivity but also those relating to whether individuals who test positive remain contagious, for how long (if at all) immunity is conferred, and whether the length of isolation is sufficient.

The need to ensure accessibility of information for higher risk communities was emphasised. Some participants felt that communication that was suitable for some groups (e.g. in emphasising science) might exclude others, perhaps those in less socio-economically advantaged positions. Over-reliance on email in NHS organisations as a means of communication was seen as particularly problematic.

I think definitely among the different medical health professions, there's different levels of, I don't know if it's health and information literacy [...] Sometimes amongst the domestic staff, or other areas, you wonder where people are getting that information. They may be more likely to have read things in the newspaper than from their work emails. [...] I think people are getting information from a lot of different places [...] And I think it's very unfair to expect people who are probably on minimum wage to go through five page daily emails to try and pull out what they should and shouldn't be doing. [It should be] aimed at a level that's communicable and legible to everyone. (L_218_Clinical)

The need to address the specific and distinctive needs of BAME communities was stressed, with some suggesting that community leaders might have an important role in information and communication.

It is important that the messaging for testing in languages or other ways that are easily understood so that people are not disadvantaged for their command of English. Everyone should have equal opportunity to be tested, regardless of race or gender. Testing facilities should operate in ways that encourage people to attend for testing and not feel discriminated. (S_282_Clinical)

Some of these issues have already begun to be addressed, as explained in [Access to testing](#).

Conclusions

The identification of relevant ethical considerations can help in design, implementation, improvement, and evaluation of public health interventions during a public health emergency.²² This analysis, which involved an Expert Group and a wide-ranging consultation, has identified eight key considerations relevant to the swab testing programme for COVID-19 in NHS workers. Progress has already been achieved in many of these areas, and further improvement will be facilitated by being highly attentive to the principles on which decisions, practices, and policies are based, through sensitivity to issues of equality and equity, and through fairness, transparency, the fundamental importance of trust, and proactive and consistent communication. Our recommendations, while they do not eliminate the ethical challenges, may go some way towards diminishing them.

The analysis illustrates the value of explicit, systematic, and consultative consideration of ethical issues and is likely to have relevance to many other current and developing areas of practice and policy in response to the pandemic, including Test and Trace and future vaccination programmes.

Report contributors**Members of Expert Group**

- Alberto Giubilini, University of Oxford
 - Calum McGregor, University Hospital Wishaw, NHS Lanarkshire
 - Claire Whitehouse, The James Paget University Hospitals NHS Foundation Trust
 - Deborah Bowman, St George's, University of London
 - Jeremy Dawson, University of Sheffield
 - Jill Maben, University of Surrey
 - John Coggon, University of Bristol
 - Jonathan Montgomery, University College London and Oxford University Hospitals NHS Foundation Trust
 - Mary Dixon-Woods, University of Cambridge (chair)
 - Patricia Kingori, University of Oxford
 - Robert Winston, Imperial College London and Centre for Data Ethics and Innovation
 - Roger Kline, Middlesex University Business School
 - Sean Ninan, Leeds Teaching Hospital NHS Trust
 - Yasmin Gunaratnam, Goldsmiths, University of London
 - Zoë Fritz, University of Cambridge
- Secretariat: Rebecca Kenny, THIS Institute

Members of the consultation team

- Akbar Ansari, THIS Institute
- Alison Powell, THIS Institute
- André Sartori, Thiscovery, THIS Institute
- Andy Paterson, Thiscovery, THIS Institute
- Bethan Everson, THIS Institute
- Brandi Leach, RAND Europe
- David Scott, University of Dundee
- Doro Unger-Lee, Thiscovery, THIS Institute
- Elka Humphrys, THIS Institute
- Graham Martin, THIS Institute
- Janet Willars, THIS Institute
- Jenny George, RAND Europe
- Joann Leeding, THIS Institute
- Jocelyn Cornwell, The Point of Care Foundation
- Kate Bendall, THIS Institute
- Luke Steer, Thiscovery, THIS Institute
- Nicola Boydell, University of Edinburgh
- Rebecca Kenny, THIS Institute
- Ruth Kern, Thiscovery, THIS Institute
- Sarah Hoare, THIS Institute

Appendix 1: Details of Expert Group

Expert member	Biography
Dr Alberto Giubilini	Alberto Giubilini is a philosopher and Senior Research Fellow at the Oxford Uehiro Centre for Practical Ethics and Wellcome Centre for Ethics and Humanities at the University of Oxford. He has published on different topics in bioethics, public health ethics, and philosophy, including the ethics of vaccination, procreative choices, end of life decisions, organ donations, conscientious objection in healthcare, the concept of conscience, human enhancement, and the role of intuitions and of moral disgust in ethical arguments. His latest book is <i>The Ethics of Vaccination</i> (Palgrave MacMillan 2019).
Dr Calum McGregor	Calum McGregor is a consultant in Acute and General Medicine, based in University Hospital Wishaw, NHS Lanarkshire. Calum was appointed as a consultant in 2012. He is interested in medical education, is the sub-dean for Dundee and Edinburgh University medical students on placement in Wishaw, and has a Masters in Medical Education. Calum is a Scottish Patient Safety fellow, and was the National Clinical Lead for Acute Care with Healthcare Improvement Scotland from 2017 to 2020.
Claire Whitehouse	Claire Whitehouse is the Senior Nurse for Nursing, Midwifery and Allied Health Professions (NMAHP) Research at The James Paget University Hospitals NHS Foundation Trust, and sits on the trust's rapid response COVID ethics board. She is also a member of the International Association of Clinical Research Nurses (IACRN), three times Florence Nightingale Foundation Research and Travel Scholar, and has a Masters in Nursing Studies (Clinical Leadership). Claire is the originator of the global #WhyWeDoResearch twitter campaign/community that seeks to raise research opportunities and voices of patients, public and staff.
Professor Deborah Bowman	Deborah is Professor of Bioethics and Clinical Ethics and Deputy Principal (Institutional Affairs) at St George's, University of London. Deborah's academic interests concern the application of ethics to clinical practice, public involvement in ethical debate, and healthcare regulation. She has published widely. Much of her work focuses on how to support clinical services, both locally and nationally. Her current portfolio of public service roles includes serving as Chair for the General Medical Council's review of its Consent Guidance, a Non-Executive Director of St George's and South West London Mental Health Trust and as a Member of The General Osteopathic Council.
Professor Jeremy Dawson	<p>Jeremy Dawson is Professor of Health Management, working jointly between the Institute of Work Psychology (within the Management School) and the School of Health and Related Research (ScHARR) at the University of Sheffield. He is a statistician by background, but has worked in the fields of work psychology, management and healthcare since 1998.</p> <p>Jeremy's research focusses mainly on team working, human resource management, climate and culture in the NHS, with current funded projects including topics such as measurement of general practice productivity, evaluation of interventions to improve staff well-being, and diversity and discrimination in the workplace. He has also worked on other topics, particularly work group diversity, work engagement and safety. He has a particular interest in areas of statistical methodology, including the testing and interpretation of interaction effects (www.jeremydawson.com/slopes.htm).</p> <p>He was previously a Senior Research Fellow at Aston Business School, Aston University, where he was also director of the Institute for Health Services Effectiveness (IHSE), leading several large-scale projects including running the NHS national staff survey for its first eight years between 2003 and 2010. He gained his PhD from Aston University in 2011.</p>

Appendix 1: Details of Expert Group Continued

Expert member	Biography
Professor Jill Maben	<p>Jill Maben is a Professor of Health Services Research in the School of Health Sciences at the University of Surrey. Jill is a nurse and social scientist having studied History at UCL after qualifying as a nurse.</p> <p>Jill's programme of work seeks to understand the links between staff wellbeing at work and patient experiences of care. She investigates the emotional costs of caring and what supports staff to care well. She is published widely and recently completed the national evaluation of Schwartz Rounds in the UK; reflective sessions that support staff to reflect on the social, emotional and ethics challenges of care. She was an invited member of the Health Education England commission 2018 into Staff and Learner Wellbeing & Mental Health and is currently studying poor mental health of nurses, midwives and paramedics. Jill was awarded an OBE in June 2014 for services to nursing and healthcare.</p>
Professor John Coggon	<p>John Coggon is Professor of Law in the Centre for Health, Law, and Society at the University of Bristol Law School, and an Honorary Member of the UK Faculty of Public Health (FPH). His research combines legal analysis with approaches from moral and political theory; especially in the contexts of mental capacity law and public health ethics and law. He is a member of the ethics committees of FPH and of the British Medical Journal. He is also a member of the Nuffield Council on Bioethics.</p>
Professor Sir Jonathan Montgomery	<p>Jonathan Montgomery is Professor of Health Care Law at University College London, Chair of Oxford University Hospitals NHSFT, and co-chair of the Moral and Ethical Advisory Group (which provides independent advice to the UK government on moral, ethical and faith considerations on health and social care related issues). He was Chair of the Human Genetics Commission 2009-12, the Nuffield Council on Bioethics 2012-17, and Health Research Authority 2012-19. His research focuses on health care law and the governance of bioethical issues. He was knighted for services to bioethics and healthcare law in the 2019 New Year's Honours.</p>
Professor Mary Dixon-Woods	<p>Mary Dixon-Woods is Director of THIS Institute and is The Health Foundation Professor of Healthcare Improvement Studies in the Department of Public Health and Primary Care at the University of Cambridge. She is a fellow of the Academy of Social Sciences and the Academy of Medical Sciences, an honorary fellow of the Royal College of Physicians and the Royal College of General Practitioners, and a Professorial Fellow at Homerton College, Cambridge. Mary is also an NIHR Senior Investigator and Co-Editor-in-Chief of BMJ Quality and Safety.</p> <p>Mary leads a programme of research focused on healthcare improvement, healthcare ethics, and methodological innovation in studying healthcare. She served on the National Advisory Group on the Safety of Patients in England, which produced the Berwick report in 2013. She also served on the review of information technology in the NHS led by Professor Bob Wachter, which reported in 2016. She was a Wellcome Trust Senior Investigator 2012-2019. Mary was the Harveian Orator for the Royal College of Physicians in 2018, the 500th anniversary of the College's founding.</p>
Patricia Kingori	<p>Patricia Kingori PhD, is a Wellcome Senior Investigator at the Wellcome Centre for Ethics and Humanities and the Ethox Centre, University of Oxford. Patricia's primary expertise lies in Sociology and her current research interests intersect the Sociology of Science and Medicine, and a critical examination of ethics in practice. This work has been supported through a range of funders, the Wellcome Trust Investigator Award and the Research Council UK's Grand Challenges Research Fund.</p>

Appendix 1: Details of Expert Group Continued

Expert member	Biography
Professor Lord Robert Winston	Robert Winston is Professor of Science and Society and Emeritus Professor of Fertility Studies at Imperial College London and a member of the House of Lords. His work includes research into education, particularly in school children, outreach and public engagement activities. Robert Winston speaks regularly at the House of Lords on education, science, medicine and the arts. He was Chairman of the Lords Select Committee on Science and Technology 1999-2002, initiating enquiries into Antibiotic Resistance, Non-Food Crops, Nuclear Waste, Science and Society, Genetic Databases, Aircraft Passenger Environment, and Science in Schools. He is a board member and Vice-chairman of the Parliamentary Office of Science and Technology. He is also a member of the board of the Centre for Data Ethics and Innovation.
Roger Kline	Roger Kline is Research Fellow at Middlesex University Business School. He was joint Director of the NHS Workforce Race Equality Standard from 2015-2017. Roger is co-author of Professional Accountability in Social Care and Health (2012) author of The Snowy White Peaks of the NHS (2014), co-author of The Price of Fear (2018) on bullying in the NHS, co-author of Fair to Refer (GMC 2019) on the disproportionate referrals of some groups of doctors to the regulator. He has devised innovative approaches to disciplinary action in the NHS and is currently a national adviser to the NHS Talent Management programme. Roger was previously a senior official in eight different trade unions.
Dr Sean Ninan	Sean Ninan is a consultant geriatrician at Leeds Teaching Hospitals NHS Trust with interests in community geriatrics, education and quality improvement. He is the dementia lead for the trust.
Dr Yasmin Gunaratnam	Yasmin Gunaratnam is a Reader in Sociology at Goldsmiths (University of London). She has expertise in critical race, disability, health and social care, migration and feminist scholarship and in qualitative and participatory research methods.
Dr Zoë Fritz	<p>Zoë Fritz is a Wellcome fellow in society and ethics, at the University of Cambridge, and a consultant physician in acute medicine at Addenbrooke's Hospital. Her research is focused on identifying areas of clinical practice that raise ethical questions and applying rigorous empirical and ethical analysis to explore the issues and find effective solutions. Zoë has a degree in Pathology from the University of Cambridge, qualified as a doctor from Imperial College London in 2001 and has a PhD in health sciences from Warwick.</p> <p>She has maintained an active clinical career while conducting research in both Cambridge and Warwick universities, and has worked with colleagues to translate her research findings into policy at both local and national levels. Zoë is currently investigating how we communicate and record uncertainty around diagnosis, particularly in the acute care setting. Her Wellcome university award will enable her to provide grounding for future interdisciplinary research to improve medical practice.</p>

Appendix 2: Terms of reference for the Expert Group

Background

Rapid scale-up of the testing regime for COVID-19 is a key element of the UK Government's response to the global pandemic. A particular commitment of the current strategy (6 April 2020)²³ is large-scale antigen testing of NHS, social care and wider critical keyworkers who are symptomatic or in household isolation, with the aims of: keeping these workers and others safe if they test positive; supporting them to return to work when well enough to do so; and enabling them to stay in work if they test negative. One risk of the current approach is that an explicit ethical framework for mass testing of key workers is not yet in place. A second risk is that concerns or barriers to participation have not yet been systematically identified or mitigated. Such considerations are likely to be vital to the success of the regime. THIS (The Healthcare Improvement Studies) Institute, a research centre based at the University of Cambridge funded by the independent charity The Health Foundation, proposes to tackle these challenges through a rapid response project.

The project is sponsored by the Department of Health and Social Care and is supported by the Wellcome Trust and the Academy of Medical Sciences. It is funded and led independently by THIS Institute.

Building on expert advice, using a consultative approach, and accounting for the views and concerns of the full range of relevant stakeholders, the project will develop recommendations for an ethical framework to provide a practical guide to decision-making, serve the interests of transparency and trust, assure individuals (particularly those being asked to put themselves forward for testing) that their concerns have been heard, and offer the basis of an agreed, nationwide approach. Evidence will be gathered through a combination of review of relevant academic literature, guidance, and policy statements, and through consultative engagement with a range of stakeholder groups including those at the sharp end of care and those in senior positions.

Purpose

The aim of the project is to produce recommendations for an ethical framework for the COVID-19 (antigen) testing regime as it applies to NHS workers by:

- (1) Convening an independent expert group
- (2) Developing an initial ethical framework for the NHS worker testing regime using expert advice and review of relevant literatures and policy documents
- (3) Consult on the framework with a range of stakeholders to include identification of relevant

influences, barriers or concerns about engagement with the testing regime and possible means of mitigating any risks or concerns

- (4) Maturing the framework in light of the consultation
- (5) Providing a set of practical recommendations to guide policy and practice.

This project is required to be delivered urgently given the pressing need for scale-up of the antigen testing regime. The project is intended to be complete by end of May 2020 with the report publicly available in early June 2020, with some contingency depending on decisions about extent of consultation.

Scope

The role of the project is advisory to the Department of Health and Social Care. It does not have a remit for the testing regime as it applies to non-NHS key workers, but its recommendations may, subject to suitable review, have relevance to those groups (e.g. those in social care).

Methods

The project will:

- 1 Convene an expert panel to guide the production of an initial ethical framework through meetings and sharing of documents.
- 2 Undertake a rapid literature review to support the work of the panel, including relevant literatures such as public health ethics and ethics of employment.
- 3 Consult on the initial framework through conducting online interviews with purposively selected participants from relevant stakeholder groups, to include: NHS workers in varying clinical and non-clinical roles from different kinds of organisations; general practitioners and their staff; NHS senior leaders, including those in executive/board positions; policy-makers; patients and the public; and experts in infectious diseases, in public health, in human resource management and organisational behaviour and in ethics. These interviews will be conducted using a semi-structured interview guide and subject to qualitative analysis.
- 4 Revise the initial ethical framework to incorporate points identified in the analysis of qualitative interviews.
- 5 Consider whether further consultation (e.g. surveys of staff) or consensus-building (e.g. using Delphi techniques) is needed following results of (3).
- 6 Update the initial ethical framework and make available in an easily accessible format.
- 7 Draw up an approach for evaluation of the framework.

Advice will be obtained on the ethical approval requirements that may be needed to conduct this project. An initial assessment using the [Health Research Authority's decision tool](#) suggests that it would be counted as "usual practice in public health" and thus will not require HRA approval.

Membership of the expert group

The expert group will meet remotely over the course of the project (April-June 2020). It is likely to meet at least three times over the lifetime of the project. Ad hoc meetings with individuals or small subgroups may also take place.

Members will be selected to represent a range of expertise and diverse perspectives relevant to the project. The group will be chaired by Professor Mary Dixon-Woods, Director of THIS Institute. The secretariat will be provided by THIS Institute.

Members will agree to:

- Contribute their expertise and views to support the goals of the project
- Attend all meetings where possible
- Comment on draft documents in a timely way, which may be at short notice.

Members will contribute to the project on an unremunerated basis and will do so in their personal capacity rather than representing any particular organisation. Members will be asked to declare any conflicts of interests on joining the group. Additional members may be recruited as needed.

Funding

The project will be funded by the Health Foundation's grant to THIS Institute. Partners and collaborators of THIS Institute may be involved in delivering this work. No payments will be made to members of the expert panel.

The project will be conducted independently of the Department of Health and Social Care and other government departments and offices.

Outputs of the project

The project will produce recommendations for an ethical framework for the COVID-19 testing regime for NHS staff and a short report summarising the evidence and opinion that has informed the development of the framework. Any quotations from the consultation exercise will be anonymised.

The recommendations are intended to be presented in June 2020, with some contingency dependent on level of consultation required. Communications about the project will be handled by THIS Institute. There will be no restrictions on the content of the outputs of the project, but timings of publication or other messages about the project may be discussed with relevant government departments/offices and other bodies.

Timescale	
Task	Date complete
Convene expert panel and hold first meeting	29 April 2020
Rapid literature review	5 May 2020
Online consultation interviews	20 May 2020
Analysis and report on interviews	30 May 2020
Decision on whether further consultation is needed based on interim analysis	22 May 2020
If no further consultation, completion of report	Early June 2020
Publication of report	June 2020

References

1. Fritz Z, Huxtable R, Ives J, et al. Ethical road map through the covid-19 pandemic. *BMJ* 2020; 369:m2033. <https://doi.org/10.1136/bmj.m2033>
2. Gale N, Heath G, Cameron E. et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:117. <https://doi.org/10.1186/1471-2288-13-117>
3. Coggon J. *What Makes Health Public?: A Critical Evaluation of Moral, Legal, and Political Claims in Public Health*. Cambridge, Cambridge University Press 2012.
4. Razaq A, Harrison D, Karunanithi S et al. BAME COVID-19 deaths – What do we know? *Rapid Data & Evidence Review*. 2020. <https://www.cebm.net/covid-19/bame-covid-19-deaths-what-do-we-know-rapid-data-evidence-review/>
5. Public Health England. *Beyond the data: Understanding the impact of COVID-19 on BAME groups*. London, Public Health England 2020. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf
6. Elwell-Sutton T, Deeny S, Stafford M. *Emerging findings on the impact of COVID-19 on black and minority ethnic people*. The Health Foundation 2020. <https://www.health.org.uk/news-and-comment/charts-and-infographics/emerging-findings-on-the-impact-of-covid-19-on-black-and-min>
7. Department of Health and Social Care. *Coronavirus (COVID-19): Scaling up our testing programmes*. Updated 6 April 2020. <https://www.gov.uk/government/publications/coronavirus-covid-19-scaling-up-testing-programmes/coronavirus-covid-19-scaling-up-our-testing-programmes>
8. NHS England. *NHS Workforce Race Equality Standard 2019 Data analysis report for NHS trusts*. 2020. <https://www.england.nhs.uk/publication/workforce-race-equality-standard-data-reporting-2019/>
9. Watson J, Whiting PF, Brush JE. Interpreting a covid-19 test result. *BMJ* 2020; May 12;369.
10. Woloshin S, Patel N, Kesselheim AS. False Negative Tests for SARS-CoV-2 Infection Challenges and Implications. *New England Journal of Medicine* 2020 doi: 10.1056/NEJMp2015897
11. 'Discrimination' on frontline of coronavirus outbreak may be factor in disproportionate BAME deaths among NHS staff. *ITV News* 2020. <https://www.itv.com/news/2020-05-13/discrimination-frontline-coronavirus-covid19-black-minority-ethnic-bame-deaths-nhs-racism/>
12. Dencik L, Hintz A, Redden J, et al. Exploring Data Justice: Conceptions, Applications and Directions. *Information, Communication & Society* 2019; 22(7):873-81. <https://doi.org/10.1080/1369118X.2019.1606268>
13. Information Commissioner's Office. *The Employment Practices Code 2011*. https://ico.org.uk/media/for-organisations/documents/1064/the_employment_practices_code.pdf
14. Health and Safety Executive RIDDOR Reporting of COVID-19 2020. <https://www.hse.gov.uk/news/riddor-reporting-coronavirus.htm>
15. Dodds C, Mugweni E, Phillips G, et al. Acceptability of HIV self-sampling kits (TINY vial) among people of black African ethnicity in the UK: a qualitative study. *BMC Public Health* 2018;18(1):499. <https://doi.org/10.1186/s12889-018-5256-5>
16. O'Donnell K, Aldridge R, Friedland J. et al, Transparency is needed on NHS charges for migrants and data sharing agreements. *BMJ Opinion*, 2020. <https://blogs.bmj.com/bmj/2019/05/13/creating-a-hostile-environment-for-migrants-transparency-is-needed-on-nhs-charges-and-data-sharing-agreements-in-nhs-england/>
17. Ford M, High death rates among Filipino nurses in UK now on global radar. *Nursing Times*, 2020. <https://www.nursingtimes.net/news/coronavirus/high-death-rates-among-filipino-nurses-in-uk-now-on-global-radar-05-06-2020/>
18. Black J, Enrolling actors in regulatory systems: examples from UK financial services regulation. *Public Law*, 2003;(Spring):63-91.
19. Edmondson A, Kramer R, Cook K. Psychological safety, trust, and learning in organizations: A group-level lens. In Kramer R, Cook K (eds.) *Trust and distrust in organizations: Dilemmas and approaches*. New York: Russell Sage Foundation, 2004: 239–272.
20. Francis R, *Freedom to speak up: An independent review into creating an open and honest reporting culture in the NHS*. 2015. http://freedomtospeakup.org.uk/wp-content/uploads/2014/07/F2SU_web.pdf
21. *What your coronavirus test result means*. NHS 2020. <https://www.nhs.uk/conditions/coronavirus-covid-19/testing-for-coronavirus/what-your-coronavirus-test-result-means/> [accessed 2020-05-31].
22. Coggon J, Syrett K, Viens A. *Public Health Law: Ethics, Governance, and Regulation*. London, Taylor & Francis 2016.
23. *Coronavirus (COVID-19) Scaling up our testing programmes*. London: Department of Health and Social Care, 2020.

At THIS Institute we aim to strengthen the evidence base for improving the quality and safety of healthcare.

Co-created by two exceptional organisations - the University of Cambridge and the Health Foundation – THIS Institute is founded on the guiding principle that efforts to improve care should be based on the highest quality evidence.

Our work is defined by a highly inclusive approach that combines academic rigour with the real concerns of patients and staff. We're open, transparent, and we do not shy away from difficult subjects.

Together we're creating an evidence base to improve healthcare.

THIS Institute is made possible by the Health Foundation.

ISBN 978-1-9996539-5-8

© The Healthcare Improvement Studies Institute, 2020

THIS.Institute The Healthcare
Improvement
Studies Institute

THIS Institute

School of Clinical Medicine
University of Cambridge
Cambridge Biomedical Campus
Hills Road
Cambridge CB2 0AH
+44(0)1223 761841
thisinstitute.cam.ac.uk
@THIS_Institute



Made possible by

