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The Independent Scientific Advisory Group for Emergencies (SAGE)

The Independent SAGE Report 4

Towards an Integrated Find, Test, Trace, Isolate, Support (FTTIS) response to the Pandemic

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Submitted to The UK Government and the People of Great Britain & Northern Ireland by Sir David King, former Chief Scientific Adviser, UK Government, Chair of Independent SAGE

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Aims of this Consultation

At this critical stage of the pandemic, an effective COVID-19 Find, Test, Trace, Isolate and Support (FTTIS) programme is essential if we are to recover our economy, protect livelihoods and secure longer-term wellbeing and health provision for all. This consultation document does not address when the current lockdown restrictions should be eased, although the members of Independent SAGE join official SAGE, NHS leaders, and many others in their concerns that this is happening too quickly. Reasons include the current level of infection, evidence that the pandemic is only just under control, and is probably not yet in some parts of the country, and the continued lack of preparedness. Instead, we examine what is needed to put in place a robust FTTIS system, which the existing system is not, and what is needed to develop the trust in that system to ensure that it is accepted by the public.

We therefore aim to highlight the key practical steps for the rapid implementation of an FTTIS system which is embedded, sustainable, and can provide a long-term response to future waves on infection. **We welcome views and comments on this set of proposals,** and how best to rapidly undertake a wide-ranging systems analysis, identifying all of the elements that need to be in place for the system to work and the lines of communication and accountability that connect them.

We also believe it is imperative to re-build trust in an FTTIS system and welcome:

- **suggestions from those who are responding to the pandemic**, providing services, as to how they believe that trust can be restored, with evidence of any lessons learned.
- **the views of the public**, and especially those representing groups that have experienced a disproportionate loss of trust, such as those from BAME communities and those with chronic conditions, of what needs to change

High level recommendations

1. **LOCAL. The most effective implementation of FTTIS is led locally, coordinated by Directors of Public Health. This should be embedded as much as possible within existing networks, and utilise Local Authority and NHS actors such as health commissioners, primary care, local hospital laboratories, school nurses and environmental health officers. This will ensure a robust system in place for future upsurges in infection, and for decision making.**

2. **TRUST. The success of a FTTIS system is based on trust, requiring accountability mechanisms to review evaluation and other evidence, advise on and oversee implementation, and conduct real-time scrutiny of emerging data and policy formulation. Effective community engagement is essential to discuss implementation, problems and solutions, working in partnership with local and national groups**.

3. **DATA. A rigorous system must be implemented to embed the FTTIS data flows as much as possible within existing NHS, local authority and PHE data structures, with real time access to enable local response. It is important to provide data dashboards for the community and ensure appropriate governance and safeguards for privacy and data misuse, to ensure trust and engagement. The future application of m-health systems such as apps must be implemented within such a framework.**

4. **ISOLATE and SUPPORT. This is the critical component of FTTIS if reductions in infection spread are to be realised. There must be facilities available for such isolation, material support including food and finance, and appropriate guarantees from employers, to ensure that those in isolation are not disadvantaged.**

5. **KEY PERFORMANCE INDICATORS (KPI). A set of key performance indicators should be reported weekly, including data that are timely, relevant, and useful to key stakeholders, at a sufficient level of granularity to support local decision-making. Suggested indicators are set out in this report. These data should be subject to community feedback.**

1. Introduction. Why is Find, Test, Trace, Isolate, and Support important?

Our nation faces the worst economic crisis since the second world war. To restore the economy and jobs we must get control of the COVID-19 pandemic. Unchecked, SARS-CoV-2, the cause of COVID-19 spreads rapidly through populations. Each person infected will, on average, transmit it to more than one other. As long as this happens, the pandemic will continue to grow. In the absence of a vaccine, the only way to prevent this happen is to break transmission, so that each infected person transmits it to fewer than one other. This has been achieved in the UK, with the number of new cases falling each week since 8th April, by means of a set of measures that have worked in two ways; social distancing, and enhanced personal protective equipment (PPE) in high risk settings. Yet, while these measures have worked, even if not as well as in many other countries, the social distancing of lockdown has come at great cost, both financially and in terms of the health and wellbeing of those particularly vulnerable, for example through worsening mental health or failure to obtain necessary care for other conditions. At some point, we must reduce these restrictions. However, to do so, we must try to find *every* new case, test them, trace their contacts, and then ask the new case and their contacts to isolate for 2 weeks to prevent further spread, with the support they need to continue with their lives in these new circumstances. We must go beyond a narrow response of simply testing people suspected of being infected and tracing their contacts, which is implied by the Westminster government's use of the term "test and trace". Instead, we recommend that ***the "test and trace" approach should be extended to include all of the elements necessary to control the pandemic, specifically Find, Test, Trace, Isolate, and Support (FTTIS).***

While FTTIS has long been a core public health function, used many times every year by health protection teams and local public health departments in cases of tuberculosis, meningitis, food-borne outbreaks and some other infections, it only works if it is well organised, with health professionals working with contact tracers, laboratories, and social services among others. This should be relatively straightforward when there are only a few cases of the disease in question. It is very different in a pandemic when there are thousands.

If COVID-19 is to be eliminated, as New Zealand has shown is possible, then at least 80% of all close contacts of those with COVID-19 infection (the index case) must remain isolated for 14 days so that they are unable to pass on infection to others. **This is clearly not happening**. If we assume the current 5000 infections per day, and 10 close contacts per person (based on current criteria), then at any one time there will need to be 50,000 contacts traced per day. At present, testing is only targeted at those with symptoms, which we can estimate at 3000 infections/day (assuming only 60% of infected people are symptomatic) which is around twice the daily number of current reported diagnosed cases (1,500 cases a day). This suggests that those with symptoms are either unaware of the need to test, find it difficult to source a test or are reluctant to go for testing. This is not the place to undertake a detailed evaluation of the operation of the system that has been created but it is sufficient to note that Baroness Harding, who has been given responsibility for implementing it, has conceded that it will not be functioning fully until September.

We argue that the current government approach to what is called Test and Trace is severely constrained by lack of coordination, lack of trust, lack of evidence of utility, and centralisation, such that achieving the goal of isolating 80% of close contacts is impossible. As lockdown is slowly released, worrying evidence shows that the pandemic is still growing in some parts of the country, such as the North West of England (and potentially in others, given the uncertainty about the estimates of the reproduction number R). Thus, while it is also extremely important to enhance support for those who are shielding and distancing, and especially

those with mental or physical health problems, there is widespread concern that current proposals to ease some restrictions are premature. A fully functioning FTTIS system is an absolute priority to minimise the risk of widespread resurgence of COVID-19.

These views are not controversial. Indeed, the recommendations from the government's SAGE, from 1st May, are summarised in Box 1.

Box 1. Advice on test and trace systems from SAGE, 1 May 2020

- At least 80% of contacts of an index case would need to be contacted for a system to be effective.
- The objectives of the system were to isolate as many contacts as possible as quickly as possible (within 48 hours of symptoms in the index case) while minimising false positives (i.e. isolating contacts when the index case did not have COVID-19).
- Ideally testing results should be available so rapidly that contacts should only be asked to isolate on the back of a positive test (although they recommended all contacts should be sought once symptoms are notified, and contacts asked to isolate as soon as they are identified even in the absence of a positive test)
- There is insufficient evidence to determine whether the testing of case contacts would impact the epidemic compared with isolation alone.
- There were concerns about the accuracy of home swabbing and whether they produced too many false negatives. A case should also have TWO negative tests before contacts are released.
- High level of adherence to requests to isolate is required for the system to be effective.

2. FTTIS as a System

"Test and Trace" as implemented in England is especially complex because of the large number of organisations involved. For instance, consider the system for testing those developing symptoms. The online guidance states that they should contact the Test and Trace service, either online or by phoning 111, to order a test. However, they can do the test in one of five ways:

- drive-through regional testing sites
- mobile testing units
- test kits delivered to their home
- hospital-based testing for NHS patients and staff
- dedicated testing centres in other care settings (for example, care homes)

The existence of multiple test providers has the advantage of improving access, but it also creates major challenges for coordination and, in particular, information flow. Accounts in the media indicate that these challenges are far from being resolved.

Our approach is based on systems theory. We have tried to identify the many subsystems that must be working for a broader FTTIS system to work as well as possible. Some of these subsystems are inside the health system and others outside it, each involved in transformations, for example the collection, processing, and transmission of information to other systems. This approach is well established at informing, for instance, population cancer screening programmes.

Key components are as follows, and summarised in Figure 1.

Figure 1. Key aspects of FTTIS

COVID 19 Find, Test, Trace, Isolate and Support (FTTIS)

Time is of the essence – contacts need to be traced and asked to isolate within 4 days of an infected person getting symptoms.

Find

- About 2 in 5 people infected with COVID19 never get symptoms.
- FTTIS relies on finding as many people with symptoms as possible.
- It needs a strong public information campaign to inform people of:
  - the symptoms of COVID19
  - the need to get tested
  - how to get tested.

Test

- It must be easy for people to get a test including:
  - those who are frail or lack mobility
  - non English speakers
  - those without internet
- People tend not to ask for a test until day 2 at least of symptoms
- Test results need to be available within 24 hours

Trace

- 80% of contacts need to be traced and very quickly
- People won't provide contacts unless they trust the system and understand the need.
- Contact tracing works best if delivered by trained personnel within local communities

Isolate

- **The main way that FTTIS suppresses COVID19 is through isolating the contacts of infected people**
- There needs to be strong public information about the need for isolation of contacts

Support

- Support for isolation should be provided :
  - financial support to compensate lost income
  - support for obtaining groceries etc.
  - accommodation for those who cannot isolate in current residence
  - follow up to check symptoms and wellbeing

2.1 Population awareness of, and access to FTTIS

A FTTIS system will only work if people are aware of it, including its purpose, its importance, its implications for them, and how and in what circumstances they should access it. This needs to be carefully managed, with someone responsible for framing the narrative around the system and communicating it, recognising the importance of reaching everyone, with a particular focus on overcoming language and literacy barriers. FTTIS will only work if those who are aware of the need to take action on developing symptoms are able to do so, taking account of differential access to telephones, the Internet, as well as the incentives for those in certain circumstances, such as the gig economy, to avoid providing this information. At present, in England, this is provided by the call centres that are at the core of the current Test and Trace programme. A more detailed description of requirements for acceptability, engagement and support are provided in Section 3.

2.2 Access to testing

The purpose is to rapidly identify infected individuals such that their contacts can be isolated before they infect others. With a requirement for a 24-hour turnaround from sampling to test result precipitating contact tracing, the system must be efficient. This is even more so with the decision to only test symptomatic cases (estimated at 60% of all infections), as opposed to widespread testing of all. Nevertheless, this is a major logistic and distributional challenge. Many people may be unable to access drive through testing sites and may face postal delays. It is therefore self-evident that a FTTIS system can only function if there is a process in place to conduct testing at scale and pace. There are, however, many concerns about this component in England, including delays in reporting test results, a multiplicity of organisations with poor communication among them, and lack of training among those managing the testing centres. There are particular concerns about the quality of samples taken at home or in drive-through centres.

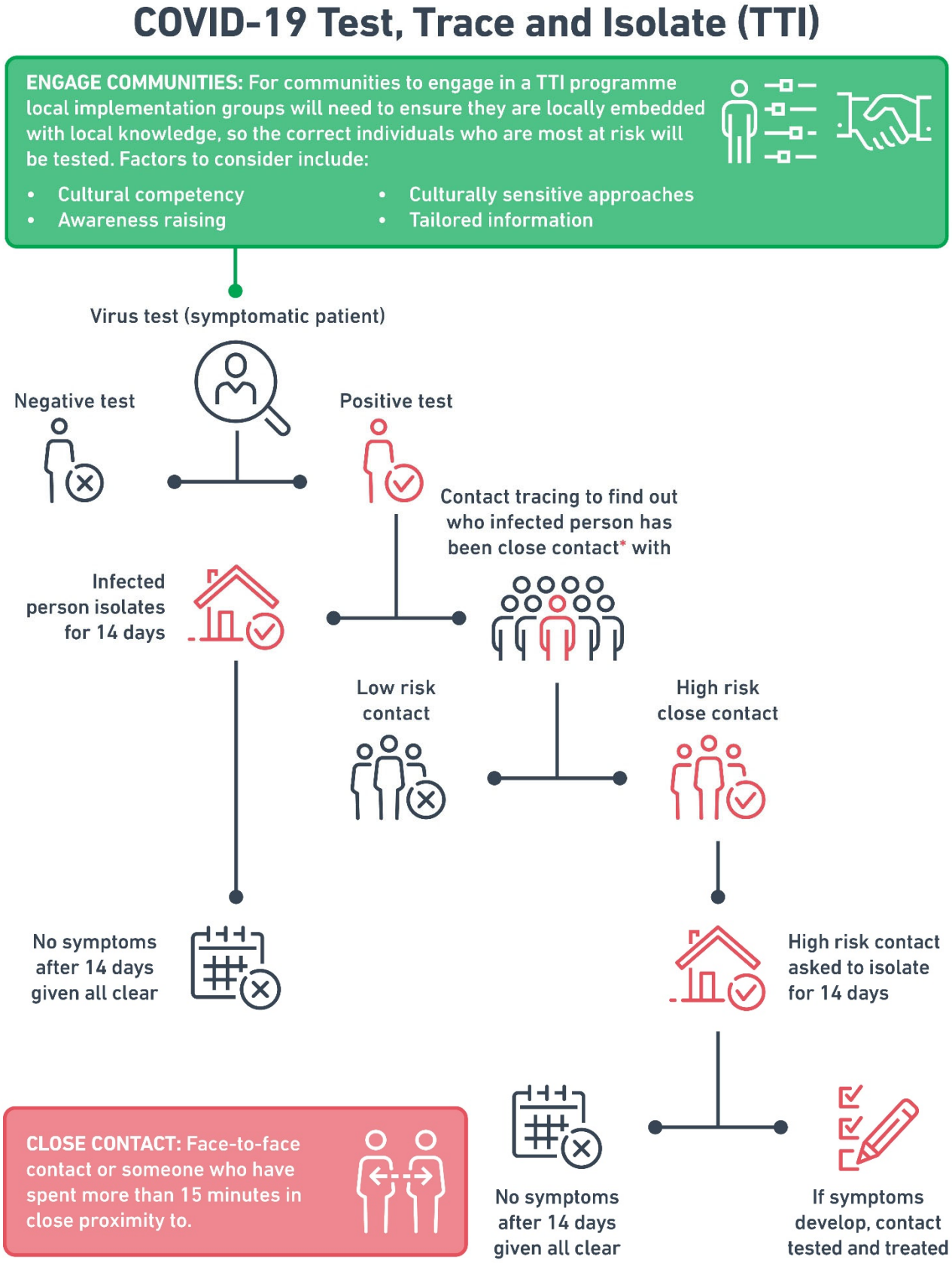
This has been addressed in other countries by the widespread availability of tests in pharmacies, local health centres and other community settings.

2.3 Contact tracing

Once someone has been identified as having COVID-19 or is suspected as such, the system must contact them to advise them to isolate. Unlike in many other countries, the four countries of the UK have opted for centralised systems, based on call centres. Normally, this would be undertaken by local public health teams, for example in the event of an outbreak of meningitis in a school. The centralised system, in England at least, is untested and is being operated by companies with no previous experience in this area, albeit with input from trained public health staff. Baroness Harding, who is responsible for this subsystem, has told the House of Commons Health and Social Care Committee that it is unlikely to be fully operational until September. In the absence of any detailed information on how it is operating, and despite detailed but unsuccessful questioning by the parliamentary Committee, we can only judge based on the growing number of accounts in the media which suggest significant and persisting problems in getting the system to work. The effective operation of this subsystem is also complicated by the apparent failure of the app that was designed to facilitate identification of contacts of those who have COVID-19. When it was planned, it was hailed by ministers as being essential. Now it is described as of marginal importance. Importantly, this is one of the many areas where the UK went its own way, taking an approach that was very different from other countries.

How contact tracing and isolation sits within an FTTIS system is shown below in Figure 2.

Figure 2. How contact tracing and isolation fits within FTTIS



2.4 Data analysis and dissemination

Once test results are obtained and contacts traced, it is necessary to have a system that can synthesise the emerging data, providing geographical identifiers for each case, which can then be provided in real time to local authority directors of public health and primary care teams. Again, detailed information from evaluations is not publicly available, but there are numerous accounts in the media which suggest that there are significant failures in communication, in particular the lack of sufficient information collected at the drive-through centres. Critically, many samples currently tested at Lighthouse Laboratories are not yet linked to NHS number, and results are therefore not accessible to GP's. GPs provide first level care for COVID-19 patients so this is a critical failure.

2.5 Local Authority Powers

As the problems with the Test and Trace system, as originally designed, have become apparent, there has been, at last, a recognition of the crucial role that local public health and health protection teams should play in a full FTTIS system. However, there have clearly been problems in communicating their responsibilities to them. Additional funding has been made available but there seem to be major challenges in distributing the funds effectively. That said, if the information that is collected is to be acted on, it is essential that those responsible for public health at a local level, which in this case is a local authority, must have the power to act. Although the government did move rapidly to enact an emergency Coronavirus Act, this does not provide local authorities with significant additional powers. Rather, it removes many of their responsibilities to act in particular circumstances, presumably in recognition of the many pressures they face at this challenging time. In other countries, local government bodies would normally have the power to impose temporary restrictions on movement or on opening of facilities. For the system to be operational, we need a rapid assessment of the powers of local authorities, and where necessary emergency legislation.

2.6 Oversight

A system of oversight is needed to ensure that the different elements of the system are working together as well as possible to achieve an FTTIS system that can suppress further growth of the pandemic as lockdown is eased. Put simply, someone must be in charge of the entire FTTIS system, with clearly defined lines of accountability. While many individuals and organisations have responsibility for the subsystems listed above, other than the Prime Minister, who is ultimately responsible for everything undertaken by his government, and who can reasonably argue that he has many other priorities, **it is not clear who else is in charge**. Whoever is in charge of oversight of the FTTIS should be supported by a programme of continuing evaluation and, where necessary, rapid targeted research, to understand why problems are arising.

2.7 Responsibility and accountability

FTTIS transcends all levels of society, from individuals and families to central government. Each has a part to play. However, given the importance of local knowledge and engagement, ***we recommend that all issues should be dealt with at the most local level that is consistent with their resolution***. In England, the upper tier local authorities must play a key role. Appendix 6 sets out what this might look like, describing the agencies involved and their responsibilities and lines of accountability.

3. Building acceptability, engagement and support

Although the FTTIS system has the potential to prevent a second wave and lock-down, as demonstrated in other countries, the system being developed has attracted a range of concerns from diverse communities and voices. Six areas of concern are:

3.1 Knowledge

Surveys show that many people are not aware of the key symptoms nor that they should get a test and self-isolate if symptomatic.

3.2 Trust

With a background of the public's decreasing confidence in the Government's management of the pandemic, trust in the current Test and Trace system is variable and challenged by:

- Inaccuracy of the test, with an estimated 20-30% false negative rate and an estimated 20% of those testing positive not actually having the infection. The latter means that many people will be asked to isolate, possibly on more than one occasion, when not infected.
- Concerns about confidentiality and security of the data, especially given data are held centrally and data breaches have occurred, including sending personal details to private companies. These concerns are especially the case for the smartphone app component of the system which uses Bluetooth technology to share data across phones and has been developed and will be implemented by a private provider. There is a concern that there may be fraudulent use of the system given it is not being carried out by local, familiar and trusted services.
- Government reporting of test data is inadequate according to the UK Statistics Authority and no clear monitoring and evaluation strategy is evident.
- No public consultation or community engagement in the development of Test and Trace, with delivery by private companies with mixed track-records.

3.3 Financial insecurity and inability to isolate

Those isolating face many challenges, including obtaining essential supplies like food and medicines. They may lose their income and need other forms of financial and non-financial support. Those suffering from mental or physical disease may face difficulties in obtaining care and the process of isolation can have profound implications for those with mental health problems, as well as other vulnerable groups such as those experiencing domestic abuse. We need a subsystem that can provide appropriate support for people in isolation. We recommend that **a strategy should be developed to ensure that those in isolation receive appropriate and acceptable support, recognising that this will require inputs from many different agencies**

3.4 Delivery by minimally trained, unfamiliar personnel

Evidence suggests better engagement and adherence if those with symptoms and contacts speak to local, familiar, trusted people e.g. GPs, health visitors or other health professionals, rather than to someone in a distant call-centre.

3.5 Reluctance to isolate

Surveys have shown that adherence to Government guidelines has decreased, with most people by the end of May reporting leaving home when they have symptoms. Without incentives, or at least being supported financially and in terms of accommodation, rates of isolation are likely to be less than that required.

3.6 Reluctance to report contacts

In addition to the challenges above, people are likely to be less willing to share contacts who face problems with authorities e.g. employment, housing or immigration issues. Another issue may be pressure from employers not to disclose contacts. Several organisations, including care homes, have reportedly asked staff not to participate as many staff taking time off work at the same time would be problematic.

4. Quality assurance

A system is needed to ensure the quality of the testing programme, including technical aspects including the quality of taking samples, the performance of the tests, the speed of response, and the acceptability to those being tested. This should consider not just the aggregate figures but also the extent to which measures of quality vary for groups within the population. For example, does the organisation of the testing system disadvantaged certain groups, such as those who do not have English as a first language or who live in remote rural areas? To this end ***we recommend that a set of key performance indicators should be reported weekly, including data that are timely, relevant, and useful to key stakeholders, at a sufficient level of detail to support local decision-making.***

We propose a set of key indicators for which data is needed so that it can be determined if a FTTIS system is capable of identifying and isolating contacts within 48 hours:

- What percentage of tests are done and result returned within 24h?
- What percentage of people with a positive test are successfully contacted within 24h to find contacts?
- What percentage of people share their close contacts with the call centre?
- What percentage of named contacts are contacted within the next 24 hours?
- What percentage of contacts comply with isolation?

These key indicators should be complemented with regular exercises to collect and report on the following questions:

- What percent of tests are completed in NHS labs, PHE labs, Deloitte commercial tests, or other scientific laboratories?
- If someone with symptoms has a test that is negative and symptoms persist, how quickly do they receive another test?
- How are the results of the tests communicated with the patients GP? Who else has access to the data?
- How are participants guaranteed that calls are genuine?
- Are GPs and local authority public health directors empowered and resourced to set up a test and trace hub in every primary care network?

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