

## **SPI-B Summary: Key behavioural issues relevant to test, trace, track and isolate**

The points below are based on rapid review and discussion of relevant theory and evidence. We *strongly recommend monitoring and rapid research into adherence rates to all key behaviours and how to improve them*, noting that based on DHSC tracker only around 50% of people are currently reporting self-isolating for at least 7 days when symptomatic with cough or fever.

Engagement with symptom reporting and contact tracing will be reduced/increased by:

1. Uncertainty about whether to report symptoms

– *very clear triaging with distinctive symptom profile and clear messaging about when and how to report symptoms*

2. Low perceived risk of coronavirus infection in self and contacts

– *emphasise social value of testing process as crucial to safely ending lockdown, emphasise testing personally valuable to find out whether infectious now and unlikely to be infectious in future (if true)*

3. Concern about consequences of triggering self-isolation for self/others

– *financially recompense all days' work missed due to reported symptoms, emphasise reduces risk of much longer/wider lockdown*

4. Concern about consequences of disclosing contacts

– *allow/communicate a) control over disclosure process, b) strict safeguards in use of, access to, and disposal of disclosure data, c) using transparent and clear messaging*

Engagement with self-isolation following testing/tracing will be reduced/increased by:

1. Awareness that most periods of self-isolation will not be due to a genuine case of coronavirus

– *emphasise social value/necessity of all self-isolating when possible risk as crucial to safely ending much longer/wider lockdown, minimise risk and impact of false alerts (by specific symptom criteria, rapid confirmatory testing, accurate phone tracking, tailoring of strength of self-isolation messages based on level of risk, e.g. contact proximity/duration, pre/post confirmation of infection by testing)*

2. Practical and psychological barriers to self-isolation

– *minimise period of quarantine as far as possible, financially recompense all days' work missed, emphasise social value of self-isolating*

*Note that it will be especially important that engagement is good among those engaging in higher risk activities (e.g. with many contacts) or are in contact with people at higher risk – these groups are likely to adhere well if their greater need is communicated to them.*

The issues above are relevant to phone-based and manual methods. We understand the advantages of phone-based methods in terms of speed and automaticity, but we note low phone-based use in many other countries and anticipate major behavioural barriers to it being used widely enough in the UK to be used as the primary method, as follows:

- Technological and practical barriers – unable to use the technology (especially older people), unsuitable phones, not turning on bluetooth, not carrying phone at all times
- Trust barriers - unwilling to be automatically tracked, concerns about data use, lower trust in accuracy of contact detection

## Symptom-based contact tracing vs test-based approaches

Addendum. SPI-B [2 May 2020]

Following the useful discussion among the SAGE subgroup re approaches to contact tracing on 1 May, we have produced this addendum to our note of 29 April to flag two additional considerations. These relate to an approach based on the concept of a very early / immediate alert based on symptoms in the index case, which is then followed with rapid confirmation based on testing the index case.

First, very early / immediate notification to contacts based on symptoms in the index case and linked to advice to reduce or cease contact with others as far as possible would allow people to take immediate action to the extent they feel able. Some people may value this very early notification, particularly if they are in regular contact with someone who is vulnerable or if they themselves are vulnerable. Providing very early notification may also act as a motivator for some people to engage with the system (e.g. by downloading the app). This is particularly true if the results of very rapid testing of the index can then follow, resulting in either a release notice (in most cases) or stronger advice to isolate.

Second, as discussed in the subgroup, an ethical dimension also exists to this – designing a system that detects but does *not* alert people that they might have COVID-19 in a sufficiently timely manner for them to avoid passing it to others may be problematic, particularly if they have regular contact with vulnerable people. The views of an ethicist would be useful.

## What is the least-intrusive model of track-and-trace you would consider effective?

Track and Trace Security Perspectives [5 May 2020]

The following paper is based on the assumption that a track and trace approach will rely heavily on the uptake and use of an app to assist contact tracing.

### NHS app

Our comments are made on the following understanding of how the app works:

- Downloading the app is voluntary, though it is heavily promoted by government as an aid to supporting the NHS during Covid.
- Downloading the app does not require uniquely identifying information from the user, but transactions with the NHS through the app can require disclosure of part of the user's home post-code.
- Once downloaded onto a mobile phone, the app exchanges a big random number (its ID) with other phones within a 4 to 10m radius. The exchange is the event of one phone with the app coming into another's Bluetooth range.
- If the adoption of the app is low, the number of exchanges will be low, and the possibilities for contact tracing correspondingly diminished. If the uptake is high, many exchanges are potentially recorded.
- The exchanged ID data is stored on a user's phone, and not centrally. It is not correlated with GPS data or with phone owner names. If the phone user starts to experience symptoms he

or she thinks are Covid symptoms, he can decide or not to share that information with the NHS through an app.

- He/she can also decide or not to upload the stored exchanged ID data. The exchanged ID data will be used by the NHS to inform contacts of the app user that they may have been in contact with someone who has a Covid infection.
- The exchange data that is centrally stored via the app does not seem to lend itself to very intrusive analytics.
- The app may ask users to give further information if they want to, to be held centrally. The data uploaded to the app may prompt not only automated notifications but human track and trace follow-ups at the local level.

#### Key issues

- This debate has already played itself out in other countries. It is clear from other contexts that tracking and tracing has drawn public opposition where centralised contact tracing apps have been proposed. In Germany, for example, public opposition has forced the federal government to back down and permit only decentralised data storage. Decentralisation of data storage was recommended by the European Union. This seems to raise three key issues relating to the use of an App to track and trace:

1. **Legitimacy and trust of the source.**
2. **Confidentiality**
3. **Efficacy & unintended consequence.**

#### Legitimacy of the source

- It is assumed at present that the proposed method for tracking and trace will be through the app developed by the NHS, currently under trial in the Isle of Wight. The NHS benefits from high levels of public trust.
- This might lead to the perception that the app is more about health and less about an invasion of privacy and correspondingly greater uptake. The more one can rely on this sense of legitimacy and trust, the less need there is for more intrusive interventions.

#### Confidentiality

- There is a key proportionality argument here. Gathering and storing this data is proportionate and ethical at this time of elevated threat but its long-term storage and use for other purposes may not be when that threat subsides.
- The NHS app is less intrusive than other contact tracing systems because information is anonymised. However, the public may have concerns that data provided voluntarily could allow individuals to be identified at some point in the future.
- On the surface, the voluntariness of app use lessens the force of a claim of a privacy violation. Since data is not being taken without peoples' knowledge, and since they can opt out at any time, privacy in the sense of "control" of data seems assured.
- But is the voluntariness of app use properly informed by an understanding of what the app does? For example, it uses an algorithm to risk-rate data about symptoms from reporters. Most app users will not understand this, or its implications.<sup>1</sup>

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<sup>1</sup> Ibid. 22; "This data is analysed by a risk-scoring algorithm according to certain parameters (such as length of contact and number of contacts with persons reported to be infected with the virus, on the

- Future epidemiological analysis would positively benefit from centralised data would enable public health authorities to identify epidemiological trends and hotspots.
- But the NHS app is liable to be mistrusted because *any* centralised data storage, even storage of highly schematic contact behaviour, is sometimes represented by privacy campaigners as another step toward a surveillance state. However weak the comparison may be between a particular phone's Covid contact data and communications data used in controversial counter-terrorism analytics, the impression of a close analogy may catch on with the public. This has led to calls for an app that never uploads data to a central data base (i.e. a decentralised system).
- Concerns over privacy could generate conspiracy theories which could, if actively propagated by hostile media platforms, result in a loss of public confidence, particularly in certain communities.

#### Efficacy & unintended consequence

- The efficacy of the NHS app is limited by the fact that downloading is voluntary and that reporting of symptoms is voluntary for those who download it.
- People may download the app simply to protect themselves by monitoring the threat posed by others but not reporting the threat they themselves might pose.
- ID data seems to be held on individual app users' phones in a privacy-protected form.<sup>2</sup>
- Although the cybersecurity of the app has been scrutinised by the NCSC, the human tracing process that might start from app data allows for health data to escape by word of mouth and other means associated with insider threat (see below).
- The UK design apparently allows for multiple phones to be used by a single person for contact-tracing. It is possible that malicious actors could try to taint data by introducing false symptom reporting.
- Those who possess the app may be able to identify others posing a risk (e.g. neighbours), leading to violations of privacy and possible stigmatisation.
- It is assumed that it is voluntary but organisations may start to use it to police entry to public spaces. For example, a business that has managed re-open could be badly damaged by allowing entry to someone who may be symptomatic (because everyone else in that public space may also be notified). This may lead to a situation where you are required to have the app and show that you are 'negative' before being allowed to enter that space. By default, it becomes an immunity passport.
- From an external security perspective, Russia will scrutinise all Western responses to Covid-19 as a significant intelligence gathering opportunity. Responses to CV19 allow it to monitor different countries' response measures, timings and effectiveness in a wartime-like scenario. In particular they will examine planning and capabilities in response to a civil contingency/ peacetime threat. There will consequently be interest in how effectively the UK can mount a contact tracing campaign as well as attempts to exploit whatever deficiencies or public concerns there may be with it.

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basis of either self-reported or verified testing data) to determine whether a user or public health authorities should be alerted about potential contact and what action should then be taken.”

<sup>2</sup> See Ada Lovelace Institute (2020), 24: *Exiting via the App Store* Ibid. 24 <https://www.adalovelaceinstitute.org/wp-content/uploads/2020/04/Ada-Lovelace-Institute-Rapid-Evidence-Review-Exit-through-the-App-Store-April-2020-2.pdf> “Some Bluetooth-based digital contact tracing apps only collect an anonymised, constantly changing ID created by other devices running an app based on the same protocol. The different protocols use differing methods to create these IDs based on a balance of public health and privacy needs.”

### Telephone contact tracing

- An adjunct/alternative is using conventional methods of contact tracing – as in the Republic of Ireland. This may prove to be more effective than the NHS app. At the very least, it is likely to be required as an adjunct to such an app because some of the UK population do not have smartphones or would be unwilling to use the app because of privacy concerns or scepticism over its efficacy.
- The conventional contract tracing method is of proven efficacy and requires little explanation. It is, however, more intrusive than the app because it requires named individuals who have reported symptoms, or who have tested positive, to name contacts who will in turn be contacted. Some individuals may be reluctant to disclose this information, for a variety of reasons. Although most people would simply find providing this information uncomfortable, certain communities may regard such enquiries as sinister; i.e. as having ulterior motives, e.g. detecting illegal immigrants, information on OCG networks and associates in extremist groups. Some may launch social media campaigns or otherwise spread rumours undermining contact tracing for these reasons or simply to exploit public unease over privacy issues.

### Insights from qualitative research on contact tracing [30 April 2020]

In high-income countries, contact tracing is used in the investigation of ‘unexpected’ outbreaks of infectious disease and is undertaken by public health departments. Contact tracing is also often used in the management and treatment of sexually transmitted infections (STIs). Both situations can offer insights into ‘test and track’ for coronavirus.

The points below offer a set of considerations for how test and track strategies may be perceived as intrusive, and how perceptions of intrusiveness might be counteracted in programme design and messaging. These will apply whether test and track is undertaken using a technological solution (and in some cases, particularly where test and track is undertaken using e.g. an app) or whether test and track is undertaken using traditional methods.

**Contact tracing can be perceived as intrusive in several respects.** A common theme across qualitative research is that contact tracing is intrusive because of what it ‘reveals’, in terms of behaviour or in terms of identity characteristics, about people whose contacts are traced.(1-3) In the context of coronavirus, this may include fear of perception by others of irresponsible behaviour, or of lack of adherence to social distancing and other regulations, with the potential for corresponding social sanction.

Contact tracing is also viewed as intrusive because of the stigma attached to disease generally. For example, tuberculosis stigma has been cited as a barrier to complete contact tracing in low-incidence countries.(4) Test and track strategies will need to counteract disease-related stigma, possibly by a combination of programme messaging and programme design.

Another facet of contact tracing that increases the perception of intrusion relates to who notifies contacts. This is, in actuality, two facets: who has access to information on contacts and how contacts are notified.

- Who has access to contact information is both a question of data security and a question of individuals’ perceptions of privacy.(3, 5, 6)

- What is done with that information is also important. There is some qualitative evidence that giving people the option to notify contacts themselves vs having someone else, or an app, undertake this task increases cooperation and decreases the perception of intrusiveness.(3, 7-9) This may or may not be possible with an app-based contact tracing method, but may be of use with respect to specific social settings and exposure contexts, e.g. households.
- Relatedly, there is some evidence from contact tracing for STIs via geosocial networking apps that automatic notification may be preferred for casual partners, whereas contact notification for more proximal relationships is still preferred.(10)

Another way to understand the intrusiveness of contact tracing is with regard to its implications for relationships. That is, another way in which contact tracing is viewed as being intrusive is because it interferes with a range of relationships in all aspects of a person's life, whether domestic, socio-sexual, professional or otherwise.(11, 12) It is not immediately clear that anonymity of contact tracing is a panacea for this,(13) though it may increase acceptability.(14) Test and track programmes will need to be designed with consideration to how individuals will perceive their relationships to be affected by a positive test or positive screen.

Finally the intrusiveness of contact tracing also needs to be understood in relation to individual vulnerabilities. For example, intimate partner violence complicates contact tracing in STIs, given the increased risk victims of violence experience both for STIs and for repeat violence after diagnosis.(15) This dovetails with the need for confidentiality from any test and track strategy.

**However, several factors appear to consistently counteract perceptions of intrusiveness.** First, contact tracing is viewed as more acceptable when framed in terms of an appeal to duty;(6, 10, 16) for example, that contact tracing is 'the right thing to do'.(17) This appeal to duty can also intersect with the perception that when in doubt, it is better to know one way or the other.(18) In the context of a national epidemic, appeals to duty can include responsibilities to family, community and nation, as highlighted in previous SPI-B guidance. It will be important as well from an ethical perspective as well to consider the perception of coercion in relation to patients' participation in contact tracing.(11)

Contact tracing is also viewed as more acceptable against a background of high levels of trust in an individualised provider.(19, 20) Personalising that provider as, for example, a health visitor or other public health clinician can also increase confidence and acceptability of contact tracing,(3, 9) even where contact tracing is undertaken using a technological solution. In designing a test and track programme, it may be appropriate to capitalise on trust in the NHS and in local health personnel.

Finally, contact tracing is viewed as less intrusive and more acceptable when there is a clear and concrete understanding on the part of patients of what will happen as a result of the process.(3, 11, 12) This is important not just in respect of how the programme will function nationally, but also in terms of what will happen to patients who 'begin the process', including who will have their information and what they can expect to happen.

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