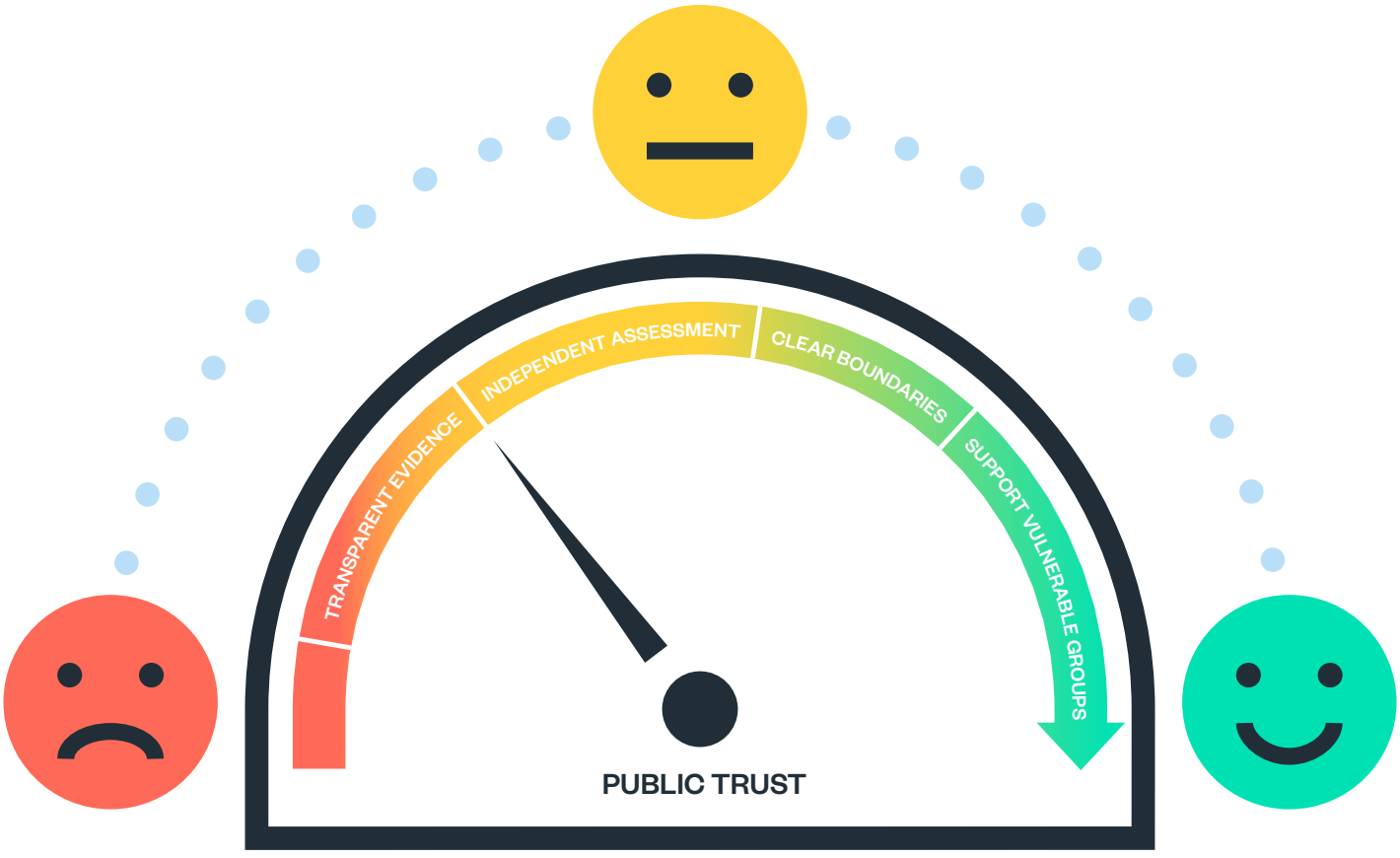
Ada Lovelace Institute

TRAVERSE

Confidence in a crisis?

Building public trust in a contact tracing app

August 2020



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Executive summary

In May 2020, the Ada Lovelace Institute, Traverse, Involve and Bang the Table convened a rapid online discussion with 28 members of the public – the 'Lockdown Debate' – to explore attitudes to the use of COVID-19 related technologies for transitioning out of lockdown.

The project was deliberative, bringing together participants from a range of backgrounds. It provided participants with a space to discuss and understand different viewpoints, to learn about the subject matter and to reflect on a variety of views as they formed their own opinions.

The core question posed to the cohort was:

> **'Under what circumstances do citizens think that technological solutions like the COVID-19 contact tracing app are appropriate?'**

Over three weeks the participants assessed the evidence and debated and deliberated on the requirements that would make a Government contact tracing app trusted and justified. Views evolved alongside the changing picture of the spread of the pandemic and the Government response.

The deliberation took place at a unique moment – opening as the Government announced the trial of a contact tracing app on the Isle of Wight, running across the 'Barnard Castle' visit, and concluding as the death of George Floyd sparked global protests against racial injustice and evidence emerged of the disproportionate impact of the virus on Black, Asian and minority ethnic communities.

Yet the four strong steers from this mini public on how to build COVID-19 technologies with legitimacy, listed on the following page, remain pertinent to current concerns.

1

Provide the public with a transparent evidence base. A lack of transparency, particularly the limited information about the first Isle of Wight trial, generated suspicion and distrust. The public would like to see clear and accessible evidence on whether technologies are effective, and under what conditions. People want to have confidence that lives would be saved and expect easily accessible information about aspects like the evolving health context or relationships with commercial providers.

2

Offer independent assessment and review of the technology. The question of who is making judgements is important to the public, and trust in decision-makers can be fragile. Trust can be strengthened with the inclusion of independent reviewers, assessors and evaluators to shape the development of the technology.

3

Clarify boundaries on data use, rights and responsibilities. Wanting independent oversight doesn't negate the desire for clarity on users' data rights. It must be easy to know and clearly justify what data would be held, by whom, for what purpose, and for how long.

4

Proactively address the needs of, and risks relating to, vulnerable groups. Support must be built in for people who may have additional vulnerabilities or be rendered vulnerable as a result of the pandemic. A public health technology must enable equal access and equal distribution of benefits; protect against the surveillance, or profiling of, different demographic groups; and ensure that new tools like immunity certificates do not become a gateway to privileges.

We publish these findings at a crucial junction for the next iteration of the NHS contact tracing app, as the Government begins the next pilot of the app.[1] Since the conclusion of this period of deliberation, the Government's technical approach has shifted – namely the decision to discontinue the original centralised NHSX app in favour of an app developed using Google and Apple's 'decentralised' exposure notification API. While this overcomes some technical issues, particularly registering iPhones that have the app running in the background, it also complicates the ability to accurately measure distance – a key issue that the NHSX team has been working on and will be testing in the pilot.[2]

The function of the app is also evolving, with the Government more firmly integrating the app into the Test and Trace programme, and including in the first pilot features such as the ability to warn of local risk levels, scan QR (quick response) codes at venues people visit and order tests. Future versions may allow people to enter personal information to create an individual risk score, which could combine personal information with the Bluetooth measures of proximity.[3]

Whatever functionality is adopted, the effectiveness of a contact tracing app, or other technologies, relies on mass adoption. This will require public trust and buy in for the decisions made around the app, and the system it is part of. Having already had one false start, it is important that the next phase is done carefully and thoughtfully. Ignoring the public and getting this next stage wrong may do greater damage than one failed app. It risks undermining trust in the public health strategy and the Government's management of the crisis.

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1 Department of Health & Social Care (2020) *Breaking chains of COVID-19 transmission to help people return to more normal lives: developing the NHS Test and Trace service*, GOV.UK. Available at: https://www.gov.uk/government/publications/developing-nhs-test-and-trace-business-plan/breaking-chains-of-covid-19-transmission-to-help-people-return-to-more-normal-lives-developing-the-nhs-test-and-trace-service (Accessed: 12 August 2020).

2 Kelion, L. (2020) 'UK virus-tracing app switches to Apple-Google model', *BBC News*, 18 June. Available at: https://www.bbc.com/news/technology-53095336 (Accessed: 12 August 2020).

3 Department of Health & Social Care (2020) *The NHS Test and Trace App (early adopter trial, August 2020): data protection impact assessment*, GOV.UK. Available at: https://www.gov.uk/government/publications/nhs-test-and-trace-app-privacy-information/the-nhs-test-and-trace-app-early-adopter-trial-august-2020-data-protection-impact-assessment (Accessed: 14 August 2020).

> **I don't understand how the population is going to download and trust an app when they don't even listen to or trust the Government and adhere to the rules of lockdown?**
> **Project participant**

At this crucial moment pre-roll out, drawing from the findings of this deliberation, as well as supporting research, we have developed a checklist for the Government, policymakers and tech developers grappling with this tricky next phase. This will help design and deliver COVID-19 technologies with public legitimacy built in.

Provide the public with a transparent evidence base

1. **Articulate the purpose of any technology.** If the technology is for public health, ensure public health experts have defined its purpose. Clearly communicate that purpose and protect against scope creep or add-ons.

2. **Publish the evidence that the technology achieves its stated purpose**. Outline the evidence (or research underway) and measures of success used to assess whether it is achieving that purpose. Ensure trials are not limited to technical accuracy or usability, but include impacts on social behaviour and health outcomes. Undertake and publish ongoing monitoring of the value of any app, for example by surveying those requesting tests as the result of an app alert, as opposed to manual contact tracing measures or due to exhibiting symptoms.

3. **Publish more and publish sooner**. Transparency should be the default setting for any information that is being collected. Be upfront and forthcoming about the app, from data and design choices to third-party agreements. Publish key documents like Data Protection Impact Assessments (DPIAs). Be open about uptake numbers and local figures where possible. Limited or drip-fed information breeds mistrust, which may be unfounded and is hard to unpick.

Offer independent assessment and review of the technology

4. **Set up an independent Group of Advisors on Technology in Emergencies (GATE)** with the remit to examine the evidence base for their use, assess and advise on their likely impact, weigh the social issues raised by the technologies and conduct a balanced cost-benefit analysis.

5. **Reinstall an Ethics Board with a wide remit and diverse voices.** Ensure it has 'teeth' to shape, stop or critique roll out, and a wide remit including efficacy, value and data practices.

Clarify boundaries on data use, rights and responsibilities

6. **Empower users**. Give users the right to know (and reject) the groups they've been categorised into and offer avenues for individuals to challenge incorrect data or erroneous outcomes and seek redress.

7. **Outline data practices upfront.** Data practices must be clearly communicated, justified and minimised. Put in place measures to enable data deletion and clearly state terms of retention of data and reasons for them.

Proactively address the needs of, and risks relating to, vulnerable groups

8. **Acknowledge and address potential social risks, particularly to the most vulnerable groups, head on.** Consider the wider social context the app will be deployed into, from access to smartphones, to the financial ability to self-isolate, and establish ongoing monitoring of social impacts. Plan for future scenarios and review risks of exclusion and potential harms so mitigation measures can be designed in from the start.

9. **Build technology alongside policy and law.** Tools will be judged as part of the system they are embedded into – the whole system must be trustworthy not just the technology. Build legal protections to give ironclad confidence that tools will not be misused by rogue employers, or allow scope creep from Government overreach (in policing or migration, for example). Ensure the policy mechanisms are in place to support use and adherence (employment protection or wage replacement if people are recommended to isolate, for example) to protect against further divergence in public health outcomes between rich and poor.

10. **Be conscious about the values being built into the technology.** The introduction of technology will shift the social-political fabric of society during a crisis and potentially beyond. Tech cannot be decoupled or isolated from the society it shapes. Measures that might undermine solidarity – like individualised risk scoring or immunity certification – should be taken with extreme caution.

Introduction

This report summarises the findings from the 'Lockdown Debate', run jointly by the Ada Lovelace Institute, Traverse, Involve and Bang the Table. The project aimed to prototype and learn from a new approach to online deliberation, in a context where traditional approaches to public deliberation through 'face-to-face' mini publics were not feasible.[4]

The process took place rapidly over a three-week period, in May and June 2020, and focused on what the public thinks and feels about the use of technologies designed to facilitate the UK's exit strategy from the COVID-19 lockdown.

This project was designed to be:

- **Deliberative:** enabling in-depth debate and consideration of evidence
- **Demographically diverse:** including people from a variety of backgrounds with a range of prior understanding of the topic under discussion.

For more on the design and methodology of this process, please see a separate report, also jointly authored with Traverse, available here.[5,6]

The rapidly evolving policy context

The project ran during the course of a rapidly evolving policy landscape, and a mainstream news cycle about the UK Government's proposed digital contact tracing app, envisaged to be designed and delivered by the NHS as a centralised app.

At the start of the process, the UK Government announced it would be trialling the app on the Isle of Wight. The model trialled was different to the one adopted by other countries in Europe, which were relying on a decentralised protocol developed in collaboration with Google and Apple – a model that the UK has since adopted.[7]

Midway through the process, the revelation that Dominic Cummings, Chief Advisor to Prime Minister Boris Johnson, had breached lockdown rules to travel to Durham emerged, causing considerable media controversy.

4 The process was facilitated and convened in real time. It was supported by a team of facilitators, notetakers and operational (IT) staff. Participants also contributed to an online platform that was not real time, Engagement HQ (an interactive microsite), reading information, and responding to questions and prompts for their own lived experiences.

5 Traverse, Ada Lovelace Institute, et al. (2020) Leaving Lockdown Public Debate. Available at: https://traverse.ltd/application/files/6715/9290/3370/Lockdown_Debate_methodology.pdf (Accessed: 12 August 2020).

6 All quotes featured in this report are anonymised quotes from project participants.

7 Department of Health & Social Care (2020) *Next phase of NHS coronavirus (COVID-19) app announced*, GOV.UK. Available at: https://www.gov.uk/government/news/next-phase-of-nhs-coronavirus-covid-19-app-announced (Accessed: 14 August 2020).

Towards the end of the process, the death of George Floyd sparked broader discussion about how best to build a sense of social solidarity across the nation, as well as acknowledging the challenges of systemic racial inequality. At the same time, evidence emerged that COVID-19 was having a disproportionate impact on Black, Asian and minority ethnic communities.[8]

When the deliberation concluded, the UK Government had not made any decision about whether to proceed with the development of the contact tracing app.

Participants engaged with the full range of COVID-19 technologies that governments across the world are developing to help deliver their 'exit strategies' from the COVID-19 crisis, such as symptom trackers, digital contact tracing apps, and public health identity systems, as well as broader data collection and data sharing infrastructures (such as the NHS DataStore). As the deliberation progressed, the discussion naturally centred on the UK's digital contact tracing app (being piloted in the Isle of Wight at the time).

It was amid this rapidly changing policy environment in the UK that the participants explored the following:

- the **values** that they felt should inform the development, design and implementation of COVID-19 technologies
- the **conditions** they felt were necessary to build public confidence in the widespread use of COVID-19 exit strategy technologies
- how their own **norms and attitudes** to technology had been shaped and impacted by the COVID-19 pandemic – in particular how their experience of technologies has changed their attitudes to issues such as privacy, trust, solidarity and human rights.

Emerging from the conversations were four clear conditions for building confidence in the future development, design and use of COVID-19 technologies, which this report explores in more detail.

Under each of these, we outline specific approaches for Government, policymakers and tech developers to take, to ensure they're building COVID-19 technologies with public legitimacy.

8 Public Health England (2020) *COVID-19: understanding the impact on BAME communities,* GOV.UK. Available at: https://www.gov.uk/government/publications/covid-19-understanding-the-impact-on-bame-communities (Accessed: 12 August 2020).

What would build public confidence in the use of COVID-19 exit strategy technologies?

The participants who debated with us in this process proposed a range of values, ideas and questions about COVID-19 technologies.

Emerging from the conversations were four clear requirements for the future development, design and use of COVID-19 technologies that would help ensure public trust and buy in:

1. Provide the public with a transparent evidence base

2. Offer independent assessment and review of the technology

3. Clarify boundaries on data use, rights and responsibilities

4. Proactively address the needs of, and risks relating to, vulnerable groups

1. Provide the public with a transparent evidence base

> **I'm trying to look at the evidence now – making the choice of having the app and not putting others at risk, if it's done based on medical research not because the Government is saying it's for the good of the country.**
>
> **Research participant**

> **Is there evidence of tracing apps working successfully in other countries? I'd feel the effort and investment is more worthwhile if we have more confidence from other countries' examples.**
>
> **Research participant**

Participants strongly emphasised the importance of a transparent evidence base on the impacts COVID-19 technologies can have on the whole system and identified a range of questions the evidence might seek to answer. The questions related to considerations of:

- **Impact and effectiveness**: can lives be saved through the app? What are the measures in place to safeguard against the risk of false positives? Is there evidence from other countries as to the conditions for effectiveness?
- **Responsibility, equity, fairness and solidarity**: how many people need to use the app for it to be effective? How are people without smartphones included?
- **Data rights and privacy**: what level of data (personalised, anonymised, pseudonymised) do people need to provide for this to be effective? Who would need access to the data (Government, NHS, private companies) and for how long?

And in particular, participants wanted transparency about:

- **The situation**: sharing specific and up-to-date information about the evolving public health crisis and the context in which tech is used.
- **The nature of third-party agreements**: particularly commercial models and commercial data-sharing agreements.
- **The implications of app notifications**: what users are expected to do in response to app alerts, and the basis for those decisions.

The situation

Participants recognised that technology solutions have value in enabling the sharing of more timely, accurate information under constrained conditions, especially as many people required reassurance and greater certainty at an uncertain time.

They would like this information to include local, national and international evidence, and any evidence generated by pilots and trials of the technologies.

> 'One of the best things I looked at early on was infection by borough, that felt quite reassuring. Camden is a big place and there aren't many infections so far... It was more reassuring to know the numbers in the local area...'

They would also like to see analysis of what initiatives and interventions have been most effective globally, and the conditions that have enabled their success.

They felt that if the technology would enable them to better understand the situation around COVID-19 locally, they would be better informed and equipped to be able to take appropriate measures. However, they also acknowledged that there were potential disadvantages or unintended consequences; for instance incentivising irresponsible behaviour if the real-time reporting suggested a low incidence of COVID-19.

Third-party agreements

> 'The Government should sign a statement that clearly outlines the benefits tech companies are getting from providing the app, i.e. just getting money out of providing the app.'

As part of this conversation, many participants acknowledged that these technologies may require the involvement of private-sector companies in delivery, given that the NHS or PHE have not traditionally held the technical skills and capacity to develop and deliver a technology solution. But they added that there should be clear oversight and accountability from public health authorities.

> 'Participants expressed concern about the risk of NHS exploitation by third-party organisations, particularly at a difficult and sensitive time for the organisation. Many felt that, "data should not be sold to third parties or used for commercial gain by private companies."'

Where public bodies do work with private-sector organisations, participants expect clarity and transparency about the nature of public bodies' arrangements with third parties. This was especially prominent when considering the role of large technology companies, where there would otherwise be substantial risk of power asymmetries.

In Ada's own research on public attitudes to uses of NHS data with Understanding Patient Data, we found that good governance, public accountability and transparency are core to public perceptions of fair partnerships between NHS and private actors.[9]

> 'I'm middle class, I trust the Government to a certain amount. Although if they are selling data to Amazon then less so. Selling data would be the worst thing to do. I don't think that'll happen though.'

The implications of app notifications

> 'In the context of a [digital contact tracing] app, if someone receives a notification that tells them they have been in contact with someone with COVID-19, a transparent approach means being clear on what this means.'

9 Patel, R. (2020) *The foundations of fairness for NHS health data sharing.* Available at: https://www.adalovelaceinstitute.org/the-foundations-of-fairness-for-nhs-health-data-sharing/ (Accessed: 12 August 2020).

> 'People need to know how to interpret this – what does 'being in contact' mean? What level of risk is this? What should they do in response? If people are to be told they need to stay at home, a transparent process would tell them why the data is telling them they need to stay at home.'

Contact tracing apps are designed to give users an alert or notification if someone they've been in contact with has COVID-19. To be effective, clarity is needed around what weight individuals should give to those notifications, and what steps are necessary or required of them in response – such as going into self-isolation. For this to happen, there must be transparent explanations about the rationale that has led to the notification: how exactly the app makes its decisions and what justification there is for alerts to be taken seriously.

This was identified as especially important in a context where many people felt that confusing and contradictory information, as well as outright misinformation, was prominent, creating a need for clear and authoritative information. Participants also expressed a desire for clear communication of how the technology operates as part of a wider public health strategy.

Steps to ensure public trust and buy in:

1. Articulate the purpose of any technology. If the technology is for public health, ensure public health experts have defined its purpose. Clearly communicate that purpose and protect against scope creep or add-ons.

2. Publish the evidence that the technology achieves its stated purpose. Outline the evidence (or research underway) and measures of success used to assess whether it is achieving that purpose. Ensure trials are not limited to technical accuracy or usability, but include impacts on social behaviour and health outcomes. Undertake and publish ongoing monitoring of the value of any app, for example by surveying those requesting tests as the result of an app alert, as opposed to manual contact tracing measures or due to exhibiting symptoms.

3. Publish more and publish sooner. Transparency should be the default setting for any information that is being collected. Be upfront and forthcoming about the app, from data and design choices to third-party agreements. Publish key documents like DPIAs (Data Protection Impact Assessments). Be open about uptake numbers and local figures where possible. Limited or drip-fed information breeds mistrust, which may be unfounded and is hard to unpick.

2. Offer independent review and assessment of the technology

The question of who was making judgements was an important one to participants, and trust in decision-makers could be fragile. They favoured the inclusion of independent reviewers, assessors and evaluators in helping to shape and inform the adoption of COVID-19 technologies, from design through to delivery.

Conversations led to the proposal of a range of measures in order to enable the fulfilment of this role. These included an independent ethics committee, measures that enable data audit and deletion, independent data stewardship arrangements, risk and impact assessments and cost-benefit analysis.

An independent ethics committee

Participants envisaged an independent ethics committee who would assess and advise on ethical issues raised by technologies – such as negative social impacts, legal implications or data and digital rights concerns. They felt this committee should be completely independent from political and government intervention, and informed by a range of relevant evidence and expertise on the development and design of technology.

Independent data stewardship arrangements (akin to the development of data trusts)[10]

> 'An idea of a data trust, an intermediary between us and the Government.'

The proper management of data and protection of individual's data rights is central to responsible governance of data. However, participants recognised that understanding and negotiating data rights can be complicated and off-putting, preventing people from managing their own data well. They were interested in ideas for reducing this burden on citizens.

10 Hardinges, J. (2018) 'Defining a "data trust"'. The ODI, 19 October. Available at: https://theodi.org/article/defining-a-data-trust/ (Accessed: 12 August 2020).

In conversation with specialists, they explored the idea of an independent data trust or data access architecture. This would be responsible for the trustworthy stewarding of sensitive data during the crisis response period, and act as an intermediary between the public, public bodies and commercial organisations.

Risk and impact assessments of the adoption and use of technology

> 'There is a lack of data around testing/results in different geographical areas. Has the risk increased due to lockdown restrictions? Data is not up to date which makes it hard to assess risk.'

Participants acknowledged that lack of consistent diagnostic testing data has made it difficult to assess the risks from COVID-19 and, in particular, to understand how the adoption and use of COVID-19 technologies may play a part in reducing these risks.

Participants also expected to understand how these technologies complied with, or related to the EU's data privacy regulations, including the GDPR. They expected to see an active role from regulators of the use of data, and clear standards for its use and development. (The Information Commissioner's Office has since issued specific guidance in this context).[11]

This reinforces a similar point in the Ada Lovelace Institute's *Exit Through The App Store?* report,[12] which recommends an advisory body (a Group of Advisors on Technology in Emergencies) to consider the effectiveness of any tool within the context of diagnostic testing capacity.

The report also recommends that any technical intervention should not be deployed until this group has examined the evidence base for their use, assessed their likely impact and recommended their deployment.

A balanced cost-benefit analysis

> 'Obviously the money that's gone into the app – and the way lockdown is going on at the moment – I wonder whether it's been worth it? It must have cost a lot of money.'

Participants were conscious of the fact that lockdowns present a range of social and political choices about the most effective allocation of scarce resources (financially but also opportunity costs – i.e. the cost of the loss of other alternatives). Given the likely high cost of developing an effective technology, participants identified a cost-benefit analysis as necessary.

Steps to take to ensure public trust and buy in:

1. Set up an independent Group of Advisors on Technology in Emergencies (GATE) with the remit to examine the evidence base for their use, assess and advise on their likely impact, weigh the social issues raised by the technologies and conduct a balanced cost-benefit analysis.

2. Reinstall an Ethics Board with a wide remit and diverse voices. Ensure it has 'teeth' to shape, stop or critique roll out, and a wide remit including efficacy, value and data practices.

11 ICO (2020) 'ICO COVID-19 contact tracing recommendations'. Available at: https://ico.org.uk/media/for-organisations/documents/2617676/ico-contact-tracing-recommendations.pdf (Accessed: 12 August 2020).

12 Ada Lovelace Institute (2020) *COVID-19 Rapid Evidence Review: Exit through the App Store?* Available at: https://www.adalovelaceinstitute.org/our-work/covid-19/covid-19-exit-through-the-app-store/ (Accessed: 12 August 2020).

3. Clarify boundaries on data use, rights and responsibilities

While participants expressed a desire for independent review, they also want access to clear information about their own data rights. They had specific expectations to know what data would be held about them, by whom, and for what purpose, and for how long.

Is there clarity on the purpose and nature of data collection, use and management, with an emphasis on privacy?

Participants queried whether the purpose and nature of data collection, use and management was intended to be short or long term, and whether it should be deployed and delivered locally or centrally.

Participants also sought assurances that information about them would be kept private – many expressed significant discomfort with the idea that people they inadvertently infected could access information about them, for instance, rather than just that they had been in contact with someone and needed to self isolate:

> 'The last thing you want is to start some scare mongering... for example, 'I was around someone with symptoms earlier,' and starting some kind of witch hunt.'

Others raised concerns that, even when anonymised, data is at risk of being able to re-identify individuals, and so greater caution should be exercised around longer-term approaches to data retention and storage:

> 'Using data mining methods means it can be traced back to us. Before social media it was harder, but now using multiple data sets it's possible to re-identify people.'

The nature of the institution or organisation accessing or using the data is also relevant, as well as the security measures applied to the data:

> 'The term 'anonymised' is getting thrown around. If it's replaced with encryption or keys it is pseudonymised. And that absolutely changes my view. If I am going to give my data for aggregate use... they will make sure the data is completely anonymised. If someone did this who wasn't an academic institution, I wouldn't trust them as much.'

Is the gathering of data proportionate and are there measures to enable audit and data deletion?

> 'We should be able to give that data away to help save lives and get society on track but we shouldn't take it any further than that. The bare minimum is what it should be.'

While many participants were open to the use of technology that enabled the effective delivery of the Government's loosening of lockdown restrictions, they stressed the importance of proportionality in terms of the data that they were willing to share, as well as the importance of making this trade-off temporarily – not permanently:

> 'As a society we currently need to give away a lot of access to freedoms – sharing data that we haven't had to share before for the wider good. Once this is all over, I want a guarantee that the laws are reversed. That we can 'reverse the car' and gain back those freedoms.'

> 'If it's a choice between privacy and freedom, either giving up your privacy and [the ability to] move freely or the other way around – I'm happy to give up a bit of privacy temporarily to get my life back.'

As a consequence, participants were concerned about measures that resulted in longer-term storage or gathering of personal data during the COVID-19 response.

> 'I read an article about the data being kept for twenty years. I think that's really worrying. I think there should be a time limit.'

Participants expected to see the terms of any retention of data and reasons for them, especially if personal or sensitive data. They proposed several measures that would ensure clarity that the technology would be enabled solely for the duration of the pandemic and recovery phases, or for a set number of days, e.g. 60 days.

They also sought reassurances that, if data was to be kept longer than that (for instance, in preparing for the risk of a future pandemic), there would be a clear articulation of why it was needed, and an independently reviewable basis on which any time frame might be extended:

> 'So there may initially be a time limit, but then they would need a good reason to extend data use. So what sort of process is adequate? Independent ethics committee to govern whether or not data would be allowed to be used for different purposes?'

Some expressed the view that, in thinking about data retention and storage for the longer term, it would be important for it to be anonymised:

> 'If it's anonymised then I'm more comfortable with it being held for a long time. It can be useful for planning or in the face of future emergencies. But if data is personal or medical then temporary means something different. We need to differentiate between these two types of data.'

Overall, there was consensus that the relevant technology should only collect information that was required in order to be effective – and it must be clear what the 'bare minimum' necessary data is for effective use.

While people were more likely to be comfortable with data being gathered and collected to inform people's interactions with the virus, as well as to produce research about its spread and impact, some expressed significant concerns about broader collection and use of data for purposes other than directly addressing public health concerns arising from COVID-19. Participants therefore stressed the importance of having processes in place to audit and ensure data deletion after access and use.

Does the public have the right to refuse to download an app or share data?

Despite the exceptional circumstances and the effects of the crisis, many participants highlighted that they did not think it should be mandatory to download or to use a digital contact tracing app. However they did feel that, should Government introduce one, there was a strong responsibility for UK residents to contribute to the response to COVID-19 by participating:

> 'We should all have responsibility. It would be ideal if 80% was the uptake. Unfortunately even if 80% did take it up, I think a lot of them won't do what's required for them to do. The Isle of Wight trials look like they've been a failure, the figures and trials skewed because people not living on the island also downloaded it. So sadly there's already been failings in personal responsibility.'

Others highlighted the importance of contextualising personal responsibility within the constraints of individuals' own social and economic situation; personal responsibility can be more challenging for some individuals to achieve than others, either due to socio-economic circumstances or more practical considerations:

> 'If we get a ping, we close our door for two weeks, but that depends on someone's economic situation. My neighbours have to work, and they are living in multi-occupied housing. Many people are living in cramped conditions – it's easier for some of us to follow the advice than others.'

Steps to ensure public trust and buy in:

1. Empower users. Give users the right to know (and reject) the groups they've been categorised into and offer avenues for individuals to challenge incorrect data or erroneous outcomes and seek redress.

2. Outline data practices upfront. Data practices must be clearly communicated, justified and minimised. Put in place measures to enable data deletion and clearly state terms of retention of data and reasons for them.

4. Proactively address the needs of, and risks relating to, vulnerable groups

Given the global events occurring at the same time as the deliberation, it's not surprising that equality and solidarity were front of mind, and these values were reinforced as they learned more about each other and their different circumstances.

This mini public wanted to ensure there would be support built in for people who may have additional vulnerabilities or be rendered vulnerable as a result of the pandemic. They were explicit that a public health technology must enable equal access and equal distribution of benefits; protect against the surveillance, or profiling of, different demographic groups; and ensure that new tools like immunity certificates do not become a gateway to privileges.

Support for people with additional vulnerabilities or those rendered vulnerable by the impact of the pandemic

> 'Bad would be not taking into account people's vulnerability to the virus. Young people, working from home, and tech savvy, or diabetic, older, and not working from home – different people need different levels of support. Take into account the individual. There could be different levels of vulnerability.'

Participants felt it was important to acknowledge individuals' vulnerability. They identified that vulnerability could be understood as physical vulnerability to the virus, but also highlighted the impact that the virus might have on individuals' mental health.

They understood vulnerability as broad, encompassing a range of factors, and identified the protection of those most vulnerable as a central value in governing decisions about the development of COVID-19 technology. As a consequence, they felt that the system should focus on protecting those who are most vulnerable and shared practical suggestions ranging from economic packages to support and enable people who would not otherwise be able to self-isolate, through to helplines to ensure that people can find out what an alert means for them.

Participants also recognised that the pandemic context was too complex and uncertain for a fully automated system to work in isolation. In the words of one participant, we need: 'humans in the chain to help you troubleshoot and help you complete the process'.

Ensuring equal access to the app for the equal distribution of benefits

> 'The lack of tech is affecting some people's ability to get food. 6 million people in this country can't turn on a device. 50% of that 6 million are under 65. We've been talking about the older generation but this is an issue for other groups too – accessibility is really critical.'

Participants were acutely aware that the impacts of the pandemic have not been equally felt by all. Many cited emerging evidence showing the disproportionate impact that COVID-19 was having on Black, Asian and minority ethnic individuals, as well as those from lower income households and older people, and the role of technology access in exacerbating this inequality.

Many participants were concerned that the use of an app as part of a strategy to manage the pandemic would cause further inequality. They were concerned that some people might be able to access beneficial outcomes, acknowledging that not every individual has access to a smartphone, or to all of the features of an app given accessibility constraints.

> 'People who are at the highest risk deserve to know if they are even at risk (like a pre-warning).'

Others raised concerns that the app may not be as effective as envisaged, given those affected most by COVID-19 include the elderly, who are also more likely to be digitally excluded, and migrants, who may not wish to use it because of fears about surveillance. Others acknowledged that it may not be necessary to have uptake from the entire population in order for it to work:

> 'I got a lot of comfort hearing that not everyone does have to have the app for the app to work – only a certain percentage.'

Avoiding risks from surveillance or profiling of different demographics

> 'You'd be easily characterised if you were put in a group in that way. Being a Black person in the UK, you are characterised by how the police and other people interact with you. People with a history of being targeted might have that distrust that this info won't be weaponised. It's happened before.'

Some people drew attention to the then rapidly evolving public debate about the death of George Floyd and the Black Lives Matter movement, to highlight the risks associated with gathering and misusing excessive data about, or profiling of people with a lower income, or Black, Asian and minority ethnic individuals.

Some recognised the trade-offs involved in collecting personal data like ethnic origin - enabling research to better understand inequalities versus the risk, or fears of, misuse.

Depending on the level of data accessed and made available, participants expected to have the right to know (and reject) their individual classification:

> 'I think you'd want a right to reply (or reject how you've been slotted). I would like to know how I'd been pigeonholed.'

Avoiding new tools like immunity certificates creating a gateway to privileges

> 'We need to consider whether the app will ever become a gateway to privileges? If we find that without the app we can't do certain things and become dependent on it, then maybe we want the app to be closed down sooner.'

While immunity certification was not a core part of the research question because of the lack of concrete proposals at the time of the debate, it came up in conversation. In discussion about the potential for immunity certification technology to be introduced or implemented, many participants expressed concerns about the potential that the process would become a 'gateway to privileges' and be 'contentious'. Some felt that the principle of restricting some peoples' rights based on something outside their control (immunity) was fundamentally unjust.

> 'It definitely makes me uncomfortable. Even if we did know people would have immunity for some time, a year, it doesn't seem right. A certain group of people would be allowed to enter certain places, do different things. Prejudiced.'

Others related immunity to the potential to exacerbate existing inequalities, for example by disadvantaging those who lack the means or capacity to access digital certification, or those who chose not to participate for another reason. They also raised the risks of acquiring immunity (particularly for vulnerable people), and the potential trade off between the health risks and the lifestyle benefits.

Steps to ensure public trust and buy in:

1. Acknowledge and address potential social risks, particularly to the most vulnerable groups, head on. Consider the wider social context the app will be deployed into, from access to smartphones to the financial ability to self-isolate, and establish ongoing monitoring of social impact. Plan for future scenarios and review risks of exclusion and potential harms so mitigation measures can be designed in from the start.

2. Build technology alongside policy and law. Tools will be judged as part of the system they are embedded into – the whole system must be trustworthy not just the technology. Build legal protections to give ironclad confidence that tools will not be misused by unscrupulous employers, or allow scope creep from government overreach (in policing or migration, for example). Ensure the policy mechanisms are in place to support use and adherence (employment protection or wage replacement if people are recommended to isolate, for example) to protect against further divergence in public health outcomes between rich and poor.

3. Be conscious about the values being built into the technology. The introduction of technology will shift the social-political fabric of society during a crisis and potentially beyond. Tech cannot be decoupled or isolated from the society it shapes. Measures that might undermine solidarity – like individualised risk scoring or immunity certification – should be taken with extreme caution.

Conclusion: the value of citizen science

Throughout the COVID-19 crisis the Government has committed to the importance of scientific guidance. We welcome the prominence of science and evidence, however even where there is agreement among experts, the science or technology alone cannot determine the best strategy or decide which risks to take. These remain political choices. During times of crisis, public involvement is more important than ever: the effectiveness, and perceived legitimacy, of any response or intervention will depend upon public confidence and trust.

> **The Government cannot hope to maintain trust without taking account of the widely different perspectives that the population has about these moral and ethical considerations**
>
> **Simon Burall, Involve**

Reflecting on the values, ideas, and considerations that the participants involved in this debate developed during three short weeks, the public has a high capacity for interrogating the complexity of any COVID-19 response and associated technology. The debate demonstrated that if you give groups of people time to talk to experts on an equal footing, they respond with very nuanced and contextualised opinions. The views participants shared weren't just about technology, but were also about the social, behavioural and governance systems they are embedded in.

Initially, participants struggled with the uncertainty of the subject matter. They found it difficult to say what they thought when there was so little concrete information about the virus or potential solutions.

As the deliberation got underway, however, they began to see this uncertainty as a key part of their views. Participants understood that the challenge of COVID-19 recovery is larger than its component parts, that it's difficult to consider those parts in isolation, and that the relationship between those parts can be just as important as the parts themselves. For example, people didn't feel they could judge the suitability of the contact tracing app without knowing about the testing system. Similarly, they recognised that considering the equality implications of the app meant considering the wider equality implications of COVID-19.

This wasn't a case of whataboutism – where people refuse to engage with a topic by pointing out problems – but rather a desire for a systems-based approach that embraced the complexity and uncertainty of the situation.

By the end of the process, participants were very aware of the unequal health and economic impacts of the virus and wanted any strategy to ensure that such inequalities would be addressed, rather than worsened, as part of the recovery process. They had shared their experiences and came to respect each others' perspectives. Importantly they wanted the Government to do the same.

Ultimately, an important question participants felt needed to be answered, in order to develop an effective approach to COVID-19 technology was: How do we create a sense of solidarity and unity in the nation again?

If the aim in deploying technological systems like the COVID-19 contact tracing app is well-founded public decision-making, then we need to consider the concerns of a diverse public with diverse experiences alongside the science. While there was robust discussion and differences of opinion, collectively the participants provided answers that, had they been considered earlier, would have helped avoid a public confidence crisis.

As a recent Ada Lovelace Institute report, *No Green Lights, No Red Lines*[13] demonstrates, apps will be judged as part of the social and political system they are embedded into. For public confidence and legitimacy to be created, the whole system must be trustworthy, not just the data or the technology in isolation.

The Ada Lovelace Institute, Traverse, Involve and Bang the Table encourage the UK Government to heed the wisdom of the public. During the next stages of the development of a contact tracing app, the perspectives and recommendations outlined in this report are vital to ensuring public trust and buy-in, and the ultimate successful deployment of any COVID-19 related technology.

13 Ada Lovelace Institute (2020) *No Green Lights, No Red Lines: Public perspectives on COVID-19 technologies.* July 2020. Available at: https://www.adalovelaceinstitute.org/our-work/covid-19/covid-19-report-no-green-lights-no-red-lines/

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The **Ada Lovelace Institute** is a research institute and deliberative body dedicated to ensuring that data and AI work for people and society. Our core belief is that the benefits of data and AI must be justly and equitably distributed, and must enhance individual and social wellbeing.

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Bang the Table was founded because, no matter how well-designed the offline consultation process, inevitably it only reaches a small segment of a community. Their mission is to enable public participation in democracy by forging constructive relationships between communities and the institutions of government.

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About the Ada Lovelace Institute

The Ada Lovelace Institute was established by the Nuffield Foundation in early 2018, in collaboration with the Alan Turing Institute, the Royal Society, the British Academy, the Royal Statistical Society, the Wellcome Trust, Luminate, techUK and the Nuffield Council on Bioethics.

The mission of the Ada Lovelace Institute is to ensure that data and AI work for people and society. We believe that a world where data and AI work for people and society is a world in which the opportunities, benefits and privileges generated by data and AI are justly and equitably distributed and experienced.

We recognise the power asymmetries that exist in ethical and legal debates around the development of data-driven technologies, and will represent people in those conversations. We focus not on the types of technologies we want to build, but on the types of societies we want to build.

Through research, policy and practice, we aim to ensure that the transformative power of data and AI is used and harnessed in ways that maximise social wellbeing and put technology at the service of humanity.

We are funded by the Nuffield Foundation, an independent charitable trust with a mission to advance social well-being. The Foundation funds research that informs social policy, primarily in education, welfare and justice. It also provides opportunities for young people to develop skills and confidence in STEM and research. In addition to the Ada Lovelace Institute, the Foundation is also the founder and co-funder of the Nuffield Council on Bioethics and the Nuffield Family Justice Observatory.

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