24 April 2020

Dear Secretary of State,

Key principles for an ethical and effective CV19 contact tracing app

The COVID-19 pandemic is a public health emergency on a scale that we have never experienced before. Our NHS and the many thousands of critical workers who have kept the UK running have been a source of great pride during these challenging times.

There are no easy solutions in managing this outbreak. Approximately 90% of the population are currently living in lockdown. While this approach appears to have been effective in achieving the immediate and ultimate goal of flattening the curve and saving lives, the impact on personal freedoms and mental health is considerable, and the economic consequences are severe. This makes the current situation unsustainable in the long-term. To emerge safely from lockdown with the support and confidence of the public, difficult practical and policy decisions will have to be taken and important value judgments made. This will require a careful combination of principles and pragmatism.

The establishment of the Ethics Advisory Board (EAB) signals a welcome commitment to the development and deployment of the CV19 app being open to independent scrutiny and constructive challenge. Since being established we have met weekly and in this letter we set out a series of principles to be adopted in order to ensure ethical issues posed by the development and rollout of the CV19 app are captured and addressed. We recognise that the app is one tool in a wider strategy of testing, tracking and tracing; indeed, an over reliance on a single approach would be high risk. However, the EAB's focus is on the CV19 app although we have reflected on this wider context.

It is our view that there is an ethical imperative to explore the use of technology which could be deployed to support efforts to stop the spread of COVID-19. But we also have a responsibility to address the ethical risks posed by the mass deployment of any new technologies. It is also the case that new approaches are not always the best and the fundamental effectiveness of the app is of overriding importance. Our advice, which provides our conditional support for the CV19 App, is provided on the information we have available to us at this point in time. The EAB reserves the right to provide different advice in the future.

At the heart of any sustainable removal of current measures will be the achievement of intelligent and risk-based physical distancing designed to reduce the *R* value and limit the pressure on the NHS. Such a response requires a combination of contact tracing, testing, and quarantining of those who are shown to be infected with COVID-19. The high proportion of infections originating in people who are presymptomatic means that standard approaches to contact tracing remain important but are too slow to be effective on their own. A contact tracing app has the potential to form part of the solution to this problem but, as with all innovative measures, this involves a degree of uncertainty.

A trustworthy approach is crucial to the success of a CV19 app. The government's perceived success or failure in this endeavour will have implications for future uses of data driven technology by government and public services for many years to come. Indeed, this is the time for the government to demonstrate its ability to use technology for the public good, in an ethical way, and to build strong foundations of trust.

Ongoing review of the app by the EAB will be helpful in maintaining public trust by continuing to provide essential scrutiny and constructive challenge.

In this letter we set out six principles that must be upheld to ensure the CV19 contact tracing app is ethical. Given that securing and maintaining public trust is paramount, these principles are based on a set of key components of trustworthy data use: value, security, accountability, transparency and control (see Appendix). The advice we give in this letter seeks to strengthen and protect these important principles. It is based on work originally developed by the Centre for Data Ethics and Innovation, and informed by engagement with expert stakeholders and the public, a review of briefing papers and presentations provided by NHSx, as well as reports produced by non-government organisations and academics.

Six principles to ensure that the CV19 contact tracing app is ethical:

- 1. Value: There must be good reason to believe that that the app will provide sufficient net-value back to the citizen or society as a whole so as to justify its introduction and any adverse consequences for individuals.
 - O The value proposition of the app to users should be clearly articulated. If the value proposition changes this should be communicated, and the process by which this happens should be transparent.
 - O To encourage citizens to download an app which does not offer a strong value proposition would be misleading and could damage trust, which could in turn reduce the effectiveness of the app and of future technological solutions.
 - The app should undergo an Equalities and Health Inequalities Impact Assessment to ensure that it does not have disproportionate negative impacts on certain groups.
 - O To avoid introducing unacceptable levels of inequity, access to the app should not give *exclusive* access to services or freedoms. While it is appropriate that the app offers benefits which increase its value proposition and therefore incentivise use, alternatives should be provided for those who cannot or do not wish to use the app.
- 2. **Impact:** There must be good reason to believe the app will be an effective tool in controlling the outbreak of COVID-19.
 - The app should be technically effective. It would be unethical to encourage citizens to download an app which is technically flawed.
 - The app should be sufficiently attractive to users to make it reasonable to expect that it will be downloaded by enough people to achieve public health benefits.
- 3. **Security and privacy**: Data sharing and storage should be secure. The data collected should be minimised and protected as much as possible, so users' privacy is preserved.
 - O Any use of data which compromises a user's anonymity should be done only for the protection of public health and in accordance with the law. Necessary intrusions into privacy should be proportionate to this legitimate aim. Where possible, consent should be requested.
 - A Data Protection Impact Assessment and a privacy assessment should be carried out to ensure appropriate compliance with privacy and security standards.
- 4. **Accountability**: There must be a reliable and understandable decision-making process in place to manage the app with clear democratic accountability, particularly with regards to introducing new functionality, data collection or use cases.

- O There should be ongoing evaluation of the app to monitor both its effectiveness and any risks that arise from its use. Decision points about continued use of the app also need to be made clear.
- 5. **Transparency**: Details on what data is gathered and why, as well as the app's code and underlying algorithms must be available publicly to enable scrutiny and give people the ability to object to decisions.
 - All communications made via the app, and about the app, should be transparent and proportionate. App alerts should state clearly what information they are based on.
- 6. **Control**: Users should be able to see what kinds of data are held about them so that they can understand how it is impacting on decisions.
 - O Downloading the app should be voluntary. The app should be built with a minimum data-sharing level with a series of clear opt-ins for further data sharing and use. Users should be able to delete the app and their data at any point.
 - Additional functionality would require clear communications and opt-ins for existing users.

For reasons of trust and transparency it is important that the value proposition of the app is well understood and clearly articulated at all stages of its deployment. This value proposition may evolve if circumstances change, particularly if the app becomes a key route to obtaining immunity certificates or is ever used as a means of accessing certain services or freedoms.

When it comes to the effectiveness of the app, the Board recognises the benefit of using self-reported symptoms alongside virologically confirmed cases to trigger proximity cascades. Self-reporting enables users to inform contacts relatively quickly that they may be at risk so that they can take the appropriate action. This is a cautionary approach and while it may cause disruption to people's lives, this inconvenience is a direct trade-off with the significant potential to intervene early and limit the spread of the virus that self-reporting offers.

Participants in focus groups with members of the public have, however, expressed concerns about the reliability of an app which is based *solely* on self-reporting. EAB members have voiced similar concerns and worried that false positive alerts could undermine trust in the app and cause undue stress to users. The impact of false negatives was an additional concern, particularly that users may develop a false sense of security. This possibility underlines the importance of clarity and effective communication. But we would also caution against proceeding with the app without widespread access to virological testing. It is our view that introducing widespread testing and incorporating this into the app as soon as reasonably possible would significantly increase both confidence in the app and its efficacy, as users will be more likely to follow its advice.

We also urge a consideration of the extent to which the app could introduce or exacerbate inequities. Ofcom data suggests that 21% of UK adults do not use a smartphone. While the community benefits of a contact tracing app should still extend to this group, an increase in manual contact tracing is a crucial additional measure which will enhance the effectiveness of the public health approach and build public confidence. If the app becomes a tool for accessing currently restricted services or freedoms, such as permission to return to work, to use public transport, or to enjoy other freedoms, this would drastically alter the value proposition of the app and potentially introduce new levels of inequity which would need to be identified and addressed.

We are aware that work to develop the app is progressing at pace and a first rollout is planned imminently. It is vital that the speed at which the app is, understandably, being developed does not undermine the importance of scrutiny or the need for transparency. Similarly, it is important that in the desire to maximise take-up of the app, commitments are not made to citizens which are then reversed at a later date. This would profoundly damage public trust.

The EAB has identified a number of more specific considerations designed to ensure the initial rollout is as ethical as possible. These are set out directly in the appendix attached to this letter and are framed around the principles identified above.

To build and maintain public trust, the app must continue to be developed in a way that is sensitive to ethical issues. The EAB has an important role to play by providing independent constructive challenge. As a group and as individuals, we are pleased to be able to fulfil this role and offer our continued support in doing so.

Your sincerely,

Prof Sir Jonathan Montgomery

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Chair

Ethics Advisory Board (CV19 App)

Appendix 1

Considerations for initial roll out of the CV19 contact tracing app

Value/ Impact

- 1. Before the app is launched in a small area, there must be good reason to believe that the app will be effective in bringing health benefits to individuals and the wider community, and in controlling the Covid-19 outbreak.
- 2. The value of the app should be transparently communicated to users based on a full understanding of the app's anticipated uses, functions, and effectiveness.
- 3. Whilst the EAB recognises that the app will not be used by all sections of society due to differing levels of access to technology across the population, in order to ensure equity, the app should only be deployed as part of a plan in which it can be explained how the benefits extend to everyone.
- 4. The app must be part of a wider package of measures so that those without the app are not afforded less protection from the virus.

Security and Privacy

- 1. The app should be designed in line with the principles of data minimisation and privacy protection, noting that users may give specific consent to voluntarily provide additional data.
- 2. Security is essential for trust in technology and if there is a reasonable doubt relating to the app's security, it should not be deployed. Commitments to the app's security should be published.
- 3. If any security breaches occur, these should be communicated to users immediately. Any security breach should be followed by a comprehensive assessment of the cause and measures should be put in place to reduce the risk of any further breaches.

Accountability

- 1. There should be clear lines of accountability for every major decision made about the app.
- 2. The governance mechanisms underpinning the decision-making process about the deployment of the app should be openly communicated to the Ethics Advisory Board who play an essential oversight role on behalf of the public.
- 3. There should be a risk register which is shared with the Ethics Advisory Board. The risk register should include clear thresholds that are monitored and could trigger the suspension or withdrawal of the app.
- 4. There should be robust ongoing monitoring and evaluation of the app's effectiveness and impact, and the outputs of which should be reflected in decisions made about future of app (as well as improvements to its functionality).
- 5. The initial terms and conditions of the app should be made available to the EAB for review prior to launch.

Transparency

- 1. All information about the app should be communicated to users in clear and plain language.
- 2. Alerts should be delivered with transparent and proportionate messaging in line with Public Health England guidance.
- 3. Any changes to the app's terms and conditions should require additional consents with the option to reject the new terms without losing access to the app.
- 4. NHSx should be as transparent as possible about the app, including regularly publishing information that is in the public interest, such as data on app take-up.
- 5. The app's code and algorithm should be publicly available at the earliest opportunity.

Control

- 1. Downloading the app should be voluntary
- 2. Users should be able to delete the app and their data at any point.

Appendix 2
Public Trust Matrix for use in considering ethical issues regarding the Contact Tracing app

Component of trustworthy data use	Specific Issue	Main concerns
Value (and impact): providing value back to the citizen or society as a whole. There needs to be specific consideration of the potential risks an individual or group might incur from downloading and using the app, and there needs to be an inclusive way of weighing these benefits and risks.	Effectiveness	How will a COVID-19 status be input into the app: self-diagnosis or virological testing? There is a risk that the quality of the data from self-testing will not be reliable or valid enough for this to work effectively.
	Equity & Fairness	Will this be equal access to all in the UK? Will there be any blackspots? Will there be any risk of discriminating against certain groups who may be less able/likely to download this app? Will there be a different process for NHS workers and key workers?
Security: Data sharing should be done competently. This means data is secure, and it is minimised and protected as much as possible, so users feel sure that their individual privacy is protected from misuse.	Prevent Misuse	Are there appropriate measures in place to prevent misuse? How do we reduce the scope for vigilante type action or for misuse by other agencies whose employees are using the app & receive an alert? Has there been thought through a range of 'bad actor' scenarios to stress test the types of misuse/abuse/breach that could arise? How will problems/errors be rectified/redressed?
	Deletion	Will there be the right to request deletion of the data associated with the app and its history? What does this mean in practice? Will there be the opportunity at the end of the epidemic for people to opt out of subsequent data use?
Accountability: There must be a reliable and understandable decision-making process, with sufficient public engagement and input.	Decision making	Accountability structures should include arrangements for inclusive decision making involving members of the public.
	Consent	If individual subjects do not give explicit consent, what mechanisms are in place to ensure broader societal consent? How will consent be designed so that it's understandable? Current consent practise focuses on individual consent. What is being planned with the app is not only consent to potentially collect information about one's <i>own</i> location, but one's proximity to others too. After the initial emergency response, this will need collective consent mechanisms and a critical approach to how the design and content design of these consent moments are put together.
Transparency: Details on who, what, and why are available publicly to enable scrutiny and give people the ability to object to decisions.	Communication	How can we ensure that we don't over promise to the public and then risk losing public trust later on when things are not what they seemed? An example of this is in the claims over anonymity: promises of anonymity can rarely be met. Is it better to be transparent on what data is being collected, and have really excellent communications and consent that explains this to people clearly? Is there a clear commitment that the data will only be used for the purpose stated? Is there acknowledgement that if the operation of the app can change over time and in the future, this is properly communicated and the process by which this happens transparent? Is there an effective communication strategy that outlines the trade-offs to relevant parties, and sets out when and why data will be shared?

Control: People can see what		
data is held about them, how it		
is impacting decisions, and have		Is usage voluntary? If requirements are imposed for people to have the
as much say over how it is used	Compulsion/	app (e.g. to return to work, to use public transport), are these reasonable
as possible.	voluntariness	and non-discriminatory beyond the health status?

^{*}The matrix is based on work originally undertaken by the Centre for Data Ethics and Innovation

Appendix 3

Membership and Terms of Reference of the Ethics Advisory Board

Membership

- Professor Sir Jonathan Montgomery (Chair), Professor of Health Care Law, University College London, Chair Oxford University Hospital Trust; Chair of the DHSC Moral and Ethical Advisory Group
- Roger Taylor (Vice chair), Chair of Centre for Data Ethics and Innovation, Chair of OFQUAL
- Professor Luciano Floridi, CDEI Board member and Professor of Philosophy and Ethics of Information at the University of Oxford; Director of the Digital Ethics Lab of the Oxford Internet Institute; Chair of the Data Ethics Group of the Alan Turing Institute.
- Nicola Perrin, Independent expert, former Head of Policy at Wellcome and Head of Understanding Patient Data
- Dame Glenys Stacey, CDEI Board member and Chair of the Professional Standards Authority
- National Data Guardian representatives (on rotation):
 - o Dr Alan Hassey, Retired GP and member of the NDG
 - Professor James Wilson, Professor of Philosophy University College London and member of the NDG
- Lay members: (from NHSx National Data Collaborative):
 - John Marsh
 - Richard Stephens
- Gus Hosein, Executive Director, Privacy International
- Professor Lilian Edwards, Prof of Law, Innovation & Society at Newcastle University¹

Terms of Reference

1. Purpose

1.1 The purpose of the Ethics Advisory Board (EAB) is to ensure that the development of the NHS COVID APP helps control the Covid-19 epidemic and return people to normal life more rapidly whilst operating in line with ethical requirements, and is transparent and open to public scrutiny. In doing this, it will provide assurance to the public that they can trust that their privacy and other interests are appropriately protected if they use the APP to participate in the project.

2. Functions

2.1 Functions for the board are:

- a) identify, respond to, define and examine relevant ethical issues as set out in to inform the successful and ethically appropriate achievement of the aims of the APP PROJECT in the public interest, including consideration of the interests of citizens;
- b) develop an ethics framework to serve as a reference point for the deliberations and work commissioned by the EAB and the APP OVERSIGHT BOARD;
- develop a model of good ethical practice for the successful completion and delivery of the APP PROJECT in the public interest;
- d) keep the APP OVERSIGHT BOARD informed about key developments in the public and professional discussion of relevant ethical aspects and policy developments in trustworthy data use;
- e) provide timely ethical review and advice on policies and other documents under development by the APP PROJECT.

¹ Became a member of the EAB after the letter was written to the Secretary of State.

act as a responsive ethics resource, providing timely advice, guidance and recommendations on ethical issues, as requested by the APP OVERSIGHT BOARD; provide timely ethical review and advice on policies and other documents under development by the APP PROJECT.

3. Reporting responsibilities

- 3.1 The EAB will provide regular and formal advice to the APP OVERSIGHT BOARD who will be free to act on it at their discretion. Advice may be both on questions set specifically by the APP OVERSIGHT BOARD as well as issues which the EAB has proactively identified in line with what is set out in [3.1]. This may include verbal advice as well as tabled papers.
- 3.2 Draft Minutes of EAB meetings shall be circulated to all members of the EAB and, once agreed, to the APP OVERSIGHT BOARD
- 3.3 There is an expectation that formal advice should be made public either through minutes or other appropriate means to increase transparency and accountability.

4. Membership

- 4.1 Members will be selected based on their personal expertise, and to contribute to the combined balance of expertise on the EAB in relation to the needs of the APP PROJECT.
- 4.2 The credibility and impact of the EAB depends on the independence and objectivity of its advice and on the confidence of others in its integrity. It is important therefore that in their Board activities members abide by the highest standards of behaviour as set out in the Seven Principles of Public Life.²
 - The EAB Membership should include representation of the [Participant Panel] and/or a member of the public .
- 4.3 During its initial stage of operation, the EAB can [through unanimous agreement] invite further members to join should it identify any significant gaps of expertise.

5. Duties

- 5.1 The EAB shall, in conducting all of its duties in accordance with these Terms of Reference, act in a way that it considers in good faith, would be most likely to promote the ethically appropriate achievement of the aims of the APP PROJECT. In doing so, the EAB must have regard (among other matters) to:
 - (a) the likely consequences of any advice in the long term and its impact on the broader governance of data use;
 - (b) the interests of 'participants' who have downloaded the app and are sharing data, as well as the general public given the publicly funded nature and society-wide relevance of the APP PROJECT;
 - (c) the interests of the broader community of stakeholders including employees, scientists and clinicians, interest groups, medical charities, civil society groups, privacy advocates and other potential collaborators;
 - (d) the impact of the NHSx operations on the community and the environment; and
 - (e) the desirability of the NHSx maintaining a reputation for high standards of conduct and promotion of trustworthy data use.
- 5.2 The Chair should ascertain, at the beginning of each meeting, the existence of any conflicts of interest and minute them accordingly.

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² The 7 Principles of Public Life, Committee on Standards in Public Life

6. Initial stage of operation

- 6.1 The EAB shall meet formally at least once a month and at such other times as the Chair shall require. Meetings should be organised so that attendance by members is maximised.
- 6.2 In its first six week of operation the expectation is that the EAB will need to be agile and flexible and that Board Members may be called to meetings as determined by development phases of the APP PROJECT. Advise and input may also be sought over correspondence but effort should be made to arrange for Board meetings.
- 6.3 The EAB will continue to operate as set out within these Terms of References during the first phase of development and deployment of the APP PROJECT. Following this, there is an expectation that the Terms of Reference and membership shall be reviewed to ensure that it continues to be constituted in the most appropriate way.

7. Secretariat and role of Centre for Data Ethics and Innovation

- 7.1 During the initial stage of operation the secretariat shall be provided by the Centre for Data Ethics and Innovation. This may include research and engagement resources to support the Probity Workstream and to provide the EAB with effective and informed advice.
- 7.2 Board Members who hold membership on both the CDEI Board and the EAB are expected to treat these memberships as separate. However, there will be an assumption that those Board Members will advise and update the CDEI Board at regular intervals and may also seek input from the CDEI Board to be shared with the EAB.