DRAFT: 25 August 2020

Report on the work of the Ethics Advisory Group to NHSx on the COVID-19 Contact Tracing App

Contents

Preface from Baroness Dido Harding

I want to take this opportunity to thank the Ethical Advisory Board for the work that is summarised in this report. The COVID-19 pandemic has presented us with a very wide range of challenges that raise complex ethical issues as well as technical obstacles. The Board has played an important role in informing and challenging NHSx on its work on digital contact tracing. Now that responsibility has been passed to the Test and Trace Programme, the principles that the Board set out have provided an invaluable guide to our thinking on the use of digital technologies in support of our strategy to keep the public safe. We must always maintain public confidence in our response to the pandemic and a sound ethical foundation is essential to demonstrating that the tools we provide to people can be trusted.

Dido Harding

Professor Sir Jonathan Montgomery

I am very grateful to my colleagues on the Ethical Advisory Board for giving up their time and sharing their expertise and wisdom during the short but intense period of our work to support NHSx in addressing some of the challenges presented by COVID-19. We have thought hard and deliberated carefully about the issues and learnt a lot about how to engage with ethical matters in a context that was new to us in many different ways. This report aims to explain how we worked, set out the advice that we gave, and record our reflections on the process. We hope that this might assist those who need to establish processes for securing ethical advice for projects in the future.

We were supported by many colleagues and visitors, but we owe a particular debt to Sam Cannicott, Farzana Dudwhwale, Maeve Ryan and Lisa Whiting who gave consistently wise counsel and ensured that the EAB ran smoothly.

Jonathan Montgomery

Introduction

The Ethics Advisory Board was established to provide constructive challenge to, and independent scrutiny of, the NHS coronavirus (COVID-19) App. Following the government's decision to halt development of this app, this Board's current advisory responsibilities came to their logical conclusion.

Much of the advice that the Board has provided, such as the ethical principles included in the letter sent to the Secretary of State, will be pertinent to future contact tracing apps or other government-led technology projects. This report provides a summary of the Board's work, so that it may serve as a useful resource for such future projects.

Our Role

The purpose of the Board, as set out in the Terms of Reference, was to ensure that the development of the NHS App helped to control the COVID-19 epidemic and return people to normal life more rapidly whilst operating in line with ethical requirements, and in a manner that was transparent and open to public scrutiny.

The decision to develop and deploy such technologies remains with politicians. Democratic accountability for such decisions is essential and it is right and proper that they are ultimately for politicians to make. The role of the Board was to ensure that if people did choose to use the NHS App, they could be assured that their privacy and other interests were appropriately protected.

The Board's role was to advise on the development and operation of the App, not to oversee it. This had two important implications. First, it was not our job to discuss contact tracing apps in the abstract but to explore how to make sure the NHS version was effective and ethical. Throughout the period of the Board's engagement a number of other countries adopted contact tracing apps and while these countries faced some similar challenges, making comparisons between apps in different countries was, and remains, difficult because there is a wide range of variables to be taken into account. These include the part contact tracing apps are expected to play in wider systems for tracing infections, the ways in which testing is made available (including different types of test and ways of accessing them) and the extent of current restrictions on liberty and freedom to associate.

Our main output was the letter that we wrote to the Secretary of State for health on 24 April 2020 (Appendix 6).The principles included in that letter offered a framework within which it was possible to discuss the value of different ways of meeting the objectives of effective control of the epidemic and protecting privacy. We noted that it would have been unethical to adopt the app without regard to the full responsibilities of the NHS. The app was to be part of a package of contact tracing measures that would ensure that the response was effective and would protect every member of society, not just those who own smartphones and chose to use the app. The EAB did not advise on this wider package, but did make it clear that the value of the app could not be considered without regard to the comprehensive response that was being planned across the test and trace programme.

Second, responsibility for compliance remained with the NHS and was not transferable to the EAB. We noted in our advice that it was for the NHS to carry out the normal Data Protection Impact and privacy assessments. We also advised that an Equalities and Health Inequalities Impact Assessment should be undertaken to ensure that there were no disproportionate negative impacts on certain groups, such as those who are less able to access digital tools. Responsibility to complete such assessments remained with the NHS.

Formation and responsibilities of Board members

The Ethics Advisory Board benefited from the experience and wisdom of bodies already active in the oversight of the good stewardship of health data. Board members were recruited from the Centre for Data Ethics and Innovation, and we had nominees from the panel of the National Data Guardian, as well as independent members. It also drew on the wide experience of two public members from the NHSx National Data Collaborative and of the Executive Director of Privacy International. As the Board's work progressed, it became clear that there would be benefit in expanding the group to include legal expertise and Lilian Edwards, Chair of Law, Innovation and Society at Newcastle University joined the Board.

Board Members were not remunerated. They were invited to participate based on the relevance of their expertise in the fields of law, ethics and medicine, amongst others. Their work was guided by the Nolan Principles. A register of members' interests is at Appendix 3.

Operation

The EAB met weekly, identifying key issues, seeking clarifications from the App development team and hearing from those involved with other aspects of the response to COVID-19 whose work the EAB identified as important in understanding the issues.

The speed at which the EAB had to work precluded wide public consultation of the sort that would have been available in more normal circumstances. To ensure that it understood issues that others saw to be at stake, the EAB benefited from roundtables with experts (including on technologies and data privacy) convened by the Centre for Data Ethics and Innovation, focus groups which enabled an exploration of public views, and shared briefings with members of the National Data Guardians Panel and the Board of the Centre for Data Ethics and Innovation. A representative from the Information Commissioner's Office observed the EAB's discussions.

Meetings

The Ethics Advisory Board met on a weekly basis from 2nd April - 18 June, with one further meeting in July, for a total of 12 meetings. Papers for discussion were circulated in advance of the meeting and a number of these meetings were attended by guests, who gave presentations relevant to the work of the EAB. Full details of the schedule of meetings, attendees and notes taken during each meeting are included in Appendix 10.

Briefings

The Ethics Advisory Board received four in-depth briefings led by NHSx in addition to the weekly meetings. Attendance of these briefings was optional. These briefings were used to update the Board on any significant developments and to provide additional information on topics including the communications strategy for the app and the pilot phase on the Isle of Wight.

Virtual discussions

In line with government guidance, meetings were held virtually. The Chair facilitated these meetings and enabled Board Members to contribute as and when they wished to both by speaking directly to the group or by writing their discussion point in the chat function of the virtual meeting room. The

Board also conducted some correspondence by email, and more formal advice was agreed in writing via email with the group.

Advice was drafted by the Chair with support from the Secretariat and shared with the EAB for agreement. It reflected the consensus reached in discussions.

Roundtables and Public Engagement

Throughout the period of the Board's engagement, the CDEI ran a number of roundtables on contact tracing apps. Each of these roundtables was attended by one or more members of the EAB and summaries of each meeting were shared with the wider group.

In order to understand public attitudes towards a contact tracing app, NHSx commissioned BritainThinks, an insight consultancy, to run a series of focus groups and telephone interviews in early April. Their research found that the main concern for the majority of participants in these consultations related to the app's reliance on self-reporting, as per the design at that time. Respondents indicated broad support of additional data collection to improve the management of NHS resources and for research into COVID-19. This engagement was carried out during the relatively early stages of the app's development - before it had received extensive media coverage - and at that time a majority of participants indicated that would at least consider downloading and using an app, if introduced.

People who have come to discuss with the EAB

On occasion the Board was joined by guest speakers who kindly agreed to share their expertise on topics relevant to the Board's work or to provide updates on their own areas of work on the app. These guests included:

- Professor Michael Parker, Director, Wellcome Centre for Ethics and Humanities
- Dr Paul Crook, Consultant Epidemiologist, Public Health England
- Professor John Watson, Deputy Chief Medical Officer, Department of Health
- Professor Ross Anderson, University of Cambridge
- Professor John Newton, National Testing Coordinator, DHSC
- Matthew Gould, NHSx
- Alex Birtles, DHSC
- Peter Whawell, Deputy App SRO, NHSx
- Dr Ian Levy, Technical Director, National Cyber Security Centre
- Professor Chris Holmes, Head of Modelling & Analytics NHSx App
- Simon Thompson, NHSx
- David Brown, NHSx

Key Ethical Issues

Trust Matrix

The EAB adopted a "Trust Matrix" as a framework to explore the ethical questions and trade-offs posed by a contact tracing app. This was based on policy work undertaken by the Centre for Data Ethics and Innovation which explored how the public sector should address citizen trust in relation to how data about people is used and shared.

The CDEI shared it with the EAB which worked to revise it in order to make the framework specific to the issues raised by the App. A set of six guiding principles were agreed. There were as follows:

Value

There must be good reason to believe that that the app will provide sufficient net-value back to the citizen or society.

Impact

There must be good reason to believe the app will be an effective tool in controlling the outbreak of COVID-19.

Security and Privacy

The data collected should be minimised and protected as much as possible.

Accountability

There must be a reliable and understandable decision-making process in place to manage the app - with clear democratic accountability

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

Control

Downloading the app should be voluntary, people should able to delete the app and their data at any point, there should opt-ins for further data sharing and use

Probing the Technology and Capabilities

The application of these principles required an understanding of the way the proposed technology worked and was being evaluated. The Board meetings regularly engaged with the question as to how an app was designed, how it would work, when, and for who. We recognised that different ethical issues would arise depending on design choices. In addition, the best way of measuring the efficacy of the app changed as a result. For instance, if proximity interactions were a priority, the app would have to be effective at recording Bluetooth interactions. If the targeting alerts was the key question, the quality of data arising from the app to make decisions about who to notify through a centralised intelligence centre became a significant question.

The Board recognised that these questions about value and impact were separate from the issues of privacy and security. Both matters were relevant to the discussions about centralisation and decentralisation of data, although media commentary tended to concentrate on the privacy dimensions. Small design decisions can have large ethical implications. For instance, the decision to change identifiers. Apple and Google's API does this every 15 minutes. The NHSX app was designed to do it once a day. Some apps don't do this at all. A more persistent identifier could allow for the app to be used in different ways, increasing the scope of its use. Persistent identifiers would allow for the option to monitor whether someone is interacting with many devices even if they were supposed to be self-isolating, turning the app into a nudge-like tool to help people understand that they aren't self-isolating, or with centralised reporting, a quarantine-enforcement tool. Each of these would give rise to significant ethical discussions for a board to review. In briefings this additional use was raised but we were not clear whether the identifier decision was made intentionally to enable those further uses or was merely something incidental.

The pace at which the design of the App evolved made it very challenging for the board was to explore the ethical implications of the technical choices and tests that were being undertaken to evaluate the effectiveness of the app. While regular briefings were given on the topic, board members did not always feel that suitably comprehensive or final answers were supplied to their questions. For example, the assessment of which devices the app would be able to detect signals changed as tests were carried out. In one briefing we were informed that NHSx believed it would work for Android 6 and iOS 10.3 and above. This would have made the app usable by a substantial size of the UK mobile phone market. But when the pilot version of the app launched, it was announced it would work only on Android 8 (and above) and iOS 13 devices -- capturing a smaller section of the UK population. This has implications for the effectiveness of the app as a tool to reduce the spread of COVID-19.

Board members felt that their ethical advice could have been more precise with greater confidence in the understanding of the technical elements of the app’s development. This required much of the advice given to be conditional on the accuracy of the information we had at the time it was expressed.

Advice Offered by the EAB

Formal Advice

The EAB provided three pieces of formal advice:

1) Letter to the Secretary of State for Health (24 April 2020) providing conditional support for the contact tracing app and setting out an ethical framework to guide its development and deployment.
2) Email to NHSx CEO (18 May 2020) considering the centralised and decentralised approaches through an ethical lens.
3) Email to NHSx CEO (11 June 2020) relating to retention of data and governance of the App.

In addition, a summary note of each EAB meeting was shared with the senior leadership team at NHSx and key issues were reported to the App Oversight Board.

Informal Advice

The EAB identified a number of the privacy and ethical concerns, which were discussed and then formulated into the advice that was sent to the Secretary of State for Health.

However, the EAB did not wait to reach its conclusions before acting to raise awareness. The EAB Chair had observer status at meetings of the App Oversight Board. This enabled him to raise matters that the EAB had identified in time to have an impact on the App's development. The Chair also communicated directly with Matthew Gould, CEO of NHSx.

Through this route, the EAB encouraged the team to articulate a more precise focus for the App to more clearly address the current public health needs, sharpened the understanding of the challenges of potentially relying on self-reporting and sought to clarify the value proposition to users.

Reflections

COVID-19 has presented a unique crisis. There has been a particular need for responses to be developed and deployed rapidly. The traditional role of oversight boards has allowed a slower pace, with much more time to consider material and to provide constructive and timely challenge. NHSX is also a relatively new organisation and the App Cell was essentially created from scratch and has had to evolve quickly. This was a new experience for all involved and it was inevitable that there would be lessons to be learnt. We focus on the most salient issues from the perspective of the EAB.

Policy Context

The COVID-19 pandemic has required policy to be developed rapidly in circumstances that were inevitably constrained by the availability of resources and necessarily limited understanding of the impact of a novel virus. This has not made the work of the EAB easy. Particular challenges arose from an initial lack of clarity about the purpose and scope of the App, and a wider uncertainty about the purpose and scope of the broader strategy to which it contributed. A number of different purposes for the App were floated at one point or another, including providing alerts to individuals that they could be infectious, reducing transmission at a population level, gathering further information on symptoms, providing intelligence to enable local public health responses by identifying local flare-ups, and facilitating research to improve responses to future pandemics. Lack of precision about what the main purpose or purposes were made it much more difficult to have sensible and well-evidenced discussions about issues such as data retention periods. It also made it more difficult to determine what would count as scope creep, and to determine what an exit strategy for the App should look like.

As policy developed, the place of the App in wider test and trace strategy has changed. When EAB was first convened at the beginning of April, it was advised that the App would have a leading role, with large scale testing and manual contact tracing being extended in due course. Given this, the strategy of leading with an App that (a) centralised the proximity information that it had collected, and (b) triggered alerts to self-isolate on the basis of reported symptoms rather than test results, might have looked like the only plausible option from a public health perspective. Success would have been dependent on a significant proportion of the population using the app and following its advice. The EAB was convened rapidly to help provide ethical advice on a technical solution based on this understanding of the underlying problem to be solved. Thus, as initially framed, EAB's task seemed to be one of providing advice on the ethics and governance of a novel data driven technology, which would be the leading pillar of a national strategy for Covid recovery, and would be rolled out nationally within a few weeks. The EAB identified that maintaining high levels of public trust would be essential if this was to be achieved and therefore focused on the features that would make the app trustworthy, including problems of false positive and negative results.

By the end of the EAB's work, policy on the contact tracing App considered it as a potentially useful complement to the Test and Trace strategy that is being led by testing and manual contact tracing. There was discussion of the balance between centralisation and the role for local authorities – where the statutory responsibility and the expertise in public health resides. These changes of policy direction created a need to retrofit elements into the design of the App. For example, how to integrate testing data into the App, and how to integrate the App's alerts with the system of manual contact tracing. In these circumstances, we are now looking for an integrated public health strategy, linked with the broader NHS infrastructure. What was initially envisaged as a tech project is now a large-scale health project, in which tens of thousands of people are employed. This will require a different form of ethics advice and governance to that set up for an independent App.

There was also a significant shift in the technological context. Although there has long been debate about platforms, the picture looked different at the outset of our work than it did by the end. When we first met, we noted that the NHSx proposal was considerably more protective of privacy than those deployed elsewhere, for example South Korea, Singapore and Australia. There was a realistic choice between so-called centralised and decentralised approaches until Google/Apple made it clear that they would not facilitate the approach that was planned in the UK. Apple and Google did not announce their collaboration until 10 April 2020 and the exposure notification tool was launched in May. Although members of the EAB expressed the view that it seemed unlikely that Apple and Google would be prepared to be flexible, this possibility was explored for some time.

Subsequent to the completion of our work, the move to a decentralised approach has altered the prominence of the various ethical issues we have identified. While privacy concerns are reduced, problems of value and impact are increased. The EAB was briefed on plans to use the data that could be extracted from the original model to assess the reliability of alerts and to refine the criteria used to issue them. This would have enabled consideration of the effectiveness of the app as a public health intervention. As decentralised apps do not permit this analysis, it is important to understand how rates of false notifications (e.g. alerts to those who have not in fact been at high risk and failures to alert those who were) will be assessed. We also need to understand how people respond to app notifications. The Government has stated that the Isle of Wight trial showed that people were more likely to self-isolate when asked to do so by an individual than an App. This is an ethically significant finding as the value of the app is dependent on people trusting the advice it offers. We anticipate that the focus of our discussions would have been on these matters had we been considering an App based on the Google/Apple API.

These developments in the policy context suggest that our advice would have been different had we been convened to support the current Test and Trace Programme. Nevertheless, we believe that the principles that we set out in our letter of 24 April remain an appropriate framework for assessing the ethical issues raised by an app. The differences in advice would have been seen not at the level of principle but in the working out of their implications. We therefore welcome the fact that the Test and Trace programme as used our principles in order to inform their work on an app for the new policy context (Appendix 11).

Transparency

The establishment of the Ethics Advisory Board signalled a welcome commitment to the development and deployment of the NHS COVID-19 App being open to independent scrutiny and constructive challenge. The transparency of the project to the EAB was enhanced by the attendance of the Chair at meetings of the App Oversight Board. However, transparency to the public of the work of the EAB could have been improved. The EAB first met on 2 April 2020 and its existence was not publicly noted until a blog on the NHSX website on 24 April 2020, by which time advice had already been sent to the Secretary of State for consideration.[1] In more normal times, a three week delay would be unremarkable, but in the light of widespread comment on ethical issues around contact tracing apps, it would have been helpful for the membership and terms of reference to have been in the public domain earlier. Similarly, it is common for publication of advice from advisory bodies to be published along with the response. This led to a delay in the EAB's letter of 24 April being made public that, although short by the standards of non-COVID-19 practice, was unhelpful in terms of the role of the EAB in providing the public confidence that ethical issues were being given due consideration.

Like many others, we believe that transparency is crucial to public trust and confidence. We would recommend that the existence, membership and terms of reference of future ethics advisory boards are placed in the public domain as quickly as possible after establishment. We also recommend that clear expectations are set on what material will be publicly available about the workings of the board. This should include meeting notes identifying topics discussed even if some details need to be redacted for reasons of confidentiality. Freedom of Information legislation could be used as a guide for what should be published. It would also be helpful if there was an indication of the anticipated time between meeting notes being approved and their being made public. Our experience is that limited transparency exposed NHSx to unfair criticism of not having recognised ethical issues when in fact they were under careful consideration.

Membership

The speed with which the EAB needed to be created meant that it was not possible to have an open recruitment competition as would be ideal for a public body addressing ethical issues. The EAB membership was drawn from two key public bodies (the Centre for Data Ethics and Innovation and National Data Guardian's panel) and from those within the existing networks of NHSx and EAB members. This enabled a group of relevant experts to be convened quickly. However, it resulted in a less diverse group in terms of background as well as 'protected characteristics' than we would expect from a traditional recruitment campaign. We remained conscious of this during the twelve weeks of our work. If the EAB were continuing, it would be important to address the recruitment process in order to enhance the diversity of the group.

Public Engagement

Both the context of social distancing and the speed at which the EAB was required to work meant that it was not possible to undertake public consultations in the manner that might have been expected in other circumstances. We have already reported on how we sought to overcome this by drawing on roundtables and focus groups. There was also a considerable amount of knowledge of public attitudes to the use of health data from previous work, with which the members of EAB were familiar and could share.

Public engagement is important for a number of reasons. Some are easier than others to achieve in the circumstances presented by COVID-19. There are three aspects that we regard as particularly important. First, open engagement can ensure that that the full range of issues is identified. This can be achieved by a systematic review of previous discussion of analogous issues. We are reasonably

---

[1] https://www.nhsx.nhs.uk/blogs/digital-contact-tracing-protecting-nhs-and-saving-lives/

confident that we have identified and addressed the most important areas of public concern. We have assessed this by considering whether the media discussions, which have been extensive, raised issues that we had missed in the advice we have given.

Second, the risks of 'group think' are reduced when there is effective engagement with public as well as expert views. Here, we have concerns that the framing of media discussions has been more limited than would be ideal. In particular, privacy has had fuller coverage than health rights and technical efficiency has been more extensively considered than public health effectiveness. While we have aimed to keep a better balance in our internal discussions, it might have been possible to explore these concerns in a more structured manner if there had been time and resources for effective explorations of public views.

Third, it is now generally a staple part of public ethical governance to use deliberative dialogues (e.g. citizen juries) to explore public opinion on how best to balance competing and sometimes conflicting values. In the context of COVID-19, we have not been able to draw on these techniques of deliberative democracy. We have therefore recognised the important of representative democracy, through Ministerial leadership and Parliamentary scrutiny, to undertake these roles.

Our 'conditional' role

There were three elements of 'conditionality' that had a significant impact on the way that we approached our task and which made it different from the experiences that members have had on otherwise broadly equivalent boards. We think these are worth some reflection. We recognise both how they came about and also how they impacted on our approach to our work.

First, the EAB was set up to help implement a decision to proceed with a digital contact tracing app. It was not established to examine whether this was the right policy. This meant that members needed to be comfortable with this task and to accept the parameters that were set for it. We were asked to advise on how to ensure that the development of the app respected ethical principles rather than whether to embark on that course. The phrasing of the terms of reference sought to make that explicit and it was discussed at the Board's early meetings to ensure that members did not feel compromised by that task. It was recognised that there were ethical arguments against using contact tracing apps at all and we noted these at our initial meeting. For example, some can reasonably conclude that equity issues, especially when the unequal access to smartphones is considered, make it inappropriate to develop an app-based technological approach. However, the nature of the EAB's task meant that those who held this position could not fulfill the role asked of the board members. We believe that this approach is acceptable provided that there are other fora in which the wider questions can be explored. We believe this has been the case in the UK in respect of the NHSx App.

Second, the fact that the EAB sat within a specific programme rather than being commissioned to evaluate the general role of apps in responding to the Covid pandemic meant that we spent limited time on alternative ways of building apps. We have not discussed approaches that required significant personal information to be provided (such as in Australia) or linked with other surveillance systems (such as credit card usage and phone records) as these were not being proposed by NHSx. For the same reason, we did not explore concerns about 'mission creep' in any detail, although we have made a general point about the need for appropriate governance of functional developments. We did consider the possibility of an app built on the Google/Apple API as this was a way of achieving the intended purpose of the NHS app and gave advice on the ethical aspects of choosing between centralised and decentralised approaches (Appendix 8). An external bioethics body would have expected to consider a much wider range of approaches. This type of work is important for wider public discussion, but not helpful to a development programme that was on a very tight timescale to deliver a specific project commissioned by Government.

Third, the EAB approached its task acutely aware of the importance of giving timely advice. Although its working life was shorter than traditional ethical advisory boards it was in fact significantly longer than was anticipated at the first meeting. The aspiration of the app team, and the commission from the Secretary of State, was for a rapid deployment in order to support the response to the Covid-19 Pandemic. We therefore approached our task with a sense of urgency and expected to have very few meetings in which to craft our advice. Our primary output, the letter to the Secretary of State, was agreed only three weeks after our first meeting as it was expected that a roll-out of the app was imminent. We did in fact have longer to deliberate than we expected but we were working with a sense of urgency against immediate deadlines, even though they were often deferred as technical issues caused delay.. We were supportive of the delays in deployment that resulted from testing of the app, as this reflected the ethical imperatives of effectiveness and impact (as we set out in our letter). However, had we known that there was more time available we might have been able to refine and clarify our advice to our greater satisfaction.

These three elements of ‘conditionality’ lead inevitably to a degree of provisionality about our advice. Although we think our advice is fundamentally sound, we would recommend that subsequent bodies do not feel constrained by the way in which was expressed. We ourselves expect to develop and refine our personal positions. As the circumstances change, the principles we have set out may lead to different conclusions than the ones that we reached given the conditions that prevailed when we expressed them. We are pleased that NHS Test and Trace has been able to use the principles that we set out to inform development of their own app and Appendix 11 sets out a summary of how they have done so.

Working on the inside

The EAB was established to give independent advice but it was internal to NHSx rather than a separate body. This brought some benefits in terms of access to decision-makers and sight of some documents in early stages of development. However, we were concerned that we did not fully benefit from this potential. We asked for a briefing on the technical data from the RAF base test and from IoW, but were not shown the data nor given the detailed answers we sought. We thought this was important in the light of reports that iOS would not permit background connectivity, as seemed to have been the experienced in Singapore. We were told in general terms that the NHSx team thought that they had found a solution but they did not explain to us how that worked and it seemed subsequently that in fact the problem had not been solved. We did not see the results of the Isle of Wight trial in this respect as we might have expected as an internal board that was able to review confidential material.

The internal advisory status of the Board also led to some challenges about how to draw the line between the confidentiality of internal documentation and the transparency of the advice given. This was particularly challenging for those members who were approached by journalists for commentary and who would generally have provided it in their professional roles. This expertise was why we wanted them on the Board but it also created some tensions that members had to grapple with. It was important to maintain the integrity of the board’s deliberations and also of individual members. At a late stage in the relatively short life of the EAB we codified our discussions on expectations of members into a Code of Conduct (Appendix 4). Clarity on this is important to enable members to provide advice on the basis of confidential material while still able to comment on wider issues within their expertise in other roles.

A third consequence of the fact that we were embedded within NHSx concerned access to independent advice, for example on legal and media issues, and direct contact with regulators and policy makers. These were not available to the EAB, as was to be expected given the short time frame in which the EAB was established and worked. This potential vulnerability was mitigated by the range of expertise amongst EAB members, by attendance at meetings by advisors within NHSx and the presence observers from bodies such as the ICO. However, if a standing advisory group were established, then it would be desirable that it had the opportunity to access independent advice when necessary. Lack of support and advice may have contributed to the fact that media interest in the EAB was limited to whether there were frustrations within the group and suspicions of tensions between it and NHSx or the Secretary of State. We were disappointed that there was no media coverage of the ethical principles set out in our advice, despite having presented a summary at a press briefing at the Science Media Centre. However, as our letter setting them out was not publicly available until some weeks after the briefing this was understandable.

Outputs

It is common for ethics bodies to publish narrative reports with recommendations (for example the Nuffield Council on Bioethics) or to provide opinions on whether a proposal is ethical and should be permitted to proceed (as is done by Research Ethics Committees or the Confidentiality Advisory Group). The circumstances in which we operated were different and our specific outputs took the form of a letter and two emails to key decision-makers. These forms of output were appropriate to our internal advisory role, but they were not suitable for raising public awareness. We are pleased to make them available as appendices to this report. Any future EAB might consider whether it should produce public facing statements as well as internal communications.

One consequence of the limited public engagement is the way we have framed our advice. We have generally sought to provide advice on the range of issues that need to be considered and to identify how risks might be managed, including the use of impact assessments. We have been less confident in making specific recommendations on how the balance should be struck on matters properly subject to democratic rather than expert decision. If there had been greater public engagement opportunities we anticipate that we could have been more explicit in our substantive advice on such matters.

One aspect of the fact that we were working within the development process was the importance of providing timely advice. This meant that we sometimes needed to communicate views even where we knew that information was incomplete or plans were still being settled. Where we felt that decisions were imminent we sent emails on issues that we feared might be overlooked by those taking key decisions (Appendices 8 and 9). Our ability to assess this was particularly challenging in an environment where media discussions suggested that journalists had received briefings that appeared to be at variance with those being presented to the board. Sometimes technical information that we regarded as ethically significant, and had requested, was not available to us at the point when we needed to crystallise advice. We were explicit in our letter to the Secretary of State that we provided advice based on currently available information and that our support was therefore conditional and might be different in the future. The conditional nature of our advice, which was therefore valid at the time of writing but vulnerable to changing circumstances, made its timely publication even more important.

Finally, we were conscious that we were established as an advisory, not a decision-making, body and therefore were careful to avoid going beyond our role. While it was appropriate for us to draw attention to the way in which competing social values might need to be balanced, we recognised that accountability for such decisions sat with Government. We therefore sought to frame our advice in a way that would inform but not prejudge their conclusions.

Advice for Future Ethics Advisory Work

While the circumstances in which we were working were very unusual, there are a number of key points that emerge from our reflection on our experience that we would urge those setting up advisory boards in the future to consider.

Clarity of purpose. It is easier to provide relevant and actionable ethical advice when there is clarity and precision about the problem we are trying to solve. This would help an ethics advisory board to work with a shared understanding of what it is aiming to achieve. The rapid formation of the EAB and changing policy context made this difficult.

Transparency is crucial to public confidence and trust. A future EAB should have an independent web presence that enables information about its role and outputs to be readily accessible. There should be clarity about the criteria for distinguishing between internal discussions and material that will be made publicly available. There should also be clarity about when any advice issued will be published and how summaries of discussions will be made available.

Membership should be diverse with open recruitment where possible. Where speed is of the essence, it may be advisable to convene groups with specific tasks to complete within a specified timescale rather than to create a standing advisory board.

Support is crucial to effective working. There needs to be a degree of independence from the body being advised. Sufficient resource should be available to enable an EAB to be informed about public concerns and views, at least indirectly through review of work done by others. There should be access to independent advice on media relations and where necessary legal matters.

Accountability. Clear expectations should be set for the role of an ethics advisory board, especially in relation to its scope and opportunities to influence. This should include clarity on structures for decision-making and accountability in relation to matters on which advice is given.

Summary

We were privileged to be able to support NHSx and Government on their work on digital contact tracing. While the App that was initially planned was not successful, this does not mean that it was misconceived. We believe that the establishment of an ethical advisory board was an important component of the decision-making and accountability framework and hope that future programmes seek such support. The decision to change the focus of the Test and Trace strategy was consistent with the principles that we proposed to assess the ethical dimensions of policy in this area. We believe that these principles remain relevant, although their implications will need to be worked through for the new policy context. Success will only be achieved if the tools that are used are trustworthy and if the public does in fact trust them. Our six principles of value, impact, privacy and security, accountability, transparency and control remain an important guide to what makes it appropriate for the public to place their trust in digital technologies that are deployed to support the public health response to COVID-19.

Appendices

1. 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;

c) 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.

f) act as a responsive ethics resource, providing timely advice, guidance and recommendations on ethical issues, as requested by the APP OVERSIGHT BOARD;

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. [1]

- 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.

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.

---

[1] https://www.gov.uk/government/publications/the-7-principles-of-public-life.

2. Biographies of Members

Professor Sir Jonathan Montgomery (Chair)

- Professor of Health Care Law, University College London
- Chair of Oxford University Hospital Trust
- Chair of the Department of Health and Social Care (DHSC Moral and Ethical Advisory Group

Roger Taylor (Vice Chair)

- Chair of Centre for Data Ethics and Innovation
- Chair of Ofqual

Gus Hosein

- Executive Director, Privacy International

Professor Luciano Floridi

- Board member, Centre for Data Ethics and Innovation
- 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

Nicole Perrin MBE

- Independent expert
- Former Head of Policy at Wellcome and Head of Understanding Patient Data

Dame Glenys Stacey

- Board member, Centre for Data Ethics and Innovation
- Chair of the Professional Standards Authority

Professor Lilian Edwards

- Chair of Law, Innovation and Society, Newcastle University

National Data Guardian representatives (on rotation):

Dr Alan Hassey

- Retired GP

Professor James Wilson

- Professor of Philosophy, University College London

Lay members (from NHSx National Data Collaborative):

John Marsh

Richard Stephens

3. Register of Interests

Professor Sir Jonathan Montgomery (Chair)

Other public appointments held at present:

- Chair, Oxford University Hospitals NHSFT
- Co-Chair, Moral and Ethical Advisory Group (DHSC)
- NED HDR-UK; Member, Faculty of Public Health Ethics Committee.

Personal and business interests:

- Professor of Health Care Law, University College London

Previous public appointments held within the last five years:

- Chair, Health Research Authority 2012-19
- Chair Nuffield Council on Bioethics, 2012-17
- Member, European Group on Ethics in Science and New Technologies 2017-19

Political activity: N/A

Other: N/A

Roger Taylor (Vice Chair)

Other public appointments held at present:

- Chair, Ofqual
- Chair, Centre for Data Ethics and Innovation

Personal and business interests:

- Director Hatmatrix ltd (currently not conducting any business)

Previous public appointments held within the last five years: N/A

Political activity: N/A

Other: N/A

Gus Hosein

Other public appointments held at present: N/A

Personal and business interests:

- Executive Director, Privacy International

Previous public appointments held within the last five years:

- Chair of medconfidential
- Trustee of Tactical Tech
- Trustee of Simply Secure

- Board member of Omidyar Network Digital Identity Portfolio

Political activity: N/A

Other:

- Fellow of the RSA

Professor Luciano Floridi

Other public appointments held at present:

- Chair, Data Ethics Group, The Alan Turing Institute
- Turing Fellow, The Alan Turing Institute
- Member, Advisory Board, Institute of AI, Foreign Office, UK
- Chair, Ethics Committee of the Machine Intelligence Garage project, Digital Catapult, UK Innovation Programme
- Member, Technology Advisory Panel, Information Commissioner's Office (ICO), UK
- Member, Advisory Board of The Institute for Ethical AI in Education (IEAIE), UK
- Member, Ethics Board, Cluster Science of Intelligence (SCIoI), German Excellence Initiative, Deutsche Forschungsgemeinschaft (DFG, German Research Foundation).
- Member, EU Commission's High-Level Group on Artificial Intelligence
- Member, Vatican Committee on the Ethics of AI
- Member, Advisory Board, Vodafone Institute for Society and Communications
- Member, Leonardo Foundation, Italy
- Member, EY's AI Advisory Board

Personal and business interests: N/A

Previous public appointments held within the last five years:

- Chair, Advisory Board on Tech Ethics within the All-Party Parliamentary Group (APPG) on Data Analytics, UK
- Member, Advisory Group on Open Finance, Financial Conduct Authority (FCA), UK
- Member, Council of Europe's Expert Committee on Human Rights Dimensions of Automated Data Processing and Different Forms of Artificial Intelligence (MSI-AUT) Ministers' Steering Committee on Media and Information Society (CDMSI)
- Member, World Economic Forum's Council on The Future of Technology, Values and Policy
- Chair, Scientific Committee of AI4People, "Europe's first global forum on the social impacts of artificial intelligence"
- Chair, Advisory Board of the 2018 International Conference of Data Protection and Privacy Commissioners, EDPS, EU
- Chair, Ethics Advisory Board of IMI-EMIF, the EU's European Medical Information Framework
- Member, Science Panel of the Commitment to Privacy and Trust in Internet of Things Security (ComPaTrIoTS) Research Hub, EPSRC, UK
- Member, Ethics Advisory Group on Ethical Dimensions of Data Protection, European Data Protection Supervisor (EDPS), EU
- Member, Royal Society and British Academy Working Group on Data Governance
- Member, Google's Advanced Technology External Advisory Council
- Chair, Facebook's Working Group on Digital Ethics Member, Advisory Board of Tencent's Internet and Society Institute

Political activity:

- Member of the Liberal Democrat Party

Other: N/A

Nicole Perrin MBE

Other public appointments held at present:

- Member, Ethics and Feedback Advisory Group, Accelerating Detection of Disease Cohort

Personal and business interests:

- Health Data Research UK (consultant to International Covid-19 Data Research Alliance)
- Employed on a consultancy basis by a number of charities

Previous public appointments held within the last five years:

- Member National Data Opt-Out Panel, NHS Digital

Political activity: N/A

Other: N/A

Dame Glenys Stacey

Other public appointments held at present:

- Board member of the Centre for Data Ethics and Innovation

Personal and business interests:

- Chair, Professional Standards Authority
- Member of the Ministry of Justice's Challenge Panel, part of the governance of the transfer of much of the probation service back into public ownership, but working on that on a consultancy basis.
- Member, parochial church council St Etheldreda's, Horley, Oxfordshire; member, parish council, Horley, Oxfordshire.

Previous public appointments held within the last five years:

- Chief Inspector of Probation for the period February 2016-end May 2019. This was a public appointment. Prior to that (for the period March 2011-March 2016).
- Chief Regulator of Qualifications and Chief Executive of Ofqual, the exams regulator - a public appointment.

Both of these appointments involved pre-appointment scrutiny by the relevant Select Committee.

Political activity: N/A

Other: N/A

Professor Lilian Edwards

Other public appointments held at present: N/A

Personal and business interests:

- Member Open Rights Group Advisory Board
- Member FIPR Board
- Member Ada Lovelace enquiry into biometrics
- 10-20% buyout Alan Turing Institute as Law lead
- Member Royal Society enquiry into information/ disinformation

Previous public appointments held within the last five years: N/A

Political activity: N/A

Other: N/A

Dr Alan Hassey

Other public appointments held at present:

- Member National Data Guardian Panel

Personal and business interests:

- Founding fellow & member of Council for the Faculty of Clinical Informatics
- Fellow of the Royal College of GPs
- Member of the RCGP Health Informatics Group
- Member of the BMA.

Previous public appointments held within the last five years: N/A

Political activity: N/A

Other:

- Retired GP, Retired from NHS Digital as IG Clinical Lead & Deputy Caldicott Guardian.

Professor James Wilson

Other public appointments held at present:

- Professor of Philosophy, University College London
- Member of National Data Guardian’s Panel and Steering Group
- Member of Faculty of Public Health’s Ethics Committee
- Member of North Central London Analytics Board
- Associate Editor of the journal Public Health Ethics.

Personal and business interests: N/A

Previous public appointments held within the last five years:

- Member, NHS Digital Data Access Advisory Group (2015–7)
- Member, NHS Digital Independent Group Advising on the Release of Data (2017-18)

Political activity: N/A

Other: N/A

John Marsh

Other public appointments held at present:

- Member NHSx Data Collaborative
- Deputy Chair - Independent Panel on Data Release PHE

Personal and business interests:

- Director, Albion Wharf Residents Ltd

Previous public appointments held within the last five years:

- Member National Data Opt-Out Panel, NHS Digital

Political activity:

- Chair, Battersea Conservative Association Trust

Other:

- Member of the Advisory Group for useMYdata

Richard Stephens

Other public appointments held at present:

- Advisory Groups for NHS England Cancer Patient Experience and Cancer Patient Experience Survey groups (adults and children/teens)
- National Data Collaborative Advisory Group
- useMYdata
- Medical Research Council Clinical Trials Unit
- Genomics England
- Trial Steering Groups for National Institute of Health Research and Macmilland
- I also have honoraria for roles as a journal Editor for BioMed Central and patient advocate with Cancer Research UK and the National Cancer Research Institute and a voluntary role with the Biobanking Methodology and Research Infrastructure European Research Collaboration Initiative.

Personal and business interests:

- Consultancy roles between 2015-2018 with Astra Zeneca and Pfizer (none exceeding £1000 pa)

Previous public appointments held within the last five years: N/A

Political activity: N/A

Other: N/A

4. Code of Conduct

Nolan Principles

Seven Principles of Public Life: Members are expected to carry out their work selflessly, with integrity, objectivity, openness and honesty. The EAB is accountable for the advice that it gives and open to scrutiny for its work. It will exercise leadership in supporting these principles and providing challenge if required.

Declarations of interests. Members will declare relevant interests on a publicly available register and provide a brief biography for public information.

Confidentiality of documents. EAB members may receive draft papers in confidence. These should not be shared and the content should not be discussed in public without seeking the advice of the Chair.

Confidentiality of discussions within the EAB is important to ensure that debate is free and robust. Members are free to make mention of the fact that issues have been discussed, but not to identify any individual views nor attribute any conclusions to the EAB that are not in the public domain.

Objectivity and independence. Board members should avoid making statements that could be viewed as the EAB taking a view that has not previously been agreed or that could be interpreted as pre-empting or pre-judging its discussion in a way that would be perceived as undermining its independence and objectivity. This does not prevent members indicating their personal views prior to EAB discussions provided they show that they remain open-minded and are open to persuasion in the collective debate.

Collective decision making. Advice from the EAB will aim to reflect the complexity of issues, not to over-simplify them. On many aspects, it will be possible to record a range of views. If members feel that divergent views or dissent should be acknowledged in advice, this should be raised before publication so that the EAB can decide collectively how this will be handled.

Collective responsibility for advice issued. Members should not contradict or undermine specific advice provided by the EAB (e.g. through adverse comment in social media, interviews, articles etc).

Freedom of Speech. Members should not be prevented from their normal activities in areas related to the scope of the EAB's work provided that they are consistent with the principles in this Code of Conduct. Members should take care to be clear when they are speaking personally and when as an EAB member.

5. Schedule of Meetings

Date	Summary of key discussion points
2nd April 2020	Presentation from Professor Michael Parker on the main ethical issues for contact tracing apps.
9th April 2020	Discussion of the need for a clear value proposition, equity issues and future uses.
16th April 2020	Discussion of the use of self-reporting in the app and the prospect of a small-area test.
23rd April 2020	Preparation and agreement of the letter to the Secretary of State.
30th April 2020	Discussion of the technical efficacy of the app.
7th May 2020	Discussion of centralised and decentralised models.
14th May 2020	Presentation on the evaluation of the Isle of Wight phase and an introduction from Matthew Gould (CEO, NHSX).
21st May 2020	Discussion of centralised and decentralised models and governance of the app.
28th May 2020	Discussion of the place of the app in the wider test and trace strategy and of data retention issues.
4th June 2020	Presentation of the user journey for version 2 of the app and a discussion of the evaluation of the Isle of Wight phase.
11th June 2020	Presentation from the Modelling & Analytics Team at NHSX.
18th June 2020	An introduction from Simon Thompson (Managing Director, Designate of App) and a discussion of policy issues relating to the app and next steps for the EAB.

6. Letter to Secretary of State

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 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.

<u>Six principles to ensure that the CV19 contact tracing app is ethical:</u>

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.
    - 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.
    - 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.
    - 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.

   - 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.
   - 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.
   - 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
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 *own* 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 as much say over how it is used as possible.	Compulsion/ voluntariness	Is usage voluntary? If requirements are imposed for people to have the app (e.g. to return to work, to use public transport), are these reasonable and non-discriminatory beyond the health status?

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

7. Response to Letter

NHS COVID-19 App

Government response to the Ethics Advisory Board's key principles for an ethical and effective NHS COVID-19 contact tracing app

May 2020

Introduction

The NHS is responding to the coronavirus (COVID-19) pandemic with a range of solutions. The aims of these solutions are to help save lives, reduce pressure on the NHS, return people to life outside the home, and provide up-to-date advice and guidance to members of the public.

Traditional methods of manual contact tracing will play a crucial role in plans to suppress COVID-19, but advances in technology enable us to more rapidly and accurately identify who an infected person has had contact with.

That is why the NHS has developed a smartphone application for contact tracing called the NHS COVID-19 app. The app is intended for two purposes:

1. **As an automated public health contact tracing system**, offering a digital proximity cascade system to help slow / stop the transmission of the COVID-19 virus by notifying those who are showing symptoms to stay at home.
2. **As a means to collect additional data** in a privacy-safe way **for use by the NHS and Public Health** to help better understand COVID-19 and manage the pandemic.

While smartphones can be used to quickly and automatically determine whether someone has been in contact with a person with coronavirus symptoms, people understandably want to be reassured that the app is safe to use and that their privacy is properly protected.

We recognise that there are concerns about the unethical use of tracing technology and the vulnerability to misuse. Our approach seeks to address issues around civil liberties, human rights, the exclusion of those without smartphone technology - and notably, a fear that "mission creep" could eventually lead to unprecedented surveillance of society at large.

It is because of these concerns that the Ethics Advisory Board (EAB) was established. We hope that your expert guidance on the ethical challenges presented by the technology provides assurance that these concerns will be addressed.

We warmly welcome and support your advice and are committed to adhering to the principles you have defined:

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.
2. **Impact**: There must be good reason to believe the app will be an effective tool in controlling the outbreak of COVID-19.

3. **Security and privacy:** Data sharing should be proportionate, and transfers and storage should be secure. The data collected should be minimised and protected, so users' privacy is preserved.
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.
5. **Transparency**: Details on what data is gathered and why, as well as the app's code and underlying algorithms should be available publicly to enable scrutiny and give people the ability to object to decisions.
6. **Control:** Users should be able to see what data is held about them so that they can understand how it is impacting on decision.

The full letter from the EAB, and detail on each of these principles, can be found here.

Executive Summary

The NHS needs as many people as possible to download the NHS COVID-19 app, because the more people that use it, the quicker we can stop the spread, protect the NHS, and help save lives.

People want to feel confident that the app will be an effective tool in the battle against coronavirus. But they also want to know that their privacy, data and rights are safeguarded.

This statement explicitly details our commitment to upholding the highest ethical standards in relation to the NHS COVID-19 app. In doing so, we hope to give the public the assurances needed to encourage them to download and use the app.

The ongoing development of the app will require that these ethical considerations be examined openly and transparently over time. As such, we welcome the continued oversight and constructive challenge provided by the EAB.

In addition, we will continue to seek expert advice and guidance on considerations relating to equality, human rights, information governance, legal, privacy and safeguarding.

We all have a role to play in the success of the NHS COVID-19 app. It is vital that members of the public who download and use the app do so responsibly. The continued oversight by the EAB is crucial. And I am pleased that we can adhere to the principles you have set for us.

At a minimum we will:

- Ensure the protection of user data is central to our approach
- Make the app voluntary to download and use
- Be clear about the decisions made in the app's development
- Communicate in clear and plain language
- Only roll out the app if we are confident it will help

The full detail of these and other commitments are set out below.

Thank you for your time and advice. We look forward to continuing to work closely together.

Detailed commitment

In response to the ethical principles put forward by the EAB, the NHS and Government have committed to the following.

EAB Principle #1: Value

Provide sufficient value back to the citizen or society as to justify its introduction and any adverse consequences for individuals. There must be good reason to believe the app will be an effective tool in controlling the outbreak of COVID 19.

Commitments:

- The value of the app will be clearly communicated to users
- The app will be used as part of a wider package of measures and with the sole purpose of responding to COVID 19 and better understanding the epidemi
- The decision to decommission the app will be assessed under clear criteria agreed in advance with the NHS and Public Health (PH). This will be published

EAB Principle #2: Impact

There must be good reason to believe the app will be an effective tool in controlling the outbreak of COVID 19.

Commitments:

- The app will be simple and easy to use with appropriately worded advice and alerts
- The purpose of the app will be clear to users and wider society
- Where there are changes, these will be clearly articulated

EAB Principle #3: Security and Privacy

Data sharing and storage should be secure. The data collected should be minimised and protected, so users' privacy is preserved.

Commitments:

- Any data shared and stored will follow established NHS procedures for data security. Where there are changes, these will be clearly articulated
- The principles of data minimisation and privacy protection will safeguard the user's identify and data
- Users may give specific agreement to voluntarily provide additional data
- If there is a reasonable doubt relating to the app's security, it will not be deployed
- Commitments to the app's security will be published
- Users will be notified if any security or data breaches occur 5
- Should a data or security breach occur, a comprehensive assessment will be undertaken. This will include actions to mitigate the risk of any further breaches

- The app will not track a user's location without agreement. Only proximity to another user will be recorded
- Agreement will be sought from people who are willing to donate their data for research
- The data that is donated for research will only be made available to those who have been approved by the NHS

EAB Principle #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.

Commitments:

- We support the independent Ethics Advisory Board (EAB) now and for future iterations of the app
- We will ensure there is a clear governance structure and engagement path to ensure decisions are not made in isolation. Stakeholders, including the EAB, will be consulted in relevant decisions related to the app
- The EAB will be actively consulted in the development, design and implementation of the app
- There is a risk register which is available to the EAB for input and comment
- The effectiveness and impact of the app will be frequently monitored using thresholds to assess the suspension or withdrawal of the app
- The user can change their mind about using the app

EAB Principle #5: Transparency

Details on what data is gathered and why, as well as the app’s code and underlying algorithms should be available publicly to enable scrutiny and give people the ability to object to decisions.

Commitments:

- Information about the data collected and how it will be used will be communicated to users in clear and plain language before they download the app or share any data
- All communications made via and about the app, will be transparent and proportionate.
- The app’s source code and underlying algorithms will be publicly available
- Changes to the app’s terms and conditions will be explained to the User
- Information that is in the public interest, such as data on app take-up, will be published
- A mechanism will be in place for users to feedback or complain
- Obligations to the legal, Caldicott Principles, Information Commissioner’s Office and NHS Constitution will be honoured to protect the user’s privacy
- The NHS will not:
    - Allow, for example, the police, security services or other law enforcement agencies to access unpublished app data, unless it is forced to do so by the courts
    - Allow app data to be used for insurance or marketing purposes
- The NHS is prepared to take all necessary action, including (where appropriate) recourse to legal proceedings to prevent such attempted access

EAB Principle #6: Control

Users should be able to see what data is held about them so that they can understand how it is impacting on decisions.

Commitments:

- The minimum set of data required to use the app will be made clear to the user
- Downloading, using and deleting the app will be voluntary
- If any data is to be retained by the NHS when the app is deleted, this will be made clear to the user

8. Email on centralisation/decentralisation

18 May 2020

Dear Matthew,

Thank you for coming to speak to the Board last week, it was appreciated by all the members.

I said that I would email with some observations about the ethical aspects of comparing the current architecture of the app with possible 'decentralised' alternatives and in particular the Google/Apple (G/A) initiative.

We have noted the considerable public debate about this issue, had the benefit of a specific discussion last week, and reviewed commentary on the main advantages and disadvantages of each approach. We have not yet had an opportunity to be briefed by David Brown on his rapid review, which I hope will happen early this week. We also understand that a publication is due from the World Health Organisation this week on the ethical considerations to guide the use of proximity contact tracing. We would want to consider both these before consolidating our advice.

As we set out in our letter to the Secretary of State, we believe that any approach should be guided by six key principles: value, impact, security/privacy, accountability, transparency, and control. And as we heard from you last week, you, too, are committed to upholding these principles as you continue to develop the NHS Covid-19 app. With that in mind, regardless of which architecture is chosen for the app, these principles should be the main guide for considering the ethical dimensions of decisions.

We have heard a number of points that are relevant to the value proposition of the current architecture but which it is thought might not be available under the G/A approach. These include matters that go to the public health benefits and also the effectiveness of the system.

- epidemiological information,
- the identification of possible 'super spreaders' who trigger a high number of alerts,
- the ability to detect unusual patterns of alerts
  that may indicate potential distortion or attempts to manipulate the system,
- the importance of being able to understand the pattern of contacts in order to enable more precise advice to be given to contacts alerted via the app,
- the possibility of rescinding alerts if appropriate as further information becomes available, which may affect the risks of false positive results and which seems important if self-reporting is to trigger an initial alert.
- the ability to trace secondary contacts

We have not yet been able to receive briefings on how far these can also be achieved with the G/A platform, which we realise is not yet operation, nor on whether there are alternative means by which some of these objectives might be met. Both these are significant in determining what the balance of ethical concerns suggests. We believe that the detailed case for these potential benefits has not been articulated clearly to the public and we think that it is important to do if trust and confidence is to be gained.

We have previously stated in our letter of 24 April 2020 that decisions on the deployment of the app, and about ways to develop its architecture, should be based on the net-value provided back to the citizen or society as a whole taking into account risks of any adverse consequences. The main benefit of the G/A platform has been identified by commentators as enhanced privacy. However, it is also possible that it will be more effective in the detection of contacts and that in the future interoperability between apps internationally may be easier on the G/A API (although this may be dependent on other aspects of the design of app in different countries).

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. Any necessary intrusions into privacy should be proportionate to this legitimate aim. We have noted that the current design of the app and associated systems includes a number of mitigations of the privacy risks and that the NHS app does not collect as much data as the international comparators that are currently deployed. In our view, these mitigations reduce but do not eliminate the greater privacy protections that are offered by a decentralised model.

We recognise that consideration of where the balance lies will need to take into account aspects of the specific context of the app's deployment in the UK. This will include many factors outside the direct remit of the Ethics Advisory Board but clearly relevant to the decisions that Ministers need to take; the wider recovery strategy, including the test and trace programme; the accuracy, reliability and availability of tests; the incidence of disease and the trajectory of the epidemic in the UK; and the social distancing requirements in place. It is for Ministers to make these judgments. In the light of public and media debates about the technology, we believe that it is important that the adoption of model with a degree of centralisation is supported by an explanation of the factors that tip the balance in its favour, including the careful articulation of the benefits to citizens of that are judged to outweigh the difference in privacy protection. This would play an important part in meeting both the principles of transparency and accountability that we set out in our earlier letter.

These principles are relevant to all approaches to contact tracing apps and perhaps just as important as the choice of which to go for, are the commitments made about how the chosen approach is governed. Reassurances about how some of the risks associated with each may be mitigated would be particularly helpful here. This is not the only feature that is likely to increase public trust. We have also previously identified that control by users is an important principle and that where possible, consent should be requested. We note that the all models could enable additional functionality and data collection if consent is given.

A clear governance model identifying how decisions to collect more data or alter the functionality will be taken would help to address trust while also demonstrate the commitment to transparency and accountability. Such trust and confidence is paramount to the success of this endeavour because of the need for a significant proportion of the public to use the app. This is much more likely to be secured if the future governance and legal basis for the app is established and explained clearly to the public before any national launch, including clear and transparent rules relating to data retention, storage and access.

I will write more formally in due course, but I wanted to keep you informed of our thinking.

BW

Jonathan

9. Email on data retention and governance

11 June 2020

Dear Dido and Matthew,

I wanted to write to you following the recent discussions amongst members of the EAB related to the governance of the app to identify two issues that we think deserve attention as priority areas in order to demonstrate that the app is worthy of public trust and a third that may emerge as prominent in the near future. We are aware that they are already under consideration but as decisions may need to be taken soon we thought it would be helpful to pass our reflections on to you.

These are:

Retention of data. It is important that the public is clear about the policy on data retention. We believe that there are at least three categories of retention requirements where it would be helpful to spell out more strongly the rationale and fix appropriate periods for retention.

- The operation of the app requires phones to store proximity logs for a sufficient period to enable those who have been in close contact with ‘infected phones’ to be alerted. This should be no longer than the period during which the data suggests infection is possible. I understand from Geraint Lewis that this is under review and a shorter period may now be specified than in the original plan. This is a welcome step in further privacy protection.
- An important part of the case for adopting the current model of the app rather than a wholly decentralised one is that it enables the data submitted when app users identify themselves as potentially affected to be used to identify patterns of possible false alerts (including misuse). This may also inform the evaluation of the app’s contribution to disease control, and help refine the risk assessments used to trigger alerts. This suggests that data must be retained during the deployment of the app and while Covid-19 alert levels remain significant. We would anticipate that the case for such retention would reduce as the scientific data underpinning risk assessments becomes more robust and as experience of the app in real world use increases. It would seem appropriate to commit to the deletion of data once it was no longer required to support understanding of the functionality of the App.
- Nevertheless, there may be compelling reasons for preserving data beyond the Covid-19 pandemic for research if it has epidemiological value and can help preparations for other pandemics. We understand that the true value of the data for these purposes is uncertain and would welcome further discussions of this matter to explore whether the data can be fully anonymised, where it should be held and curated, and how access would be governed so that it was limited to legitimate research purposes.

Governance. We have been pleased to assist NHSX in developing the app as an internal advisory board. We believe that once it is reasonably stable and has been deployed nationally, it will be appropriate to establish clear arrangements for accountability and perhaps independent oversight in respect of the following key matters on which public confidence is properly based:

- Changes to app functionality (including additional data collection) - There may be strong arguments for introducing additional functionality to the app. This could include personalisation of advice as well as introducing new uses. Who will be accountable for any changes to functionality? How will changes to the app be communicated to users? We think ethical advice on these issues would be important and will be happy to continue to provide that to NHSX while responsibility sits there.

- Data access - What governance processes are in place to ensure any data is used for the defined and restricted purposes for which it has been collected? Who will oversee this process? This requires an independent gatekeeping function and is not an appropriate function for an ethics advisory board, although the EAB could assist by developing principles to govern access decisions. It would be helpful to confirm whether access for research purposes will be governed by NHS Research Ethics Committees and the Confidentiality Advisory Group or whether a dedicated access process will be developed. We would also welcome greater clarity on what secondary administrative uses are intended for the data and how the public can be assured that data are only used in accordance with the specified purposes.

Equality and Discrimination issues. In our letter of 24 April to the Secretary of State we noted that the app will not be used by everyone and that those without the app were afforded appropriate protection from the virus. We suggested that if the app became a tool for accessing otherwise restricted services, then there was a potential for increasing inequity and that this risk needed to be considered and addressed. We also identified in our initial trust matrix (Appendix 2 to the letter) that there could be a risk of misuse by non-government agencies. These challenges will become pressing if the app is in widespread national use. It is important that trust is not undermined by public fears about these matters. As these extend beyond the scope of the app's operation they also extend beyond the remit of the EAB. However, we believe that the success of the app will be dependent on public assurance in this area.

Kind regards,

Jonathan Montgomery

Professor Sir Jonathan Montgomery

Chair, Ethics Advisory Board

10. Meeting Notes

Minutes of Ethics Advisory Board,
2nd of April 2020

Attendees:

EAB Board 'core group'

- 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 Bobbie Farsides, Professor of Clinical and Biomedical Ethics, Brighton and Sussex Medical School; - Chair of Nuffield Council working party on research with children
- 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.
- Dr Alan Hassey, Retired GP and member of the NDG
- 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
- Professor James Wilson, Professor of Philosophy University College London and member of the NDG

Speakers	*Staff and secretariat*
Professor Michael Parker (Director of the Wellcome Centre for Ethics and Humanities)	

Guest Speaker (Prof Michael Parker)

Prof. Parker set out his view of the key ethical issues:

- ⅓ of global population in lock-down. We are not in a usual time
- This can only work if there is genuine trust from people
- This means communications are really important. If you do not get this right, this is not going to work.
- Normally we would like to explore the landscape - there is not a lot of time to do this.

Following the presentation, the **Chair** highlighted two issues:

1. Timescales: there is an ongoing discussion of launch date
2. Mechanism by which we will have impact - ensuring our advice and recommendations reach the right people at the right time

Summary of Meeting

1. The Terms and Conditions were *agreed*.

2. There is a fundamental question of whether the App is likely to be effective. The EAB needs to consider whether it is ethical to encourage people to download and use it.

3. What is the offer to users? How is this being articulated?

EAB would like to review initial communication thoughts - it is vital that communication is transparent, clear and honest about potential uses

4. The reliance of self "diagnosis" was questioned. Is the App likely to rely on data of questionable quality? How will it be validated? Are there plans for the App to receive data from antibody tests? How is this being communicated?

5. EAB discussed the issue of compulsion and agreed that this would be ethically (and practically) challenging). However, the value of incentives was discussed and it was agreed that these need to be proportionate to the offer to users, while recognising there also be equity issues.

6. Questions about firm barriers around secondary data use. What promises/guarantees are being made? How will these affect uptake and future use (and trust)?

7. There is a question about what data is deleted if people remove the App from their phones. The secretariat agreed to provide an answer to this from the App development team

****

Minutes of Ethics Advisory Board

9th April 2020

Attendees:

EAB Board 'core group'

- 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.
- Dr Alan Hassey, Retired GP and member of the NDG
- 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
- Professor James Wilson, Professor of Philosophy University College London and member of the NDG

Staff, secretariat and advisors

Summary of the Key Issues Raised

1) The Board noted the findings from the public focus groups which revealed a general acceptance that an App could be valuable and many people would consider downloading and using it. However, there is a scepticism in the reliance on self-reporting which could undermine trust in the App.

2) Self-reporting remains an issue for the Board (in relation to the fundamental effectiveness of the App), as well as other stakeholders. It is clear that there are lots of variables relating to the topic of self-diagnosis, including the availability of tests, timing of the launch of the App, as well as the wider strategy. The EAB would like to further review the evidence in relation to the reliability of the data, as well as engage with others to understand the broader strategy. EAB would welcome support from NHSx to facilitate this.

3) It is evident that the value proposition to users still needs clarifying. EAB would like to review this further alongside the onboarding communications. The EAB highlighted that wording around tracking needs careful thought and explanation - noting that location data could be valuable, but may also deter people from using the App.

Of particular interest is how possible future uses are being explained and how the value or purpose of collecting geo-location data is being articulated. The Board highlighted the need for transparency. For example, if things were to change, people may need to be given the opportunity to express preferences/choices about interacting with the app in light of those. In addition, the Board would also like to review how alerts users receive after they have been in contact with someone who self-diagnoses are worded.

4) The Board discussed equity issues and agreed that this is something that requires a watching brief. While the Board understands that the effectiveness of the App may not be undermined if certain groups cannot access the technology, issues of equity may undermine trust. Furthermore, the more useful the App is to individuals, the more stark the equity issues could become. The EAB understands that DCMS is leading work on making smartphones more accessible and the EAB noted that this is important work and would like to understand its objectives and approach.

5) EAB welcomed the roundtable the CDEI convened to consider privacy and data collection issues. One of the requests from the roundtable was that the code is made available as open source. We would encourage NHSx to make such a commitment and ensure that the code is available at launch as this would address trust issues and demonstrate a commitment to transparency.

Actions:

1. Investigate whether there is a plan to make the app code publicly available

2. Provide updated communications about the app when available
3. Provide information on the risks of malicious attacks on the app
4. Provide information on the range of measures that may be introduced alongside the app
5. Share an update on government work looking at improving access to technology

****

Minutes of Ethics Advisory Board
16th April 2020

Attendees:

EAB Board 'core group'	**Others**
Professor Sir Jonathan Montgomery (Chair) Roger Taylor (Vice chair) Professor Luciano Floridi Dr Alan Hassey (representing NDG) Nicola Perrin Dame Glenys Stacey Professor James Wilson (representing NDG) *New members* Gus Hosein John Marsh Richard Stephens	*Staff, secretariat and advisors* *Guests* Dr Paul Crook, Public Health England Professor John Watson, Public Health England

Key points from the meeting

1. Updates

1.1. The Chair welcomed three new members to the meeting and provided an update on the recent App Oversight Board.

1.2. The Board discussed the recent announcement that Apple and Google are intending to work together to develop a contact tracing app and were interested to know if this presented a challenge to the NHSx work. The Board were informed that currently it did not appear that plans had changed as a result of the announcement however the secretariat would share further information when available.

Action: Update the Board on any developments from the Apple and Google announcement

2. Self-reporting, testing and alerts

2.1. The Board discussed the challenge of self-reporting and the corresponding alerts that would be sent to users. Guests from Public Health England (PHE) provided further context to this discussion, setting out their views regarding the importance of alerts linking up with PHE guidance. The Board discussed the challenges around self-reporting and verified test results and the fact that there is a likely trade off between speed and accuracy. There was also a discussion about whether introducing a testing element would undermine anonymity which is also important for securing trust in the app.

2.2. The Board reiterated their belief that whilst self-reporting helps by speeding up the process, confirming test results is also important to preserve public trust. The secretariat agreed to share the wording of the alerts to ensure this matched with the Board's expectations.

2.3. The Board discussed the importance of monitoring the app's effectiveness, whilst preserving the privacy of users.

Action: Share wording of the alerts with the Board when available

3. Small Area Testing

3.1. The Board discussed NHSx's plans for a small area test to test the app in a defined location. The Board raised many questions about the pilot including whether there were plans to test the app in line with lifting restrictions, and whether the alerts would be simulated or based on real proximity events. The secretariat informed the Board that plans were changing rapidly and decisions on these topics were seemingly yet to be made, however the Board could feed in their views.

3.2. The Board suggested that the risks need to be carefully considered before the pilot goes ahead, including contingency planning if it were to go wrong. The Board felt that if the test was intended to provide an evidence base for effectiveness prior to launch, it was important that the testing environment should be as representative as possible to a full-scale launch in order to draw meaningful conclusions. They also noted that risks should be closely monitored throughout and a thorough review post-testing should be conducted and used to inform the decision on a full-scale roll out.

3.3. The secretariat agreed to draft text setting out requirements that should be agreed to prior to a pilot. They also agreed to seek answers to the questions raised by the Board, share regular updates on developments, and seek their advice between meetings if required.

Action: Draft text setting out requirements for an ethical pilot
Action: Share further information on the details of the pilot when available

4. Prioritisation of ethical issues

4.1. The Board was asked to provide feedback on a document setting out a prioritisation framework for ethical issues. The Board liked the approach and suggested that further detail on security components would be helpful.

5. Membership

5.1. The Board were asked to consider whether there were gaps in the Board's expertise that could be filled by bringing in additional members. Suggestions were made regarding patients from vulnerable groups and someone with a specialism in equality issues. The Chair and Vice-Chair agreed to follow-up on this topic outside the meeting.

****

Minutes of Ethics Advisory Board
23rd April 2020

Attendees:

EAB Board members	**Others**
Professor Sir Jonathan Montgomery (Chair) Roger Taylor (Vice chair) Professor Luciano Floridi Dr Alan Hassey (representing NDG) Nicola Perrin Dame Glenys Stacey Professor James Wilson (representing NDG) Gus Hosein John Marsh Richard Stephens	*Staff, secretariat and advisors*

Key points from the meeting

1. **Updates**
   1.1. The Chair welcomed everyone to the meeting. The Board agreed the notes of the last meeting were an accurate record
   1.2. The Chair set out how the main purpose of the meeting was to discuss and agree the next steps for sending a letter to the Secretary of State.
   1.3. The Chair suggested there should be an additional voluntary briefing call on Tuesday evenings following the App Oversight Board to update the EAB between meetings. It was agreed this would be useful.
   1.4. The location of the first phase of roll-out has been confirmed as the Isle of Wight. This would be accompanied with an increased rollout of testing on the Island as part of the broader track and trace programme.
   1.5. The evaluation criteria for the first phase of rollout is still being developed but the board was told that there is a specific focus on accessibility and equalities.

Action: Set up weekly briefing calls for the EAB on Tuesday evenings

2. **Digital and traditional contact tracing measures**
   2.1. In response to a paper circulated on the challenges faced by digital and manual contact tracing, the board discussed how epidemiologists view digital contact tracing

as being part of a wider range of measures, rather than a single solution to lockdown.

2.2. The Chair updated the Board on a presentation given to the App Oversight Board, whereby the app forms one of six pillars. The Chair noted that whilst the EAB does not have the remit to advise on the other five pillars, the context is important in considering the ethical implications.

2.3. The board questioned whether the app is intended to be used across the devolved administrations. The Chair noted that the devolved administrations have representation on the oversight board however the primary decisions are made by the UK government and English health bodies. The secretariat suggested that the role of the EAB is to advise NHSx which is an English body, however other administrations may choose to adopt the app.

3. Letter to the Secretary of State

3.1. The Chair apologised for the pace at which the letter was being developed. He explained that this is due to the swift developments regarding the app. He outlined that the priority was to seek agreement on the shape and key foundations with drafting points to be followed up outside the meeting.

3.2. The board agreed that the principles of “value” and “impact” should be separated as value relates to whether the app is fair and impact is concerned with whether it will work.

3.3. The board discussed and agreed a range of points where there was clear consensus including adding a requirement for a thorough data protection impact assessment, amending wording to capture the fact people may be inconvenienced by the app and include additional detail on the background and experience of the EAB membership.

3.4. The group agreed that it is important to acknowledge that developments are occurring rapidly due to the circumstances, however the speed should not impede or lessen the necessary scrutiny and oversight.

3.5. The board discussed how they should be able to provide strong, independent advice however any advice is time bound, based on the information made available to them at that time. The board felt strongly that their advice given at one stage should not be used as a licence for unauthorised justifications at a later stage without thorough engagement first.

3.6. The board discussed whether there is an ethical imperative to use, or explore the use of, technology to help solve a crisis if there is an expected benefit. One member noted that there is a tendency to focus on the risks because clearly these have the greatest ethical implications, however it was important to recognise these in the context of the benefits the app will bring.

3.7. The board discussed the importance of getting the app right in the context of how it may affect the use of technology across the public sector. If the app does not work or does have put in place safeguards to facilitate public trust, this could have a broader impact.

3.8. The board agreed to include details on the importance of the EAB needing to have an ongoing role in reflecting on the challenges surrounding the app, rather than just at major stop-go points.
3.9. There was a discussion about the need to place transparency as central to this work. The board wanted greater transparency about their role and hoped more information would be put in the public domain soon - including publication of its terms of reference and membership.
3.10. The group agreed that references may not necessarily be helpful in the context of a letter, but it should be clear that the Board's thinking has built on reports and expertise of a wide range of people.
3.11. The Board agreed to express conditional support for the App in its letter to the SofS.
3.12. The secretariat agreed to circulate the amended letter very shortly to be signed off at the end of the week.

Action: Share DPIA and privacy notice, and Terms and Conditions with EAB
Action: Update letter in line with board member's comments
Action: Circulate revised letter to board members for final comments before sign-off

****

Minutes of Ethics Advisory Board
30th April 2020

EAB Board members	**Others**
Professor Sir Jonathan Montgomery (Chair) Roger Taylor (Vice chair) Professor Luciano Floridi Dr Alan Hassey (representing NDG) Nicola Perrin Dame Glenys Stacey Professor James Wilson (representing NDG) Professor Lilian Edwards Gus Hosein John Marsh Richard Stephens	*Staff, secretariat and advisors*

Key points from the meeting

1. **Updates**
   1.1. The Chair welcomed the EAB's new member (Lilian Edwards).
   1.2. There were no comments on notes from the previous meeting.
   1.3. The Chair updated the EAB on the publication of the letter and highlighted that both NHSx and the EAB wanted this to be published as soon as possible.

1.4. The Chair updated the EAB on the App Oversight Board including the news that a new equalities board would be established. There is also a plan for Privacy International to carry out a privacy assessment of the App.

1.5. The plans to roll the app out on the Isle of Wight are progressing and are expected to be announced and launched next week. The Board were keen to understand more about the evaluation that would accompany this stage of the rollout, particularly on evaluating the app's effectiveness. The secretariat agreed to provide further information.

Action: Provide further information on the evaluation of the IoW.

2. App functionality

2.1. Board members wanted to know the proportion of phones in the UK that support the app.

2.2. Despite the technical briefing that the EAB received, there remained further questions about the extent and implications of data centralisation. The Board agreed that bringing in further expertise would be helpful to consider these important questions.

2.3. Board members noted that if even pseudonymised, the data was still personal data and this should be consistent across all documentation.

2.4. It was noted that there have been questions about technical fixes such as keeping the phone unlocked and having the app running in the foreground for it to function effective.

Action: Provide further information on outstanding app functionality questions.

3. Communication

3.1. EAB highlighted that delays in communication would risk giving the impression that NHSx is not being transparent.

3.2. The group discussed the ongoing debate in the media and elsewhere about the centralisation and decentralisation approaches.

Action: Share initial communications materials

4. Documentation

4.1. In addition to the terms and conditions, data protection impact assessment and privacy notice being published, the EAB emphasized the need for simple and easy to understand information to explain how data is being used.

4.2. Members expressed a desire to see a data flow map.

Action: Share updated versions of the relevant probity documents
Action: Share data flow material

****

DRAFT: 25 August 2020

Minutes of Ethics Advisory Board

7th May 2020

EAB Board	Others
Professor Sir Jonathan Montgomery (Chair) Roger Taylor (Vice chair) Professor Luciano Floridi Dr Alan Hassey (representing NDG) Nicola Perrin Dame Glenys Stacey Professor James Wilson (representing NDG) Professor Lilian Edwards Gus Hosein John Marsh Richard Stephens	*Staff, secretariat and advisors* *Guests* Professor Ross Anderson

Key points from the meeting:

1. Updates

1.1. The Chair referred to the ongoing public debate about centralisation versus decentralisation.

1.2. It was agreed that the first discussion should focus on the technical questions followed by a second meeting on the epidemiological value proposition. The Chair suggested the Board use the framework from the letter sent to the Secretary of State to consider how each approach correlates to the principles outlined.

1.3. There were no comments on the notes from the last meeting.

1.4. The Chair updated the Board on the App Oversight Board including news about the launch of the app on the Isle of Wight. It was reported that there was a general sense of momentum, with 33,000 downloads and 21 requests for home testing swabs on the Island. The Chair expressed the Board's view about the importance of securing public trust as well as understanding the evaluation aspects of the Isle of Wight rollout to the App Oversight Board.

1.5. The letter sent by the Board to the Secretary of State has been cleared for publication.

1.6. The Chair invited comments on the Terms & Conditions and Privacy Notice for the app.

1.7. Board members noted the report from Privacy International on V1 of the App.

1.8. The Vice Chair gave an update on an international meeting that was held by CDEI with a number of countries that are developing apps to share experiences of their different approaches.

2. Discussion on centralised and decentralised

2.1. Professor Ross Anderson, Professor of Security Engineering at the University of Cambridge joined the meeting.

2.2. Professor Anderson talked about the issue of false positives (and negatives), the role of the App as a medical device, and raised questions about the app's evaluation. He also highlighted the need to consider how the data collected would fit in with the broader track and trace programme.

2.3. Board members highlighted the importance of having a clearly defined set of purposes for the app.

2.4. Board members reflected on the need for a strong communications strategy and made reference to inaccurate comparisons that some parts of the media have made and the damage such a narrative will have on trust.

3. Review and evaluation of Isle of Wight rollout

3.1. An overview was given of the paper setting out plans for the review and evaluation of the Isle of Wight launch.

3.2. Board Members recommended that evaluation be ongoing and suggested that findings should be used to assess the reliability of previously used evidence.

****

Minutes of Ethics Advisory Board

14th May 2020

EAB Board members	**Others**
Professor Sir Jonathan Montgomery (Chair) Roger Taylor (Vice chair) Professor Luciano Floridi Dr Alan Hassey (representing NDG) Nicola Perrin Dame Glenys Stacey Professor James Wilson (representing NDG) Professor Lilian Edwards Gus Hosein John Marsh Richard Stephens	*Staff, secretariat and advisors* *Guests* Professor John Newton, PHE Matthew Gould, NHSx Orlaith Fraser, NHSx Alex Birtles, DHSC

Key points from the meeting:

1. Updates

1.1. The Chair welcomed Alex Birtles (Advisor to Baroness Dido Harding) and made reference to the consideration that an Ethics Board sits across the test & trace programme.

1.2. There were no comments on the notes from last meeting.

1.3. Alex Birtles gave an overview of the four components of the test and trace programme: Testing, Tracing, Containment and Certification. Alex invited the

Board's involvement across the full scope of the programme. The Board welcomed this proposition.

1.4. The Chair referred to the draft Terms of Reference for the Board for an ethics board sitting across the programme and requested comments overnight. The Chair suggested these be reviewed again in 3 months' time given this short window.

1.5. Members suggested that the Board might consider inviting new members to broaden the expertise, if it does take on a broader role across the programme.

2. Evaluation of the Isle of Wight

2.1. Dr Orlaith Fraser gave an overview of the approach to evaluation across the programme, including the Isle of Wight rollout and welcomed advice from the Board as the programme progressed to the national phase.

2.2. Dr Fraser discussed the evaluation themes for the app which include questions on the app's functionality and assessments of user attitudes to the app and the insights gained from its deployment.

2.3. Household surveys are being delivered on the Isle of Wight to gain additional insight on attitudes to the app and barriers to using it.

2.4. Dr Fraser noted that evaluation would be ongoing and that insights gained from the Isle of Wight phase would be used to develop and improve the national rollout strategy.

3. Update from NHSx and Matthew Gould

3.1. Matthew Gould expressed thanks to the Board for their work and acknowledged the challenge of working on such a fast-moving project and the unique circumstances under which it is being delivered. Mr Gould noted in particular the usefulness of the principles developed by the Board in navigating this new challenge.

3.2. A policy team is being established to respond to issues arising from the app.

3.3. Mr Gould stated that the ultimate goal is to do the most good in the fairest, most equitable and transparent way. He reiterated that the app is not a standalone solution but part of the broader test and trace strategy.

4. Advice on centralised and decentralised approaches

4.1. An overview of the discussion paper on the centralised approach was given.

4.2. Board members requested further detail on the decentralised system to be included in the paper and agreed to provide comments overnight.

5. The Public Health Context

5.1. Professor John Newton gave thanks to the Board and recognised the importance of their role.

5.2. Professor Newton gave an overview of the test and trace programme and explained that the app was complementary to a broader effort of increasingly rapid and widespread testing, integration with manual contact tracing and updated advice on isolation.

5.3. There was discussion of the secondary functionality of the app and the value of the data it might gather in comparison to traditional methods. Professor Newton highlighted that the novelty of the digital approach makes it impossible to know for certain the exact value of the data in advance. However he did note that the volume and granularity of the data could be very interesting.

****

Minutes of Ethics Advisory Board
21st May 2020

Attendees:

EAB Board	**Others**
Professor Sir Jonathan Montgomery (Chair) Roger Taylor (Vice chair) Professor Luciano Floridi Dr Alan Hassey (representing NDG) Nicola Perrin Dame Glenys Stacey Professor James Wilson (representing NDG) Gus Hosein John Marsh Richard Stephens Professor Lilian Edwards	*Staff, secretariat and advisors*

Key points from the meeting

1. **Updates**

1.1. The Chair updated on the potential wider role for the EAB in providing ethics advice to the full trace and test programme.

1.2. Tha Chair provided updates on the app timeline and potential changes to how symptom reporting and testing would factor into the app alert system.

1.3. The EAB agreed that the question log should be regularly updated and circulated as a standing item at the board.

Action: Secretariat to update the question log and circulate weekly.

2. **Centralised and decentralised approaches**

2.1. The EAB recommended that policy work which weighs-up the centralisation de-centralised approaches is published.

2.2. The EAB discussed the risks and benefits of the approaches, including the objective of epidemiological research and whether this is a central concern.
2.3. The EAB discussed whether changes to the app functionality towards test results rather than self-reporting affect the overall value proposition.
2.4. The EAB discussed international developments, including the fact that Spain has announced that they intend to develop a decentralised app, and that challenges related to interoperability should be considered.
2.5. The EAB discussed the results from a recent survey that suggested an NHS app would be more trusted than an Apple-Google version, however the board recognised that this may be due to branding, rather than the underlying technology.
2.6. The EAB agreed that its advice to NHSx (sent via email from the Chair to NHSx CEO) on the approaches remains accurate.

3. Governance

3.1. The Chair introduced the paper on governance of the app.
3.2. The EAB discussed potential ethical questions in relation to the voluntary nature of the app, whether there should be limits placed on the retention of data, and whether there should be further provisions on anonymisation.
3.3. They considered how other bodies such as the National Data Guardian are approaching these questions.
3.4. The EAB discussed whether to focus advice on specific questions such as data retention, or advise on an overarching governance framework.
3.5. The was a question on the role of existing guidance such as the Control of Patient Information regulations.

Action: The secretariat to further develop proposals on governance.

4. AOB

4.1. EAB members requested to see an updated data protection impact assessment (DPIA).

Action: The secretariat to request an updated DPIA and share when made available.

****

Minutes of Ethics Advisory Board
28th May 2020

Attendees:

EAB Board	**Others**

Professor Sir Jonathan Montgomery (Chair) Roger Taylor (Vice chair) Professor Luciano Floridi Dr Alan Hassey (representing NDG) Nicola Perrin Dame Glenys Stacey Professor James Wilson (representing NDG) Gus Hosein John Marsh Richard Stephens Professor Lilian Edwards	*Staff, secretariat and advisors* *Guests* Raghuv Bhasin, Test and Trace Programme

1. Updates

1.1. The Test and Trace strategy has been launched by the Government and the app will not be part of this initial rollout.

1.2. The NHSx policy team is scoping issues that may be brought to the EAB for advice.

1.3. The secretariat updated the EAB on the question log and asked for feedback on where more information is needed.

2. Test and trace programme

2.1. The representative from the Test and Trace programme provided an update on how the work was progressing, detailing the four parts of strategy including: Testing, contact tracing, containing and enabling.

2.2. EAB members discussed how the app fits into the plan.

2.3. It was noted that there is a desire to work with the EAB and others on how to develop a transparent system and discussions were ongoing on how best to structure this work.

2.4. The EAB asked about the governance arrangements and it was said that this work is still in development.

2.5. The EAB asked for further details about the “contain” element of the programme, and it was explained that part of this included providing resources to local authorities to manage localised outbreaks.

2.6. The EAB emphasized that the sooner good governance could be implemented, the more successful and trustworthy the programme would be.

2.7. The EAB noted the publication of the initial privacy notice and data protection impact assessment and expressed concerns around some of the terminology in the documents as well as the length of the data retention period.

2.8. The Chair suggested that it will be important for the EAB to bring in a wider network of stakeholders if they provide advice on the wider programme.

2.9. The EAB agreed that timing and pace can be a challenge but this should not hinder the need for good governance and transparency.

3. International experience

3.1. The EAB discussed a report from the Johns Hopkins Project on Ethics and Governance of Digital Contact Tracing Technologies.

3.2. The EAB found the report interesting and helpful with the caveat that certain elements were unique to the US context.

4. Data retention - Governance

4.1. The EAB discussed the question of data retention and emphasized the need for any set period to link to specific purposes and justifications with a clear legal basis.

4.2. The EAB discussed how NHSx should consider what data exists and could be analysed that comes from less intrusive sources.

4.3. A question was raised on timings for feeding in advice and the group agreed that it is important to make sure advice was not sent too late.

4.4. The Chair suggested he send a note to the senior leadership within NHSx, highlighting the EAB's initial thoughts and ensure that requests for advice do not come too late into the decision making process.

Actions:

- Secretariat to continue developing question log
- Secretariat to update the EAB on any developments regarding their role in the wider programme
- Chair to draft a note to NHSx on advice related to governance of the app

****

Minutes of Ethics Advisory Board
4th June 2020

Attendees:

EAB Board	**Others**
Roger Taylor (Vice chair) Professor Luciano Floridi Dr Alan Hassey (representing NDG) Nicola Perrin Dame Glenys Stacey Professor James Wilson (representing NDG) Gus Hosein John Marsh Richard Stephens Professor Lilian Edwards Apologies Professor Sir Jonathan Montgomery (Chair)	*Staff, secretariat and advisors* *Guests* Peter Whawell (Deputy App SRO, NHSx) Dr Orlaith Fraser (Evaluation in Data and Analytics, Test and Trace Programme, NHSx) Ian Levy (NCSC / App Cell) David Evans (Information Governance Policy NHSx)

1. Updates

1.1. The EAB agreed that the wording of the notes from the previous meeting should be strengthened in relation to concerns around the privacy documents published for the wider test and trace programme.

Action: Secretariat to amend wording on notes from the previous meeting in line with the suggestions.

2. User journey

2.1. The EAB were updated on how V2 rollout of the app would work, with the launch first being tested on the Isle of Wight prior to national rollout.

2.2. The main changes to V2 include integration with testing meaning alerts will be based on contacts with cases confirmed by testing, rather than based on self-reported symptoms, and there is an updated list of symptoms.

2.3. The EAB were informed that there are benefits expected even at low levels of app adoption because transmission chains can still be interrupted.

2.4. There was a discussion on the geographical challenges that arise from a national rollout and the evaluation team hope to be able to identify take-up blackspots.

2.5. The EAB wanted to know how they can best support the work that must be undertaken prior to national launch in terms of building public trust in the app and this was welcomed.

2.6. The EAB discussed the new system where there are two types of symptoms that correspond to “gates” in the user journey. Questions were raised on whether people are informed that their data is used for research and the implications this has for the app’s governance. Representatives assured EAB members that these questions were being considered.

2.7. The EAB noted that one limitation of the app is that it is not possible to monitor whether people are complying with the guidance.

2.8. The EAB made a further request to see a data flow diagram on how the app links up with the testing system and NHSx agreed that they would share this when available.

2.9. NHSx emphasized that the app is not integrated with manual tracing so if someone reports symptoms and is directed to a manual tracer this tracer will have no details of app behaviour.

2.10. There was a discussion on whether the app could be developed to advise contacts of a case to go for a test and when to isolate. NHSx agreed to consider this further.

Action: Secretariat to follow-up on providing V2 app access to EAB members
Action: NHSx to provide data flow diagram

3. Evaluation of the Isle of Wight test

3.1. The EAB received a presentation on the evaluation of the Isle of Wight test phase, which included information on how the evaluation was conducted and key findings.

3.2. The main evaluation process was a survey sent out to all residents conducted by NatCen that received 18,000 responses including both those who did and did not download the app.

3.3. The demographic breakdown showed that older people were less likely to use the app.

3.4. It was noted that there were a number of limitations with the evaluation, including the inability to assess long term impacts and the fact that the Isle of Wight is not demographically representative of the UK.

3.5. The EAB emphasized the importance of understanding findings around how likely different groups are to download this app and how this may need to be addressed by the wider programme.

4. **Data protection impact assessment**
    4.1. It was noted that the EAB had not received V2 of the DPIA.
    4.2. A representative from NHSx outlined the changes from the first version of the data protection impact assessment (DPIA).
    4.3. The DHSC is now the sole data controller so the DPIA has been put into a new template.
    4.4. The NHSx Information Governance (IG) Policy Team are now coordinating the IG across the pillars of the test and trace programme.
    4.5. The EAB discussed the timelines and expressed a strong preference for receiving the DPIA as soon as possible so they can provide constructive comments prior to publication.
    4.6. The EAB emphasised the importance of version control for privacy notices.
    4.7. The EAB asked what the role of the ICO was in developing and advising on the documentation and NHSx informed the EAB that the ICO was being consulted in addition to NHSx's own legal advice.

Action: Secretariat to follow-up with NHSx on sharing the V2 Data Protection Impact Assessment for comments.

****

Minutes of Ethics Advisory Board
11th June 2020

<u>Attendees:</u>

EAB Board	**Others**
Professor Sir Jonathan Montgomery (Chair) Roger Taylor (Vice chair) Professor Luciano Floridi Dr Alan Hassey (representing NDG) Nicola Perrin Dame Glenys Stacey Professor James Wilson (representing NDG) Gus Hosein John Marsh Richard Stephens	*Staff, secretariat and advisors* *Guests* Professor Chris Holmes, Head of Modelling & Analytics NHSx App

1. **<u>Updates</u>**
    1.1. Notes from the previous meeting and the amended notes from the meeting of the 28th May were accepted.
    1.2. The Chair thanked the Board for their comments on the second version of the DPIA.
    1.3. The Chair confirmed that the app will become part of the wider test and trace programme and noted that a new Managing Director for the app has been announced.
    1.4. The Vice Chair shared an update from an international roundtable on contact tracing apps, which focused on the importance of evaluation which was held by the CDEI.

1.5. Members agreed to share insights from other international examples for further discussion at future meetings.
1.6. The Chair welcomed Chris Holmes to the meeting to provide an update on modelling and analytics from NHSx.

2. Modelling & Analytics Team Update and Discussion

2.1. Chris Holmes explained that the team has been setting up the in-house analytical environment, to establish a secure environment to support the modelling and analytics functionality required.
2.2. Chris Holmes gave an overview of how the analytics environment functions, explaining that no analyses occur without formal approval. The team has established a modelling and analytics advisory group, chaired by Professor Jonathan Van Tam.
2.3. The group will produce operational dashboards which will visualise the data, and provide useful insight into local outbreak hotspots but will be done in a way which prevents any kind of re-identification. This will use Bayesian hierarchical models to ensure smooth representation while preserving non-identification.
2.4. Chris Holmes explained the advantages of being able to fine tune risk scoring in a centralised model because it is possible to learn from data and modify the risk model accordingly.
2.5. The app may also provide insight on the impact of non pharmaceutical interventions (NPIs), for example restaurants opening, because it allows analysis of an increase of incidence rate at the same time of the introduction of such an NPI.
2.6. The Chair questioned the efficacy of the tracking of outbreak hotspots, given that an individual's postcode doesn't necessarily correlate to where they spend much of their time, and therefore have contact events. Chris Holmes highlighted that the app isn't the only means of measuring localisation and described the postcode like a margin of error, accounting for the fact that it relates to where a user spends a certain proportion of their time.
2.7. There was a discussion around the representation of ethicists on the Modelling and Analytics Group.
2.8. Members discussed how the digital tracing links to manual testing. It was noted that an advantage of digital apps is there is no recall bias and it is possible to understand distance.
2.9. There was a discussion around the role of an app as a useful tool for monitoring epidemiological characteristics of the outbreak even with relatively low uptake.

3. Data Protection Impact Assessment

3.1. The Chair invited members to share views on the updated DPIA.
3.2. Members discussed Article 22 and Lilian Edwards agreed to share some further thinking for the EAB to review.
3.3. Members expressed a desire for clarity on the use of the term “research” in the DPIA, and highlighted that examples would be useful to provide this.
3.4. It was noted that NHSx confirmed there are no trackers in V2 of the app.

****

Minutes of Ethics Advisory Board

18th June 2020

Attendees:

EAB Board	**Others**
Professor Sir Jonathan Montgomery (Chair) Roger Taylor (Vice chair)	*Staff, secretariat and advisors*

Professor Luciano Floridi Dr Alan Hassey (representing NDG) Nicola Perrin Dame Glenys Stacey Professor James Wilson (representing NDG) Gus Hosein John Marsh Richard Stephens	*Guests* Simon Thompson, NHSx David Brown, NHSx

1. Updates

1.1. The Chair noted the statement that was shared as an email update before the meeting.

1.2. There were no comments on the notes from the previous meeting.

1.3. The Chair updated that the revised DPIA for the analytical environment has not yet been approved and therefore has not been shared.

2. Update from Simon Thompson

2.1. Simon introduced himself and acknowledged the importance of having a well defined value proposition for the app and establishing its role in the broader Test and Trace programme. He highlighted the potential advantages of, and necessity for speed, precision and reach for the next version of the app.

2.2. Simon acknowledged the need to communicate both individual and collective benefits and to address scenarios that may deter people from using an app to ensure mass adoption and efficacy. He referred to the need for transparency about how exactly an app is effective, including the data it relies on.

2.3. Members noted that the change of approach raised new ethical questions about the alternative model which they would now have to consider, including questions about how to carry out analytics, identifying false positives and negatives and understanding how the app works within the broader programme.

3. Update from the app policy team

3.1. The team introduced two policy items currently under consideration on which they were seeking the EAB's advice; the use of the app by children and situations which may result in false positives or negatives, including but not limited to the workplace.

3.2. The policy team explained that setting an age limit for use of the app is complicated by a number of factors; medical, legal and ethical. Members provided advice and recommendations on some of the issues raised and offered continued guidance on these matters.

3.3. The policy team gave an overview on their work so far on developing guidance to minimise false positives in certain situations. The team acknowledged that there was a need to maintain critical network infrastructure alongside consistency.

4. AOB

4.1. Members discussed the ongoing role of the EAB and noted the continued need for transparency and the importance of being enabled to fulfil their role as defined in their Terms of Reference.

4.2. Members noted that many of the questions raised during their discussions thus far will remain pertinent in the new approach and warrant ongoing discussion.

4.3. Members agreed that a report on their work so far should be produced to inform the next phase of the programme.

****

Minutes of Ethics Advisory Board
9th July 2020

Attendees:

EAB Board members	**Others**
Professor Sir Jonathan Montgomery (Chair) Roger Taylor (Vice chair) Professor Luciano Floridi Dr Alan Hassey (representing NDG) Nicola Perrin Dame Glenys Stacey Professor James Wilson (representing NDG) Professor Lilian Edwards Gus Hosein John Marsh Richard Stephens	*Staff, secretariat and advisors* Sam Cannicott, CDEI Dr Farzana Dudhwala, CDEI Lisa Whiting, CDEI Maeve Ryan, CDEI Professor Michael Parker *Observers* Hayden Thomas, NHSx *Guests* Baroness Dido Harding, Executive Chair, Test and Trace Programme

1. **EAB final report**
    1. The Chair invited the group to provide comments on the draft version of the report that was shared prior to the meeting.
    2. The board agreed that much had been learnt during the process of advising on the app and that the final report documenting those lessons should be sent to Baroness Harding and Matthew Gould and made available publicly.
    3. It was noted that the parameters of the app evolved during the period of the board's activity and this made providing advice challenging at some points.
    4. It was acknowledged that the pace at which all teams were working meant that sometimes the board did not have all the information they would have liked in order to provide advice.
    5. There was a discussion of the conditionality of the board's advice and some key examples of this, including; accepting that an app was being developed and the role of the board was to advise on how to make it ethical rather than whether or not to develop an app, accepting that the focus should be on the NHSx app and not international examples and accepting in the letter of 24th April that the app would be rolled out and that they would advise on how to do so as ethically as possible. It

was noted how the conditional nature of the advice made its timely publication all the more important.

6. The board agreed on some recommendations for the ongoing response, based on its experience, including; maintain a focus on the purpose of any future solution before the technology and take time to consider future options well in advance.

2. Update from Baroness Harding, Executive Chair of Test and Trace

Baroness Harding thanked the EAB for all their work and reiterated the commitment from the programme to provide value to citizens while ensuring accountability and transparency.

3. AOB

The Chair thanked the EAB and the Secretariat for all of their work throughout the process and agreed to share a final version of the report for the board's comments in the coming weeks.

11. Use by NHS Test and Trace of the Principles

A summary of the advice of the Ethics Advisory Board as taken forward in the NHS Test and Trace App, August 2020

The EAB provided advice to the development of a COVID-19 app during spring 2020. This advice was based around key principles:

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.
2. **Impact**: There must be good reason to believe the app will be an effective tool in controlling the outbreak of COVID-19.
3. **Security and privacy:** Data sharing should be proportionate, and transfers and storage should be secure. The data collected should be minimised and protected, so users' privacy is preserved.
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.
5. **Transparency**: Details on what data is gathered and why, as well as the app's code and underlying algorithms should be available publicly to enable scrutiny and give people the ability to object to decisions.
6. **Control:** Users should be able to see what data is held about them so that they can understand how it is impacting on decision.

These six principles, and subsidiary points made about them by the EAB, are mapped below against the responses we have made in developing the NHS Test and Trace App.

Ethical issue (First raised April 2020)	**How we have embedded the advice (Aug 2020)**
Value There must be good reason to believe that that the app will provide sufficient net-value back to the citizen or society.	The App is designed make fast, accurate digital contact tracing possible while protecting the user's privacy and identity. It uses the minimum amount possible of personal data.
● 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.	We have set out the aims and functions of the app to the user in our privacy notice and associated comms. We have ensured that the app itself sets out clearly what it does and what data is used, and we have ensured the app's text is written in language appropriate for an 8-9 year old reading level. This is a key part of our transparency.
● To encourage citizens to download an app which does not offer a strong value	This consideration has been a key part of development of the app – we have worked

proposition would be misleading and could damage trust, which could in turn reduce the effectiveness of the app and of future technological solutions.	closely with the Information Commissioner's Office, using their contact tracing principles, to ensure the app uses the minimum possible amount of person data. This has been done to build trust. We have developed a comms package in a number of key languages (languages chosen because their speakers are less likely also to speak English) to make the app available to all. Our testing of the app will include high risk groups and geography to ensure we understand the value the app can offer to all citizens.
● The app should undergo an Equalities and Health Inequalities Impact Assessment to ensure that it does not have disproportionate negative impacts on certain groups.	An EHIA has been carried out for the early adopter pilot of the app and this will be refreshed for national roll out. Similarly a Public Sector Equality Duty Statement has been written.
● 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.	The key services available through the app (contact tracing, advice and the access to ordering a test) are also available through other routes. Similarly, citizens can leave their details at a venue they visit to be contacted in the event of an outbreak there, without needing to use the app. The symptoms checker is widely available through the NHS and online.
Impact There must be good reason to believe the app will be an effective tool in controlling the outbreak of COVID-19.	Our development of the app has been backed by modelling and analytics expertise from a range of sources including the Turing Institute to ensure the app will be as effective as possible in controlling COVID-19. However, the early adopter trial also offers the opportunity for more learning and the app will be subject to further refinement as we learn more.
● The app should be technically effective. It would be unethical to encourage citizens to download an app which is technically flawed.	The development of the app using the decentralised model because we judge that the Google / Apple approach has the highest likelihood of achieving the app's stated goals, while collecting the minimum data necessary. At every stage of development, the intention of the UK government has been to adopt the

	technical solutions which support efforts to control the spread of COVID-19. An exposure notification framework was developed by Google and Apple, which supported digital contact tracing. A review was taken to assess the Google / Apple API against the functionality judged beneficial for managing the spread of COVID-19. The functionality of the Google / Apple API was assessed alongside rigorous testing of the original app. Testing revealed that reliability of the original app was not sufficient and would therefore not be effective in helping manage the spread of COVID-19.
● 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.	We have articulated six functions of the app – half as "We" (societal) benefits and half as "Me" (personal) benefits. This approach has been tested with focus groups and we anticipate the inclusion of functionality aimed at personal benefit will be attractive to users.
Security and Privacy The data collected should be minimised and protected as much as possible.	The App has been designed to use as little personal data and information as possible. All the data that could directly identify the user is held on their phone and not shared anywhere else.
● 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.	The legal basis for processing personal data under the General Data Protection Regulation (GDPR) and Data Protection Act (DPA) 2018 law is: • *GDPR Article 6(1)(e)* – the processing is necessary for the performance of its official tasks carried out in the public interest in providing and managing a health service • *GDPR Article 9(2)(h)* – the processing is necessary for medical diagnosis, the provision of health treatment and

	management of a health and social care system - *GDPR Article 9(2)(i)* – the processing is necessary for reasons of public interest in the area of public health - *DPA 2018* – Schedule 1, Part 1, Section 2(2)(f) – the management of health care systems or services - *DPA 2018* – Schedule 1, Part 1, Section 3 – Public Health purposes
● A Data Protection Impact Assessment and a privacy assessment should be carried out to ensure appropriate compliance with privacy and security standards.	A DPIA has been carried out and discussed in depth in draft with the Information Commissioner's Office in their role as a critical friend. Considerable changes have been made in response to their feedback to draw out the privacy protecting measures. A privacy notice has also been provided. Unusually, the DPIA as well as the PN will be published.
Accountability There must be a reliable and understandable decision-making process in place to manage the app - with clear democratic accountability	The app is part of the Test and Trace Programme, which is itself a part of the Department for Health and Social Care. Responsibility for the app flows through Baroness Dido Harding, the Chief Executive of Test and Trace, to the Secretary of State for Health and Social Care. While the Ethics Advisory Board has been concluded, an advisory group for the entire Test and Trace Programme is being set up. DHSC also has a Moral and Ethical Advisory Board which has informed thinking on COVID more widely. Use of the app is entirely voluntary and the user can change their mind about using it and delete it at any time.

● 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.	The app will be kept under continued evaluation to ensure it is functioning as effectively as possible. And changes to app functionality will be notified to users and where necessary the DPIA and privacy notice will be refreshed. Decisions about the ultimate conclusion of the app will be for Ministers and subject to the usual democratic accountabilities.
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	Information about the data collected and how it will be used is communicated to users via a privacy notice for the app which is written in non-technical language as far as possible. The app DPIA is also available – while this is not so accessible to the general reader, it provides valuable transparency to privacy and data specialists. The app's code and underlying algorithms will be available publicly to enable scrutiny. Changes to the app's terms and conditions will be explained and information in the public interest (such as app take up) will be made available. Users will be able to feed back on the app and the privacy notice highlights how they can complain about any data privacy concerns to DHSC. The accessibility statement directs users to a complaints route – via either DHSC or the Equality and Human Rights Commission.
● 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.	The app has been written to have a reading age of 8-9 years which should make it accessible to all. Assistive technologies that have been built in by Apple and Android, such as Voiceover, are compatible with the app.
Control	Downloading the app is entirely voluntary and this is made clear in the privacy notice and

Downloading the app should be voluntary, people should able to delete the app and their data at any point, there should opt-ins for further data sharing and use	associated communications. Users can delete the app and their data at any point. Features for example Check In (QR codes), Symptoms, Booking a Test are all opt in and are not required to be used. Users are asked whether they give permission to share their contacts if they test positive for COVID.
• 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.	See above.
• Additional functionality would require clear communications and opt-ins for existing users.	The DPIA trails possible future functionality in a roadmap, but if any further functionality is introduced it will also be clearly communicated to users. The functionality of the app has been defined to enable the user to use functions separately if they so choose.