

NPHET Ethics Sub-Group Update

1. The Ethics sub-group has provided ethical advice to the development team for the covid tracker app. A copy of the advice can be found in the Appendix below.
2. The Ethics sub-group conducted a stocktake of its work thus far. The discussion addressed what worked, what could be done better and areas that could still be addressed by the group. It was agreed that meetings would continue for the month of June and the subject would be revisited at that point.

Appendix

Observations on the COVID Tracker Ireland App

The Pandemic Ethics Advisory Group (PEAG), a subgroup of NPHE, received a request from the COVID Tracker Ireland App Development Oversight Group to review the project from an ethics perspective. The PEAG welcome the opportunity to provide constructive feedback on the ethical implications of the use of the COVID Tracker App in the control of the COVID-19 pandemic. These observations are based on information available to the group at this time and contained in the App Development and Product Overview document, the product brochure as well as the Data Protection Impact Assessment form.

A number of key ethical principles and procedural values have been described in the “Ethical Framework for Decision-Making in a Pandemic”¹. This high-level document describes a number of substantive ethical principles (including minimising harm, fairness, proportionality, and privacy) and procedural values (including transparency, inclusiveness and accountability) that are helpful in considering the ethical issues related to the development and deployment of the contact tracing app. Careful attention to the principles and values can serve to safeguard the interests of the population and protect against potential infringement of privacy, stigmatisation or discrimination.

Digital proximity tracing offers potential to assist in the response to the COVID-19 pandemic and, harnessed effectively and responsibly, could streamline and accelerate the contact tracing process and thus limit the spread of the outbreak². In addressing such a complex public health challenge as COVID-19, in line with the principle of minimising harm, there is an ethical imperative to explore innovative approaches which have the potential to reduce suffering and/or save lives. To be ethically justifiable, the app must have the potential to provide a significant benefit to society, such as a substantial contribution to disease suppression to outweigh any risks to individual rights and freedoms. It is, however, important to avoid falling into the trap of assuming that such innovation is a good in and of itself, or that

¹ Department of Health (March 2020). Available at: <https://www.gov.ie/en/publication/dbf3fb-ethical-framework-for-decision-making-in-a-pandemic/>

² Ferreti L, Wymant C, Kendall M eta I. *Science* 08 May 2020:Vol. 368, Issue 6491, eabb6936

it necessarily benefits society at large. There is a need to avoid reductionist thinking and technological solutionism³ and ensure the necessary governance and oversight mechanisms are in place to deal with the ethical issues raised by the development and deployment of the COVID Tracker App.

Transparency around the Value Proposition

Contact tracing, whether conducted in the traditional manner or, in addition, via an app, is a public health measure, rather than an individual health intervention. The purpose of both methodologies is to reduce the spread of disease through the population and, as such, it is not aimed at providing direct protection to the individual user. As with many other public health interventions, individuals may be asked to accept interference with their individual rights in the interests of achieving a wider social good. However, it is vital that any such measures are equitable, reasonable, proportionate, in compliance with national and international legislation and which does not discriminate against particular groups or individuals. **It is essential that explicit information regarding the limitations and implications of the technology be openly communicated to all potential users.** Downloading the App is voluntary which is to be welcomed and demonstrates respect for persons. The development team do not mention if any incentives will be offered to encourage or incentivise individuals to download the App. In accordance with the WHO Interim Guidance⁴, incentives or inducements should not be offered to individuals who download or use the App, as this could disadvantage certain individuals or groups who do not have a smart phone or have the digital literacy skills to use the App.

Scientific Validity and Effectiveness

The efficacy of digital proximity tracing apps has yet to be proven and, in effect, their current international roll-out should be regarded as experimental⁵. For this reason, the app should

³ Recasting complex social phenomena like public health as “neatly defined problems with definite computable solutions or as transparent and self-evident processes that can be easily optimized—if only the right algorithms are in place!” Morozov, Evgeny. *To Save Everything, Click Here: the Folly of Technological Solutionism*. 2013:5. This can detract from efforts to address more fundamental structural inequalities.

⁴ Ethical considerations to guide the use of digital proximity tracking technologies for COVID-19 contact tracing. WHO. Interim Guidance 28th May 2020.

⁵ During the Ebola outbreak in Sierra Leone, an Ebola Contact Tracing application was deployed. The app improved data completeness, storage and accuracy, in contact tracing. However, there were significant challenges with the use of an app in this setting and epidemic context. Danquah LO, Hasham N, MacFarlane M, et al. *BMC Infect Dis*. 2019;19(1):810.

not be regarded as a replacement for traditional surveillance measures. As the developers themselves acknowledge, the proposed contact tracing app is being deployed as part of a package of public health measures. The COVID-19 Tracker App should not detract from or be conflated with established public health practices of contract tracing. **The App should only be deployed when testing and manual contact tracing capacity is considered adequate to deal with the demand which will be generated by digital proximity tracing.** Moreover, supports must be available to make sustained self-isolation possible and consideration needs to be given to employment protections for those who may have to self-isolate on repeated occasions.

The COVID-19 Tracker App uses proximity of mobile phones as a proxy for contact. There are questions regarding the reliability of data retrieved via Bluetooth and whether environmental or other factors such as being in the open air, separated by physical infrastructure (e.g. walls that may allow Bluetooth connection but limit the spread of infection), being in densely populated urban areas, or the use of PPE, might impact data quality, and potentially lead to false positives or false negatives. This may result in giving people a false sense of security or induce unnecessary anxiety in users. Careful consideration also needs to be given to the impact of receiving information and instructions through the App. The effectiveness (e.g. likelihood to comply with the public health advice) of receiving this information through a digital message rather than through a personal contact should be examined.

Innovation is promissory by nature and does not always fulfil its initial promise. Given the emerging nature of digital contact tracing, and in line with the procedural value of responsiveness, the app once deployed should be subject to continuous and rigorous review. It will be essential to measure its effectiveness and impact, not only to build public confidence in its reliability, but also, to foster trust in public and private entities involved in its design and implementation. **If the app is proven to be ineffective in suppressing COVID-19 for whatever reason, then its use should be phased out at the earliest juncture.**

Transparency and Trustworthiness

The effectiveness of the technology is reliant on the proportion of the population that installs and uses the app. Estimates regarding the proportion of population needed for successful

implementation range from 40% to 75%.^{6,7} Garnering public trust in the technology will be critical to reaching these targets. At the heart of this enterprise, is the trust individuals will have to place in the HSE and Department of Health to use and share their data in a way which does not harm the individual but serves public health goals. However, trust is only meaningful when it is directed towards activities and institutions which are trustworthy⁸. The necessary elements of trustworthiness include honesty, competence and reliability. Rather than simply focussing on how to engender trust amongst the general public in relation to the App, an emphasis should be placed on ensuring the trustworthiness of the App and the accountability, integrity, and transparency of the governance of its development, deployment and use.

The explainability of the technology as well as its intentions and limitations is critical as the technology is part of a decision-making process which could have considerable impact on individuals' lives (e.g. the ability to work or socialise). People will need to understand and value the App if their acceptance of it and use are to grow. Any perceived lack of transparency would risk undermining trustworthiness.

Privacy Concerns

The use of a mobile phone app built on gathering and sharing of proximity information, even if pseudo-anonymised, does raise privacy concerns. The Privacy-by-Design approach adopted by the developers and the privacy preserving protocols are thus appreciated. **The PEAG notes the focus on data minimisation, data security, and oversight and considers complete transparency about the proposed and actual data uses planned now and in the future as a necessary pre-requisite to the deployment of the App.** It must meet the requirements of the European Data Protection Board's Statement on the Processing of Personal Data in the Context of the COVID-19 Outbreak⁹.

⁶ Effective configuration of a Digital Contact Tracing App: A report to NHSX; 2020 https://github.com/BDI-pathogens/covid-19_instant_tracing/

⁷ Ada Lovelace Institute. Exit through the app store? A rapid evidence review on the technical considerations and societal implications of using technology to transition from the COVID-19 crisis. Ada Lovelace Institute; 2020 <https://www.adalovelaceinstitute.org/wp-content/uploads/2020/04/Ada-Lovelace-Institute-Rapid-Evidence-Review-Exit-through-the-App-Store-April-2020-1.pdf>

⁸ O'Neill. Linking Trust to Trustworthiness. *International Journal of Philosophical Studies* 2018;26(2):293-300.

⁹ EDPB, Statement on the Processing of Personal Data in the Context of the COVID-19 Outbreak, Adopted 19 March 2020. Available at: https://edpb.europa.eu/sites/edpb/files/files/file1/edpb_statement_2020_processingpersonaldataandcovid-19_en.pdf

Data is being collected in different formats by different organisations (public and private) and being shared and stored with various third parties for a variety of reasons. **Details on what data is being gathered, by whom, for how long it will be stored and for what purpose must be communicated to the public in an accessible manner to support informed decision-making. Making information around these issues accessible, should not impact on the specificity of the information provided.** In some instances, the data processed by the APP appears to be more properly regarded as pseudo-anonymised rather than anonymous. Where this is the case, it should not be described in documentation and/or notifications to potential users as anonymous.

The PEAG urges caution in overstating claims of anonymity. Demographic and symptom data, approximate geographical location and IP addresses are all being collected by the App and anonymisation is not a guarantee of anonymity. Collection of sensitive health information (albeit anonymised) would be considered highly valuable data and could be subject to malicious attacks resulting in data breaches. Health information is of great commercial value, thus utmost vigilance is required to ensure its security.

It is also important to recognise public concerns relating to any form of state surveillance. Efforts will be needed to allay fears that surveillance mechanisms introduced to manage an unprecedented public health emergency will become overly intrusive or a routine part of life or that their scope will be broadened from disease surveillance to include other forms of population monitoring. **Safeguards against “scope creep” should be implemented to protect against the potential for exceptional public health measures to become normalised and to evolve into a culture of “hyper” surveillance.** While digital proximity tracing can be justified under exceptional circumstances e.g. in a pandemic Such safeguards should include defining strict parameters of use, establishing a robust system of governance, clearly communicating intent and including “sunset” provisions. Many of these protections are specifically described in the project documentation. It is noted that the removal of all personal data will be *implemented* within 90 days of the end of the COVID-19 crisis (as determine by NPHE). **It is recommended that removal of personal data should be *completed* within 90 days of the end of the crisis and that objective criteria for declaring an end to the crisis be developed in conjunction with NPHE and be made publically available.**

Symptom Checker

Caution is recommended in relation to the symptom checker which relies upon self-reporting. This is likely to impact upon the reliability and/or accuracy of the data collected. One could argue that such self-tracking empowers the individual to take responsibility for their own health while protecting other members of society; alternatively, it could be considered an extension of the medical or “panoptic” gaze. The quantified-self movement¹⁰ has shown that self-tracking is often ineffective in instilling long-lasting behaviour change and can lead to people being excessively concerned about health issues which can impact on their wellbeing¹¹.

Receipt of false positive notifications could potentially undermine trust in the App and cause undue anxiety to users. A high rate of false positives might have the knock-on effect of reducing compliance if users are repeatedly required to self-isolate. False negative notifications are equally problematic. Given that the reported asymptomatic spread of infection is estimated to be between 44-60% and peak infectiousness occurs 0.6 days before symptoms appear¹², a false negative may provide users with a false sense of security which could lead to user complacency in terms of other public health activities, such as handwashing or social distancing. **In communications around the App, specifically the symptom checker function, information should be made available about the prevalence of asymptomatic transmission.** There is also the potential for false reporting by the user (perhaps motivated by a wish not to have to self-quarantine) which could impact on the reliability and utility of the data. This underscores the importance of explaining to users the limitations of the app and how best to use it, as well as ongoing evaluation and oversight of the App with special attention given to the impact it has on user behaviours. Given the wide case definition for COVID-19, symptoms will be shared by many other common illnesses. While it is accepted that the focus of the App is on COVID-19, **there is also a duty of care to inform users that, while their symptoms might not be an indication of coronavirus, they may be an indication of another health issue that requires medical attention.**

¹⁰ Using technology to track one’s habits and behaviour has been referred to as the Quantified Self.

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¹² British Society of Immunology and Academy of Medical Sciences, COVID-19 Immunology Research. What do we know and what are the research priorities? (May 2020). Available at: <https://www.immunology.org/news/covid-19-immunology-review-what-we-know-and-priorities-for-research>

Symptom data collected by the App is unlikely to be representative of the population given that the app will attract certain demographic groups. This creates a risk of creating a skewed data picture which has the potential to create inequities in terms of the public health response. Mitigation steps to protect against the introduction of such bias should be taken.

Inclusiveness, Equity and Fairness

Efforts must be made to ensure that the risks and benefits of new technologies are equitably distributed in a way that does not unduly burden or benefit particular sectors of society. From a contact tracing perspective, consideration must be given to the accessibility and usability of the app, so that there is no arbitrary divide created between individuals or groups. The people most vulnerable to the virus are among the least likely to download or use the app due to their inability to access smartphones and internet or because of low digital literacy, poverty or language barriers. It is worth noting that the need to have a smartphone that is less than five years old will inevitably preclude many members of the population from participating. **It is vital that the app does not introduce new or exacerbate existing social, health or digital inequities.** While assurances have been given that efforts will be made to address discrepancies in relation to accessibility and language, there is little detail as to when and how this will occur. **Consideration must be given as to which groups are most likely to be excluded or under-represented and measures taken (e.g. additional or alternative resources provided, targeted testing, and diverse and accessible communication strategies) to support these groups and to uphold their rights.** Notifications provided by the Covid Tracker App should be accessible to all users, with information being provided in several languages and in a manner accessible to those with a physical or intellectual disability.

Governance and Accountability

A robust governance framework must be put in place and information about this framework should be publicly available and open to scrutiny. The role of commercial companies should be made explicit. This should involve a reliable and understandable decision-making process for managing the App - with clear lines of accountability, particularly with regards to introducing new functionality, data collection or use. There should be ongoing evaluation of the App to monitor both its effectiveness and to identify and address any risks associated with it. It is noted that the Oversight Group consists of representation from the HSE, DoH and

DEPR. The PEAG recommends that the membership of the oversight group be expanded to provide for robust independent and inclusive oversight.

An effective system of monitoring compliance with, and enforcement of, governance rules and procedures will be necessary to maximise the benefits of the App while minimising risks to the public. It is not clear if the intention is to provide a legislative basis for the COVID Tracker App. The advantage of such an approach is that it would strengthen the governance framework and could foster public trust in the App, by clearly setting out the limited purposes for which the data collected could be used, limit who could access the data, provide safeguards against data being used by employers, insurers or others to disadvantage and/or discriminate against App users. Such a regulatory instrument could also contain penalties for misuse of data. In any case, individuals must have access to a mechanism to contest and seek effective remedies to any unauthorised collection and use of their data.

It would be prudent to give some consideration to potential unintended data protection and data security risks, such as the malicious use of data, cyber-attacks, and data leakage and what measures should be in place to avoid or mitigate such risks.

Information on PEAG Terms of Reference and Membership

The purpose of the Pandemic Ethics Advisory Group is to act as an advisory body to Government, policymakers and health service providers.

Terms of reference:

To function as an expert sub-group of the National Public Health Emergency Team (NPHE) that will review and answer ethical questions relating to Covid-19 preparedness and response.

To provide expert ethical advice to the NPHE, the Department of Health, the HSE and others as appropriate.

Membership

The group is multidisciplinary in composition to ensure that a range of expertise and perspectives is represented.

Dr Siobhán O'Sullivan, Chief Bioethics Officer, DoH (Chair)

Dr Simon Mills SC, Law Library

Prof. David Smith, Healthcare Ethics and Law, RCSI

Dr Barry Lyons, Director of Patient Safety, College of Anaesthesiologists of Ireland, Consultant, Dept. of Anaesthesia & Critical Care Medicine, CHI Crumlin

Mr Stephen McMahon, Director, Irish Patients Association

Dr Joan McCarthy, Healthcare Ethics, School of Nursing and Midwifery, UCC

Dr Louise Campbell, Medical Ethics, School of Medicine, NUI Galway

Dr Andrea Mulligan BL, School of law, TCD

Mr Mervyn Taylor, Executive Director, Sage Advocacy