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Contact tracing applications: ethical, cultural and educational challenges

Rapport¹

Committee on Culture, Science, Education and Media Rapporteur: Mr Duncan BAKER, United Kingdom, European Conservatives Group and Democratic Alliance

Summary

Digital health technologies, such as contact tracing applications (CTAs), have been promoted worldwide by governments as well as private companies to mitigate the Covid-19 pandemic, but they also have countless other health, lifestyle and wellness applications. Their ethical and legal frameworks remain however unclear, with risks related to unlawful interference with the right to a private life, and must be evaluated carefully to ensure compliance with the data protection standards laid down by Convention 108 and its modernised version, Convention 108+.

The report analyses the position of Council of Europe bodies, key aspects such as efficacy and accuracy issues, voluntariness and autonomy, inequities and discrimination as well as adoption and adherence rates. It also highlights the difficulty in assessing CTAs' impact on public health as well as the need for scientific evidence and impact assessment, and for public debate and parliamentary scrutiny.

The Committee puts forward a number of recommendations to member States as well as to the European Union, in particular regarding interoperability, with a view to ensuring a careful balance of all interests at stake and the protection of human rights and fundamental freedoms, not only in fighting the pandemic but also in designing future technology aimed at tackling future health crises.

¹ Reference to committee: Doc. 15165, Reference 4543 of 20 November 2021.

A. Draft resolution²

1. The Parliamentary Assembly notes that over the past two years, data collection and processing by using digital public health technologies, such as contact tracing applications (CTAs), have been promoted worldwide by governments as well as private companies to mitigate the Covid-19 pandemic, identify subjects at risk of contamination or ensure compliance with confinement rules.

2. In May 2020, the World Health Organisation issued guidelines for their use and related ethical considerations. The Consultative Committee set up according to the Council of Europe Convention for the protection of individuals with regard to automatic processing of personal data (Convention 108), the Data Protection Commissioner as well as the Committee on Bioethics (DH-BIO), also issued several statements, raising concerns and providing useful guidelines. The Council of Europe 2020 Data Protection Report highlighted that, by adopting widely diverging systems, countries have limited the efficiency of the measures taken and the influence they could have exercised on actors in the digital market.

3. CTAs and countless other health, lifestyle and wellness applications are also available in app stores; their ethical and legal frameworks remain unclear, with risks related inter alia to unlawful interference with the right to a private life.

4. These applications need to be evaluated carefully and public authorities must monitor their implementation to ensure compliance with the data protection standards laid down by Convention 108 and its modernised version, Convention 108+.

5. The Assembly stresses that the collection and processing of personal and health data must be justified by legitimate public health objectives and be suitable and proportionate to achieving the intended goal. The data collected via these applications should not be accessible to third parties that are not involved in public health management. Data collection and processing must be transparent and concise, and reader-friendly information on the purpose of data collection, data storage and sharing must be easily available. Decisions on downloading and using applications must remain voluntary and respect personal autonomy. Discrimination due to the digital divide should be avoided. Furthermore, data protection authorities must be involved in the development, oversight, and audit of digital contact tracing systems.

6. The effectiveness of such digital technologies largely pertains to the technical designs, implementation methods and the level of public trust. Therefore, the Assembly considers that the lack of citizens' involvement in the debate may explain the low adoption rates of the available applications in many Council of Europe member States. In this respect, Resolution 2333 (2020) and Recommendation 2176 (2020) on "Ethics in science and technology: a new culture of public dialogue" highlighted that it is essential to involve the general public in decisions which highly impact on their lives, especially during crises.

7. Digital epidemic surveillance is – and should only be – intended to prevent forward transmission and break the chains of infection. However, to date substantial scientific evidence of CTAs' impact and effectiveness remains relatively limited.

8. CTAs which have been developed in most European countries do not collect identifiable health data, at least not without explicit consent; moreover, sensitive health-related information, including when collected via manual contact tracing (e.g. in testing centres) cannot be shared with third parties, including the scientific community, without consent.

9. While this approach serves the purpose of protecting privacy, the fact that contact tracing and testing datasets cannot be processed and combined without citizens' consent may hinder the ability of governments to analyse aggregated data, including user demographics or temporal, spatial and public health impact trends of CTA usage and exposure notifications.

10. The Assembly stresses that a timely and accurate assessment of the CTAs' public health impact is a key prerequisite of an effective public health policy. A continuous quality improvement of public health processes and interventions is essential. In particular, digital epidemic surveillance must respond to an evolving situation, taking into account the changing transmission and immune-evasion properties of a virus.

² Draft resolution adopted unanimously by the committee on 11 October 2022.

11. Data protection standards must be considered as an advantage in conditions of uncertainty such as a pandemic. However, these regulations must be interpreted in a way that allows for detailed data collection, with the appropriate safeguards. A right balance between data protection standards and health impact assessments must be struck not only to help fight the current pandemic but also to design future technology aimed at tackling future health crises.

12. The Assembly believes that technology can make a significant contribution to the promotion of public interests only by ensuring a careful balance of all interests at stake and by carrying out an in-depth assessment of the risks posed to human rights and fundamental freedoms in a democratic society.

13. To that end, the Assembly calls on Council of Europe member States to:

13.1 ensure that recourse to digital public health technologies is part of a comprehensive national epidemiologic strategy, articulated in different tools, balancing all interests at stake and based on an appropriate evaluation of its real impact and effectiveness;

13.2 monitor the implementation of these new technologies as well as their compliance with data protection standards, and ensure that the collection and processing of personal and health data is justified by legitimate public health objectives and is adequate and proportionate to achieving the intended goal;

13.3 consider the possibility of voluntary data donorship for contact tracing applications or other future technologies, which include an opt-in for users who would like to consent to have their personal data anonymised and processed to collect evidence for scientific research and impact assessment, with appropriate safeguards to preserve privacy;

13.4 keep the public well informed about public health interventions, in particular regarding the impact and effectiveness of new digital technology, including via parliamentary hearings and public information campaigns, with a view to raising citizens awareness, building citizens' trust and strengthening the effectiveness of new technology;

13.5 counter negative attitudes or low interest in the population through systematic, targeted information campaigns, both through the media and with civic initiatives in schools, that are context-specific, based on science, address doubts and concerns raised, debunk disinformation and highlight individual and collective responsibility for one's own health as well as other people's health;

13.6 encourage voluntary access to CTAs in resource-limited settings, for example through reduced mobile data costs, higher availability of and compatibility with low-cost devices and conditions facilitating the use of CTAs such as a help function, a tutorial, or testimonials of other users;

13.7 initiate, if not done yet, and promote globally the signature and ratification of the Convention for the protection of individuals with regard to automatic processing of personal data (Convention 108) as amended by the Protocol ETS No. 223 (modernised Convention 108) which certainly contributes to the convergence towards a set of high-level standards in the area of the protection of privacy and personal data;

14. The Assembly resolves to enhance cooperation with the Consultative Committee set up by the Convention 108 to share best practices regarding the implementation of privacy and data protection principles and rules in public interest areas, and to identify areas of possible joint actions to raise awareness on, and enhance compliance with, international standards in the field.

15. The Assembly also encourages the European Union to continue developing co-ordinated solutions at European and international level, including beyond the EU, to promote safe international travel and global control of the Covid-19 pandemic as well as future threats to public health.

B. Explanatory memorandum by the rapporteur, Mr Baker

1. Introduction

1. Over the past two years, data collection and processing by using digital public health technologies, such as contact tracing applications (CTAs), have been promoted worldwide by governments as well as private companies to mitigate the Covid-19 pandemic, identify subjects at risk of contamination or ensure compliance with confinement rules. The widespread use of these novel digital tools seemed an appealing solution to limit infection, also for the World Health Organisation (WHO), which swiftly issued guidelines for their use and ethical considerations in May 2020.³ In many countries, however, their introduction was met with hesitation due, inter alia, to privacy issues.

2. Nowadays, countless other health, lifestyle and wellness applications are also available in app stores, to help people quit smoking, count steps, eat healthier, guide lifestyle changes, etc. The ethical and legal frameworks remain unclear to this day and a global debate has emerged around the risks associated with such tools. These go beyond the legal challenges posed by unlawful interference with the right to a private life of individuals. They can threaten human rights and fundamental freedoms during and after a crisis and traverse the blurred line between disease surveillance and population surveillance.

3. Furthermore, the effectiveness of such digital technologies largely pertains to the technical designs, implementation methods and the level of public trust towards those tools. Thus, there might be a need for appropriate legislation and policies, including in education, to frame and control a privacy-friendly use of such digital tracking technologies.

4. These considerations prompted our Committee to table a motion for resolution⁴ in October 2020⁵.

5. My report aims at identifying the problem and putting forward relevant recommendations not only to safeguard human rights and fundamental freedoms but also to analyse the balance that must be struck between data protection concerns and the need to assess the effectiveness of these tools in protecting public health.

6. My analysis builds on the background report by Professor Wolfgang E. Ebbers, whom I thank for his work, and on the valuable contribution by the experts who participated in our committee hearings.6 The discussions pointed to the need for the scientific community to assess the effectiveness and impact of CTAs to improve public health policies, while complying with data protection standards. I propose to modify the title of the report as follows "Contact tracing applications: ethical, cultural and educational challenges". I have also taken account of contributions by other scientific experts7 and by members of the Committee.

2. The position of Council of Europe bodies on contact tracing applications

7. The Council of Europe Consultative Committee of the Convention for the protection of individuals with regard to automatic processing of personal data (Convention 108), the Data Protection Commissioner as well

³ World Health Organisation (2020), <u>Ethical considerations to guide the use of digital proximity</u> tracking technologies for COVID-19 contact tracing, May 2020.

⁴ D<u>oc. 15165</u>

⁵ On a related subject, <u>Resolution 2383</u> on *Covid passes or certificates: protection of fundamental rights and legal implications*, adopted by the Assembly on 22 June 2021, also raises concerns about potential unlawful discrimination and the need for a clear legal basis, comprehensive data protection guarantees and measures to prevent criminal misuse of Covid passes.

⁶ The Committee organised a first hearing on 2 December 2021, in Paris, with the participation of Mr Pat Walshe, Data Protection consultant, Privacy Matters, UK; Ms Elisabeth Ehrensperger, Director of the Foundation for Technology Assessment, TA-SWISS, Bern, Switzerland; Mr Wolfgang E. Ebbers, Endowed Professor at the Erasmus School of Social and Behavioural Sciences, Public Administration, Erasmus University Rotterdam, The Netherlands; and Mr Tore Tennøe, Director, Norwegian Board of Technology, Oslo, Norway. A follow-up hearing was organised on 4 March 2022, in Paris, with the participation of Professor Ebbers, Mr Christophe Fraser, Senior Group Leader in Pathogen Dynamics at the Big Data Institute, and Professor in the Nuffield Department of Medicine, University of Oxford, UK; and Ms Alessandra Pierucci, Chairperson of the Committee on the Convention for the Protection of Individuals with regards to Automatic Processing of Personal Data (CETS No. 108). Finally, the Council of Europe Data Protection Commissioner, Mr Jean-Philippe Walter (Switzerland) also exchanged views with the Committee on 21 June 2022, in Strasbourg.

⁷ Mr Viktor von Wyl, Tenure Track Assistant Professor at the Medical Faculty, Institute for Implementation Science in Health Care, University of Zurich, Switzerland, and Mr Gar Mac Críosta, Chair Linux Foundation Public Health Advisory Group, Health Service Executive lead for Digital Contact Tracing, Ireland.

as the Committee on Bioethics (DH-BIO) issued several statements in 2020-2021, on contact tracing applications raising their concerns and providing useful guidelines. Indeed, these applications allow for massive surveillance and collection of personal data (e.g. on monitoring people's movements and vaccinations, evidence of past infection, symptom detection, test results, enforcement of confinement measures or digital tracing of contacts), the storage, analysis and use of which raise serious questions regarding the protection of privacy. Data protection standards laid down by Convention 108 and its modernised version, Convention 108+, must be implemented when adopting any extraordinary measures.

8. In order to assist Parties to Convention 108 in addressing privacy and data protection issues when setting up and implementing measures to fight against the Covid-19 pandemic, two joint declarations by the Chair of the Committee of Convention 108 and the Data Protection Commissioner of the Council of Europe were issued in 2020. Those declarations recall that the general principles and rules of data protection are fully compatible and reconcilable with other fundamental rights and relevant public interests, such as public health. It is essential to ensure that data protection frameworks continue protecting individuals and that the necessary privacy and data protection safeguards are incorporated in extraordinary measures that are taken to protect public health.

9. According to the first joint statement of 30 March 2020 on the right to data protection in the context of the Covid-19 pandemic⁸, States must only take temporary measures that are necessary and proportionate to the legitimate aim pursued and which respect democracy, the rule of law and human rights, including the rights to privacy and to protection of personal data. Special attention is required in certain sectors such as public health, employment, telecommunications and education.

10. The second joint statement on Digital Contact Tracing of 28 April 2020⁹ recalls that "large-scale personal data processing can only be performed when, on the basis of scientific evidence, the potential public health benefits of such digital epidemic surveillance (e.g. contact tracking), including their accuracy, override the benefits of other alternative solutions which would be less intrusive". The need for these measures to constitute an integral part of a national epidemiologic strategy should be underlined, and the importance of the choice of the tracing model and its inclusive nature highlighted. The joint statement also points to conditions of acceptability, and therefore of effectiveness, of such a system, among which trust and voluntariness are first and foremost.

11. As for the legitimacy of the data processing, the joint statement advocates for a legal basis directly provided by law, while keeping the voluntariness in the use of the application. Carrying out a privacy impact assessment and the "privacy-by-design" principle figure among the guarantees to be used in relation to such processing operations¹⁰. The necessity to thoroughly apply the purpose specification principle is highlighted. The practical applicability of important concepts must also be presented (such as the sensitivity, quality, minimisation of data, the right of data subjects with respect to automated decision-making, the necessity for de-identification of data, data security requirements, the link between the choice of digital architecture used and the protection of privacy, the importance of interoperability, transparency, temporary nature of databases, oversight and audit).

3. Key aspects of contact tracing applications

12. The following are some key features which should be taken into account when developing CTAs, highlighting some of the major recommendations and guidelines issued by WHO as well as relevant Council of Europe bodies. They mainly pertain to data protection, ethics, and risks of discrimination. It should also be noted that the acceptability of these systems depends on the understanding and trust that they inspire in the population.

3.1. Efficacy and accuracy issues

13. Despite the wide reception of contact tracing applications around the globe, there is still a lack of scientific evidence about their efficacy, and often no risk assessment studies. Thus, the accuracy and effectiveness remain ambiguous, and even if they can contribute to the pandemic response, the data quality

⁸ See <u>here</u>.

⁹ See <u>here</u>.

¹⁰ However, privacy by design would likely impede both the evaluation of this technology and the deployment of evidencebased interventions to stimulate uptake; see <u>Tracking and promoting the usage of a COVID-19 contact tracing app</u>, <u>Nature</u> <u>Human Behaviour</u>, 21 January 2021.

and integrity risks may outnumber their advantages. This uncertainty and the lack of knowledge on their scientific efficacy in turn can make a risk assessment of these technologies utterly challenging.¹¹

14. The development and deployment of a novel technology usually require a great deal of investment and time for the sake of effectiveness. These technologies may only be effective in countries with an adequate technological infrastructure. A widespread use of smartphones or other appropriate devices as well as easy access to the internet are indispensable. A digital proximity tracking technology should be adopted by a sufficiently high rate of the population to be effective for contact identification.¹² However, reaching the targeted usage rate, while safeguarding freedom of choice is not easy and public attitudes may vary significantly.¹³

Their effectiveness also depends on the users' speedy response to any alerts.¹⁴ Furthermore, some 15. applications are not compatible with older smartphones and applications can lead to false alarms.¹⁵ The risk of over-reporting interactions can also lead to a redundant number of "false positives". This, in turn, could result in needless self-isolation or might even lead to users' distrust in the reliability of warnings.¹⁶

As stated by the Council of Europe data protection authorities, the key question is: "considering the 16. absence of evidence of their efficacy, are the promises worth the predictable societal and legal risks?" If the benefits override those of alternative and less intrusive solutions, then the legal and technical safeguards to mitigate the risks at stake must be in place.¹⁷ I will further elaborate on the current impact assessment challenges in the next chapter.

3.2. Data protection and privacy

17. Deployment of trace and track applications requires data protection and privacy laws to be in place in order to provide a legal basis and define limits for data processing and usage. All digital public health tools breach individual privacy through access to information on the individual's health status, behaviour or location.18

A possible risk is often referred to as "surveillance creep", which implies using the crisis as an 18. opportunity to establish and retain tracking of citizens during and after crises. Consequently, governments might retain tracking citizens' data which could be used in other contexts such as law enforcement.¹⁹

19. Several regulatory instruments offer safeguards to the right to privacy and data protection, in particular Convention 108 and at EU level, the General Data Protection Regulation, the e-Privacy Directive, as well as the EU Charter of Fundamental Rights. These tools also allow abridgement of rights in specific circumstances, including public health crises. These must be proportionate to public benefits and must lead to faster restoration of other suspended rights and freedoms, such as freedom of movement and assembly.²⁰

The processing of personal data gathered by such applications has also raised considerable 20. fundamental rights concerns. Some countries have developed bio-surveillance programmes that share some characteristics of both a pandemic response and counter-terrorism programmes.²¹ For instance, an Alibababacked government-run application that supports decisions on who should be guarantined for Covid-19 in China also shared information with the police.²²

¹¹ Gasser, U., <u>Digital tools against COVID-19: taxonomy, ethical challenges, and navigation aid, The Lancet, August 2020.</u> ¹² 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, April 2020.

¹³ Williams, S., Armitage, C. and Tampe, T., Public attitudes towards COVID-19 contact tracing apps: a UK-based focus group study, March 2021.

¹⁴ Klenk, M. and Duijf, H., Ethics of digital contact tracing and COVID-19: who is (not) free to go, SSRN, August 2020.

¹⁵ McLachlan, S., Lucas, P., Kudakwashe, D., <u>Bluetooth smartphone apps: are they the</u> most private and effective solution for COVID-19 contact tracing?, Cornell University, May 2020.

¹⁶ Leprince-Ringuet, D., Contact-tracing apps: why the NHS said no to Apple and Google's plan, April 2020.

¹⁷ Joint statement on Digital Contact Tracing by Alessandra Pierucci, Chair of the Committee of Convention 108 and jean-Philippe Walter, Data Protection Commissioner of the Council of Europe, 28 April 2020.

¹⁸ Lee, L., Heilig, C., White, A., Ethical justification for conducting public health surveillance without patient consent, January 2012.

¹⁹ Klar, R., Ethical Dimensions of COVID-19 Tracking Apps: Privacy-Preserving Proximity Tracing Pepp-Pt and Data Protection', May 2020.

²⁰ Kolfschooten, H., <u>EU coordination of serious cross-border threats to health: the implications for protection of informed</u> consent in national pandemic policies, European Journal of Risk Regulation, February 2020. ²¹ Kim A., Tak, Implementation system of a biosurveillance system in the republic of Korea and its legal ramifications,

November/December 2019.

²² Mozur P, Zhong, R., Krolik, In coronavirus fight, China gives citizens a color code, with red flags, New York Times, 1 March 2020.

21. It is crucial to distinguish digital public health technologies that allow third-party sharing of information for non-health-related purposes from those that do not. Additionally, track and trace applications must clarify upfront the duration, the type of data collected, and the duration of information storage. Heightened surveillance empowered by digital public health technologies must stop after the end of the emergency. Finally, information collected should reside on a user's own device, rather than on servers run by the application developer or a public health entity.

3.3. Voluntariness and autonomy

22. Digital technologies have the potential to threaten not only privacy but also personal autonomy. The most obvious form of violation of personal autonomy is making their use mandatory. All workers in India have been obliged to use a government-backed Covid-19 tracking application.²³ Even when such technologies are not mandatory, some companies might require their use to gain access to their services.

23. Some mobile phone applications include permissions to collect data beyond the stated purpose of the application, undermining people's ability to consent to being tracked or having their information shared. For instance, Bluetooth-based proximity tracking applications require users to keep their Bluetooth turned on creating additional risks. Allegedly, a Polish app forced patients to take selfies as a proof of their confinement or else face a police visit.²⁴

24. For the use of those applications to be voluntary, individuals should decide whether to carry a smartphone, download and install the applications, leave them operating in the background all the time, react to alerts, and share the contact logs after testing positive.²⁵ In addition, users should be free to uninstall those applications at any time and remove any data that has already been collected. Potential users should be able to make informed decisions on the application's functioning and on the transmission, access and use of data.

25. Those who decide not to use or to remove the application should not be sanctioned or restricted in any way. In China, people were required to use contact tracing applications to access public areas, such as subways, malls and markets. Even though the use of applications is based on voluntariness, the implied restrictions make it *de facto* compulsory.²⁶ Voluntariness can also be impeded through indirect coercion if a government threatens to impose a second lockdown if not enough people download the application. In France, for instance, the use of tracing applications was discussed in parliament alongside easing lockdown measures. Peer pressure and societal expectations can engender an environment in which people feel compelled to act.²⁷

3.4. Inequities and discrimination

26. There is a manifest inequality in terms of access to track and trace applications. For instance, high-risk groups, such as the elderly, may not have access to smartphones and may therefore be excluded from the use of this technology.²⁸ Thus, these tools could deepen the digital divide and cause an unequal distribution of burdens and benefits amongst the population.

27. Disadvantaged workers and their families may be less likely to work from home and run a higher risk of infection.²⁹ Thus, in the case of a selective quarantine due to tracking applications, a larger proportion of disadvantaged workers could be quarantined and be more likely to bear the social, economic, and psychological ill effects of quarantine.³⁰ Once again, voluntary access to such technologies in resource-limited settings should be encouraged, for example through lower mobile data costs or low-cost devices.

²³ Clarance, A., <u>Aarogya Setu: Why India's Covid-19 contact tracing app is controversial</u>, BBC, 15 May 2020.

²⁴ Hamilton, A., Poland made an app that forces coronavirus patients to take regular selfies to prove they're indoors or face a police visit', March 2020.

²⁵ Dubov, A., Shoptaw, S., <u>The value and ethics of using technology to contain the COVID-19 epidemic</u>', The American Journal of Bioethics, May 2020.

²⁶ Ponce, A., <u>COVID-19 contact-tracing apps: how to prevent privacy from becoming the next victim</u>', ETUI research paper, May 2020.

²⁷ Floridi, L., <u>Mind the app - considerations on the ethical risks of COVID-19 apps</u>', University of Oxford, June 2020.

²⁸ Pagliari, C., <u>The ethics and value of contact tracing apps: International insights and implications for Scotland's COVID-19 response</u>, Journal of global health, July 2020.

 ²⁹ Gasser, U., <u>Digital tools against COVID-19: taxonomy, ethical challenges, and navigation aid</u>, The Lancet, June 2020.
³⁰ Klenk, M., Duijf, H. (2020) '<u>Ethics of digital contact tracing and COVID-19: who is (not) free</u>

to go?, May 2020.

28. Since these technologies can collect data, they have the capacity to include race, ethnic groups, gender, political affiliation, and socioeconomic status. Some sensitive data are not necessarily related to public health and can cause stigmatisation of ethnic or socioeconomic groups.³¹

29. The stratification of the population might deepen existing divides leaving some groups more vulnerable to the crisis. At the same time, data collection should also capture epidemiological factors such as social and economic differences that are known to drive disparities in infection rates. Such efforts, especially when taking place in low trust environments, need to be supplemented by robust safeguards, including analytical capacities to contextualise the data to avoid further stigmatisation of underserved groups and provide evidence-based action against persistent health inequalities. ³²

4. Difficulty in assessing CTAs' impact on public health

30. Many countries in and outside Europe accompanied the introduction of CTAs with efforts to monitor and assess their effectiveness and impact on public health. The European Centre for Disease Prevention and Control (ECDC) together with WHO, developed an indicator framework to evaluate the public health effectiveness of digital proximity tracing solutions, with a list of indicators that can be used as a basis for a standardised evaluation of the public health effectiveness of CTAs.³³

31. Scientists all over the world have collected scientific evidence as to why and how citizens were downloading and activating CTAs and when they anonymously notified others after testing positive. Experts call the first two steps "adoption" of CTAs, while the latter reflects one aspect of users' "adherence" to CTAs' recommendations.

32. Initial scientific reports focused on what makes users follow the recommendations.³⁴ CTAs send anonymous notifications that the user has been in contact with an individual who has thereafter tested positive. Many of these notifications are accompanied by public health recommendations, such as messages containing instructions to "get tested", "quarantine" and "not receive any visitors". Do people follow those recommendations? If not, deploying CTAs to protect public health would not achieve its goal to prevent onward transmission.

33. So far, substantial scientific evidence on the public health impact of CTAs seems to be relatively limited. The paucity of data collected has made evaluating their effectiveness very challenging, with few reports on even basic metrics such as the number of active users, number of positive tests entered, number of notifications sent and received, and data that would enable the inference of both the accuracy and the effectiveness of the notifications.

34. At the hearings organised by the Committee, some experts highlighted the strictness in the implementation of data protection standards.

35. CTAs using the Google-Apple Exposure Notification (GAEN) system are designed in such a way that they do not collect identifiable health data, at least not without explicit consent. Manual contact tracing, via labs and testing centres for instance, may lead to the accumulation of very sensitive, health-related information. This data cannot be shared with third parties without consent, including the scientific community, or only in an aggregated and anonymised way.

36. This principle also applies to data collected via touchpoints of CTA users with the health system, for example when getting tested or traced by manual contact tracing. These data are vital for CTA effectiveness analyses but have been virtually unavailable for technical and data protection reasons.

³¹ Quinn, P., <u>Crisis communication in public health emergencies: the limits of 'legal control' and the risks for harmful outcomes in a digital age</u>, December 2018.

³² Garattini, C., Raffle, J., Aisyah, D., Sartain, F., Kozlakidis, Z., <u>Big data analytics, infectious diseases and associated</u> <u>ethical impacts</u>, Philos Technol., 2019.

³³ Indicator framework to evaluate the public health effectiveness of digital proximity tracing solutions (europa.eu), June 2021.

³⁴ Ebbers W. and others, *Evaluation of the CoronaMelder: A Summary after 9 Months*, 2021, <u>https://coronamelder.nl/media/Evaluatie CoronaMelder na 9 maanden english.pdf</u>; Ebbers W., *Eind Rapportage van de Evaluatie van 'CoronaMelder-App Meldingen van Een Kans Op Besmetting', Een Kwantitatief Onderzoek* (Rotterdam, 2021), <u>https://doi.org/https://www.eur.nl/media/94469</u>; Dominik Menges and others, A Data-Driven Simulation of the Exposure Notification Cascade for Digital Contact Tracing of SARS-CoV-2 in Zurich, Switzerland', *JAMA Network Open*, 4.4 (2021), e218184–e218184, <u>https://doi.org/10.1001/JAMANETWORKOPEN.2021.8184</u>.

5. Insights into CTAs' adoption and adherence

37. Clearly, the higher the CTA adoption and adherence rate, the higher the chances of effectively breaking chains of infection³⁵. The numbers and rates of adoption vary per country³⁶ and per time period and are generally quite low according to the recent studies³⁷.

38. In 2022, many countries started to lift isolation and quarantine requirements and several apps are no longer in place, at least temporarily, for instance the Dutch, the Swiss and the Icelandic apps.

39. To assess the adoption rate, the related numbers are often expressed as proportions of a country's entire population. An alternative is to look at only the eligible target population based on compatible phones and age range.³⁸

40. Data sources include surveys and numbers of downloads from the main app stores as a proxy to express the proportion of users. However, this method can lead to overestimating the proportion of CTA users as they can have more than one smartphone, delete the app or change smartphones.

41. An alternative is to take the number of active users as a basis, while complying with data protection standards. The UK app for example pings a small and anonymous 'status' packet back to a server, whereas for example in Switzerland a more indirect method was used.³⁹ Some app stores also provide metrics which allow for a better estimation of the number of active users rather than the number of downloads.

42. Likewise, the more users adhere to the recommendations, the higher the chances of effectively breaking chains of infection. Rates vary among countries and time periods as well as the calculation methods, which is why this report does not present country-based statistics.

43. For instance, until 2022, users in the Netherlands could only share a user code in cooperation with public health authorities and every instance was registered and used for epidemiological analyses of routine contact tracing data.⁴⁰ Ireland issued codes as part of a structured series of phone calls performed by contact tracers, and in 2022 it moved to a more automated approach. Switzerland used self-report questionnaires.⁴¹

44. Germany on the other hand uses data directly collected from the CTAs themselves, for which the user gave explicit consent in order to evaluate the effectiveness of the German *Corona-Warn-App*.⁴²

³⁵ Chris Wymant and others, 'The Epidemiological Impact of the NHS COVID-19 App', 408 | Nature |, 594 (2021), https://doi.org/10.1038/s41586-021-03606-z.

³⁶ See for an example <u>https://investigativedesk.com/data-covid-19-tracing-apps/</u>.

³⁷ See for example Muhammad Shahroz and others, COVID-19 Digital Contact Tracing Applications and Techniques: A Review Post Initial Deployments, Transportation Engineering, 5 (2021),100072 https://doi.org/10.1016/J.TRENG.2021.100072; My Villius Zetterholm, Yanqing Lin, and Päivi Jokela, Digital Contact Tracing Applications during COVID-19: A Scoping Review about Public Acceptance, Informatics 2021, Vol. 8, p. 48, 8.3 (2021), 48, https://doi.org/10.3390/INFORMATICS8030048; Dominik Rehse and Felix Tremöhlen, Fostering Participation Digital Information Economics Policy, in Contact Tracing, and 58 (2022),100938. https://doi.org/10.1016/J.INFOECOPOL.2021.100938; Aleix Bassolas and others, Optimizing the Mitigation of Epidemic Spreading through Targeted Adoption of Contact Tracing Apps, Physical Review Research, 4 (2022), https://doi.org/10.1103/PhysRevResearch.4.023092.

³⁸ WHO/ECDC, Indicator Framework to Evaluate the Public Health Effectiveness of Digital Proximity Tracing Solutions (Geneva, 2021), https://doi.org/10.2900/642768.

³⁹ Ewa Strzalkowska and Isabel Molina, 'Calculation methods for estimating the number of active Swisscovid apps work for the Swiss Federal Statistical Office small area estimation in the structural survey', 2020. The method used automated and anonymous dummy requests to the CTA backend system at random time points (in Switzerland on average one request per five days). This ca be used as a basis to estimate the number of apps that are actually active, resulting in a more reliable insight into the adoption rate than keeping track of the number of downloads.

⁴⁰ Wolfgang Ebbers and others, Evaluation of the CoronaMelder: A Summary after 9 Months, 2021, https://doi.org/https://coronamelder.nl/media/Evaluatie_CoronaMelder_na_9_maanden_english.pdf.

⁴¹ Tala Ballouz and others, 'Adherence and Association of Digital Proximity Tracing App Notifications With Earlier Time to Quarantine: Results From the Zurich SARS-CoV-2 Cohort Study', *International Journal of Public Health*, 66 (2021), 62, https://doi.org/10.3389/IJPH.2021.1603992/BIBTEX.

⁴² <u>https://www.coronawarn.app/de/analysis/</u>.

45. Alternatively, countries can use voluntary, anonymous self-report surveys on adherence to recommendations, as was the case in Germany⁴³, Switzerland⁴⁴, the Netherlands⁴⁵, and the United Kingdom⁴⁶. This would comply with data protection standards. However, the data might be biased and non-representative due to the uncertainty of self-reporting.

46. Recent scientific reports pointed to several factors that facilitate or hamper CTA adoption and adherence.⁴⁷ Higher education and income levels for instance relate to higher levels of adoption.⁴⁸ Perceived effectiveness, benefit, social influence, peer pressure and trust in a technological innovation and in a government's action are also relevant indicators. The higher the level of these factors, the higher the chances of adoption and adherence, which in turn leads to better CTA performance.

47. CTAs can be perceived as not directly affecting one's own health, once infected, but only protecting others and society as a whole, by reducing contagion. However, in the case of new variants or entirely new viruses, one could personally benefit from early detection and timely treatment, and CTAs may have a key role to play both for the individual and for society.

48. These observations show the importance of a timely, substantial and thorough assessment of the public health impact of this digital technology, which, if negative, may cause the population to reject or abandon the innovation. A government's action in honestly and accurately informing the population about public health measures may increase trust in government.⁴⁹

49. Furthermore, voluntary access to CTAs in resource-limited settings should be encouraged, for example by minimising mobile data costs, promoting low-cost devices, and facilitating conditions such as a help function, a tutorial, or testimonials of other individuals who use the technology.⁵⁰

50. Another important aspect to consider is related to public attitudes towards public health measures which may restrict individual freedoms for the sake of public interest. Low CTA adoption can also be explained by a limited sense of individual and collective responsibility for one's own health as well as other people's health, including that of vulnerable groups. This phenomenon is similar to anti-vaccination attitudes, which were discussed in Resolution 2455 (2022) on Fighting vaccine-preventable diseases through quality services and anti-vaccine myth-busting, adopted by the Assembly on 24 June 2022.

51. Negative attitudes or low interest can be tackled through systematic, targeted information campaigns, both through the media and with civic initiatives in schools, that are context-specific, based on science, address doubts and concerns raised, debunk disinformation and highlight individual and collective responsibility for one's own health as well as other people's health.

6. The need for public debate and parliamentary scrutiny

52. The evaluation of the Dutch app and the review of the Swiss app⁵¹ highlighted the importance of public debate in relation to two important issues, namely location tracking and adoption rates.

⁵⁰ <u>Michel Walrave, Cato Waeterloos, Koen Ponnet, Ready or Not for Contact Tracing? Investigating the Adoption</u> Intention of COVID-19 Contact-Tracing Technology Using an Extended Unified Theory of Acceptance and Use of Technology Model, 14 June 2021.

⁴³ <u>https://www.coronawarn.app/en/science/2021-08-02-science-blog-3/#4-testing</u>.

⁴⁴ https://www.ssph-journal.org/articles/10.3389/ijph.2021.1603992/full.

⁴⁵ https://www.rijksoverheid.nl/documenten/publicaties/2021/03/23/eindrapportage-evaluatie-coronamelder-eur-23-maart-2021.

⁴⁶ Louise E Smith and others, 'Adherence to the Test, Trace and Isolate System: Results from a Time Series of 21 Nationally Representative Surveys in the UK (the COVID-19 Rapid Survey of Adherence to Interventions and Responses [CORSAIR] Study)', *MedRxiv*, 2020, 2020.09.15.20191957, https://doi.org/10.1101/2020.09.15.20191957.

⁴⁷ <u>https://publichealth.jmir.org/2021/1/e25701/;</u> <u>https://www.sciencedirect.com/science/article/pii/S1574119221000833;</u> https://bmjopen.bmj.com/content/12/1/e053327.

⁴⁸ Viktor von Wyl and others, 'Drivers of Acceptance of COVID-19 Proximity Tracing Apps in Switzerland', *MedRxiv*, 2020, 2020.08.29.20184382, https://doi.org/10.1101/2020.08.29.20184382; Nynke van der Laan, Nadine van der Waal, and Jan de Wit, 'Eindrapportage CoronaMelder Evaluatie - Survey LISS Panel Wave 4', 2021, 118, https://doi.org/10.2/JQUERY.MIN.JS.

⁴⁹ Viktor von Wyl and others, 'Drivers of Acceptance of COVID-19 Proximity Tracing Apps in Switzerland: Panel Survey Analysis', *JMIR Public Health and Surveillance*, 7.1 (2021), https://doi.org/10.2196/25701.

⁵¹ Paola Daniore and others, 'The SwissCovid Digital Proximity Tracing App after One Year: Were Expectations Fulfilled?', 2021, https://doi.org/10.4414/SMW.2021.w30031.

53. In early 2020, policymakers and scientists urged caution and expressed concern related to data protection issues.⁵² In the UK⁵³ and the Netherlands⁵⁴, scientists wrote open letters to express their concern about the risks of privacy infringement.

54. This was understandable. Regarding location tracking, US developers of Covid-19 apps said that it was vital they be allowed to use GPS location data in conjunction with the new contact tracing system to track how outbreaks move and to identify hotspots.⁵⁵ The UK National Health Service also initially considered then abandoned the idea of centrally recording the de-anonymised ID of someone who is infected and his or her contacts. This feature would indeed enable a form of surveillance.⁵⁶

55. Apple and Google, whose operating systems power a vast majority of all smartphones, started implementation work in their operating systems on a decentralised, privacy-preserving proximity tracing protocol for notifying people who have been in contact with people who have tested positive for Covid-19, which was eventually adopted by many countries. Both companies stressed that privacy and preventing governments from using the system to compile data on citizens was a primary goal.⁵⁷

56. The Dutch evaluation team found out that up until October 2021, the majority of Dutch citizens still believed that the CTA was tracking their location⁵⁸, which possibly hampered the app uptake.

57. Furthermore, the findings of a March 2020 Oxford University study⁵⁹ were misinterpreted by the media claiming that at least 60% of a country's population needed to install a CTA to make it work, which was never stated in the original study. The researchers themselves complained that their work had been profoundly misinterpreted, and that in fact much lower levels of app adoption could still be vitally important for tackling Covid-19.⁶⁰

58. In the Netherlands, the majority of Dutch citizens up until October 2021 still believed that at least 50% of the population needed to install the app to make it work. At the same time, the majority of the Dutch population also indicated that the actual adoption ratio was below 50%.⁶¹ Likewise, in Switzerland, a comparatively lower proportion of *SwissCovid* app users was met with disappointment by the public and the media.⁶²

59. These examples highlight the need for public debate and parliamentary scrutiny from the initial stages on matters like apps' effectiveness or data protection concerns, also to avoid misinformation in the media, undermining people's trust and limiting their uptake of novel technology.

60. Ms Emilija Gargcin, a representative of the Council of Europe Advisory Council on Youth (CCJ), speaking before our Committee on 4 March 2022, also warned against the risk for young people growing up in a "datafied" society, with little control over their data, with many commercial apps changing privacy settings with software updates. Collecting data should not be an easy way for governments to circumvent engagement with citizens, in particular young people. Governments need instead to clearly communicate how health-related data collection and processing are different from commercial collection and use.

61. Public debate, including but not only at parliamentary level and following a proper assessment in each country, is also needed in the later stages to decide whether and how to use this technology and communicate with the public, with a view to fighting a future pandemic or other threats to public health.

- ⁵⁵ https://www.reuters.com/article/us-health-coronavirus-usa-apps-idUSKBN22G28W.
- ⁵⁶ https://drive.google.com/file/d/1uB4LcQHMVP-oLzIIHA9SjKj1uMd3erGu/view.

⁵² <u>https://techcrunch.com/2020/04/20/academics-contact-tracing/</u>.

⁵³ https://drive.google.com/file/d/1uB4LcQHMVP-oLzIIHA9SjKj1uMd3erGu/view.

⁵⁴ <u>https://www.uva.nl/binaries/content/assets/uva/nl/persvoorlichting/uva-nieuws/brief-minister-president-rutte-ministers-</u> <u>de-jonge-van-rijn-grapperhaus-de-heer-sijbesma-inzake-covid-19-tracking-en-tracing-en-gezondheidsapps.pdf</u>.

⁵⁷ https://www.reuters.com/article/us-health-coronavirus-usa-apps-idUSKBN22G28W.

⁵⁸ L.N. van der Laan, N.E. van der Waal, and J.M.S. de Wit, 'Eindrapportage CoronaMelder Evaluatie - Wave 5', November, 2021.

⁵⁹ Luca Ferretti and others, 'Quantifying SARS-CoV-2 Transmission Suggests Epidemic Control with Digital Contact Tracing', *Science*, 368.6491 (2020), 0–7, https://doi.org/10.1126/science.abb6936.

⁶⁰ https://www.technologyreview.com/2020/06/05/1002775/covid-apps-effective-at-less-than-60-percent-download/.

⁶¹ L.N. van der Laan, van der Waal, and de Wit.

⁶² Daniore and others.

7. Balancing data protection principles and the need for scientific evidence and impact assessment

62. Over the past two years, concerns about privacy protection and security were indeed justified. Several gaps were found in Google and Apple's exposure notification framework. A substantial privacy flaw was uncovered in April 2021⁶³, when the Android version of Google's exposure notification framework let other preinstalled apps potentially view sensitive data, including whether someone had been in contact with someone who tested positive for Covid-19.⁶⁴ Also, the Google Play Services component has frequent contacts with Google servers, potentially enabling location tracking.⁶⁵

63. Despite these weaknesses showing that data protection must remain a priority and may also have a negative impact on CTA adoption, according to experts, in general the available CTAs are well-engineered.⁶⁶ However, to protect public health, potentially sensitive data are needed for the scientific community to be able to prove CTAs' effectiveness and impact⁶⁷. Furthermore, as discussed above, high CTA adoption is influenced by proven effectiveness.⁶⁸

64. The public must always be honestly and accurately informed about public health interventions. According to the scientific community we consulted, transparency on whether CTAs are effective can however be at odds with data protection regulations. For a proper assessment of CTAs' health impact via sound data analyses and modelling, CTA data are needed, notably those related to the number of exposure notifications, to the risk scoring function (probability of notified contacts then testing positive), to testing and voluntary or mandatory quarantine.

65. Many if not all European CTAs are designed, secured, and protected to such an extent that it is virtually impossible to access data, not even by governments and independent scientists.

66. Continuous quality improvement of public policy interventions and processes is essential to public health.⁶⁹ CTAs in particular must remain responsive to an evolving situation with changing transmission and immune-evasion patterns and other new scientific evidence. For instance, time and distance determine whether being in contact with infected users constitutes such a high risk that one is notified and advised to test for the coronavirus.

67. From the start, many CTAs had a time parameter set within a range from five to fifteen minutes and a distance parameter set to about one and a half metres. What if a much more infectiousness variant emerges and spreads, like the Omicron variant? Should the parameters be changed then? To answer these questions, CTAs' datasets must be combined and analysed. However, in most cases they lack the users' consent to be processed.

68. An early study on CTAs based on GAEN showed that the EU General Data Protection Regulation (GDPR) is not to be seen as "a hindrance, but rather as an advantage in conditions of uncertainty such as a pandemic"⁷⁰, as it offers a functional blueprint for a system design that is compatible with fundamental rights.

⁶³ https://9to5google.com/2021/04/27/android-covid-19-contact-tracing-loophole/.

⁶⁴ https://blog.appcensus.io/2021/04/27/why-google-should-stop-logging-contact-tracing-data/.

 ⁶⁵ Douglas J. Leith and Stephen Farrell, 'Contact Tracing App Privacy: What Data Is Shared by Europe's GAEN Contact Tracing Apps', *Proceedings - IEEE INFOCOM*, 2021-May (2021), <u>https://doi.org/10.1109/INFOCOM42981.2021.9488728</u>.
⁶⁶ Vasileios Kouliaridis and others, 'Dissecting Contact Tracing Apps in the Android Platform', *PLOS ONE*, 16.5 (2021), e0251867, <u>https://doi.org/10.1371/JOURNAL.PONE.0251867</u>.

⁶⁷ There are three ways to collect data to measure the effectiveness of technological innovations: 1) Direct way: data are generated by CTAs, such as the number of notifications sent and received (in the case of the UK); Semi-direct way: data are collected via touchpoints, such as public health authorities (testing centres, etc.) and used for epidemiological analyses. For example, these can register if someone applies for a test after receiving a CTA notification (in the case of the Netherlands); 3) Indirect way: data are collected via questionnaires, cohort studies or by observing users' behaviours (in the case of Switzerland).Cohort studies use voluntary, anonymised or pseudonymized questionnaires with consent to comply with data protection rules, although they are often "self-report" questionnaires and are therefore less effective. CTAs or touchpoints use more sensitive information and can be timelier and more reliable methods, although they provide less data on adherence to recommendations, which is key to measuring the effectiveness of CTAs. Therefore, all three methods can be useful and need to take data protection into account.

⁶⁸ Wymant and others; Kevin Jenniskens and others, 'Effectiveness of Contact Tracing Apps for SARS-CoV-2: A Rapid Systematic Review', *BMJ Open*, 11.7 (2021), <u>https://doi.org/10.1136/BMJOPEN-2021-050519</u>; Luca Ferretti and others, 'Quantifying SARS-CoV-2 Transmission Suggests Epidemic Control with Digital Contact Tracing', *Science*, 368.6491, (2020), 0–7, <u>https://doi.org/10.1126/science.abb6936</u>.

⁶⁹ European Centre for Disease Prevention and Control, <u>Mobile applications in support of contact tracing for Covid-19 - A</u> <u>guidance for EU / EEA member States</u>, 10 June 2020.

⁷⁰ Laura Bradford, Mateo Aboy, and Kathleen Liddell, 'COVID-19 Contact Tracing Apps: A Stress Test for Privacy, the

69. A more recent study underlined that the lack of detailed and centralised data limits evaluations of CTA effectiveness.⁷¹ The effectiveness of CTAs was often doubted, especially in the early days. Yet concrete data for comparing the effects of digital contact tracing with manual contact tracing are largely missing.

70. Nevertheless, a balance between the need for data protection on the one hand and the need for health impact assessments on the other hand should be struck. This is key not only for Covid-19 CTAs but also for future technology to be designed to fight future health crises.

71. At the hearing organised by the Committee on 4 March in Paris, Ms Alessandra Pierucci, Chairperson of the Committee on the Convention 108, stressed that privacy and the right to the protection of personal data were not and should not be depicted as an obstacle neither to saving lives nor to the achievement of other fundamental rights and public interests. I share her views that Convention 108 as well as its modernised version, Convention 108+, which have been drawn up precisely to reply to the manifold challenges raised by new technologies, are flexible enough to ensure the balancing of the protection of personal data with other rights and public interests.

72. For example, the monitoring of a life-threatening epidemic is explicitly mentioned (paragraph 47 of the Explanatory Report of Convention 108+) among those interests for which the processing of personal data was legitimate. Further processing for scientific research is also compatible with that purpose, subject to appropriate safeguards (article 5). Restrictions on certain data protection principles are allowed in respect of scientific research purposes, but only if provided for by law and when there was no recognisable risk of infringement of the rights of data subjects (Article 11, paragraph 2).

73. Ms Pierucci also warned that personal data, in particular health-related data, could end up in the hands of unwanted actors such as insurance companies or insurers, employers, or even other public actors for unforeseen purposes. This should certainly be avoided.

74. The intervention of data protection authorities in the aftermath of the launch of contact tracing apps did not consist in a ban of such digital tools, but rather in a call to ensure the application of appropriate data protection standards, for example : 1) that a data protection impact assessment is carried out before starting the processing ; 2) that the technological set-up is aimed at avoiding the processing of unnecessary data ; 3) that data processing is not carried out for unforeseeable purposes ; 4) that a high level of data security is granted, as well as data quality considering that the implications of the processing could be serious (self-isolation, testing) for the individuals identified as potential contacts of someone infected ; 5) that the data subject has the right not to be subject to automated decisions without a clear facility to challenge the consequences of such decisions, particularly in the light of inaccuracies which may occur in the systems.

75. Data protection rules are essential to ensure trust. As the sharing of health information with one's personal doctor should be based on trust, the same should happen with any kind of processing carried out by authorities, even with the help of private actors, in the interest of public health.

76. There might be a margin to render certain processing legitimate for scientific research, but this should be provided for by the law and with the appropriate safeguards. Convention 108 and Convention 108+ allow for exceptions in extraordinary circumstances, if well defined by legislation preserving the essence of data protection principles and re-expanding them once the emergency is over.

77. Furthermore, recourse to CTAs must be efficient and based on a comprehensive national epidemiologic strategy articulated in different tools. Technology can highly contribute to the achievement of public interests but problem-solving cannot be reduced to an uncritical delegation to technology without a careful balancing of all interests at stake and an appropriate evaluation of its effects and efficiency.

78. Those points were also highlighted before our Committee by Mr Walter, Council of Europe Data Protection Commissioner, speaking in Strasbourg on 21 June 2022. In particular, he stressed that opting for the blind use of technology without evaluating its impact and effectiveness is based on the false perception that technology as such is a panacea for all problems. Technology can make a significant contribution to the promotion of public interests only by ensuring a careful balance of all interests at stake and by carrying out an in-depth assessment of the risks posed to human rights and fundamental freedoms in a democratic society.

GDPR, and Data Protection Regimes', *Journal of Law and the Biosciences*, 7.1 (2020), 1–21, https://doi.org/10.1093/JLB/LSAA034.

⁷¹ Emily Seto, Priyanka Challa, and Mhi; Patrick Ware, 'Adoption of COVID-19 Contact Tracing Apps: A Balance Between Privacy and Effectiveness', *J Med Internet Res*, 23.3 (2021), 25726, https://doi.org/10.2196/25726.

8. Interoperability

79. An important aspect to consider is related to the communication between apps and the implementation of a Covid-19 app that operates in different countries. This is key to containing the pandemic and to preparing for future threats.

80. Within the EU, interoperability guidelines for CTAs were adopted by consensus by the eHealth Network in May 2020.⁷² The European Commission set up an EU-wide system to ensure interoperability, a so-called 'gateway', ensuring that apps work across borders.

81. Three national apps (Germany, Ireland, and Italy) were first linked in 2020. In total, 20 apps are based on decentralised systems and can become interoperable,⁷³ and I was recently in touch with EU officials to understand the state of play. Two important studies have recently been procured by the European Commission.

82. The first one on "Lessons learned, best practices and epidemiological impact of the common EU approach on digital contact tracing apps" has three objectives:

82.1 To provide an up-to-date and comprehensive overview of the approach and lessons learned regarding EU-level actions on cross-border interoperability, coordination, implementation and epidemiological impact of digital contact tracing;

82.2 To propose a monitoring framework and methodology to gather and evaluate evidence on the use and performance of digital proximity tracing solutions in the EU;

82.3 To provide an up-to-date and comprehensive assessment of the impact of digital contact tracing across the EU Member States based on the developed monitoring framework and methodology.

83. This study is conducted in close cooperation with all EU Member States that developed and used national digital contact tracing apps during the pandemic and results are expected by the end of 2022.

84. The European Commission is also analysing cross-border contact tracing via a 'Feasibility study on contact tracing tools and applications used at national and EU level and integration within the Early Warning and Response System (EWRS), selective exchange module'. This is not specifically on digital proximity tracing apps and has two main objectives:

84.1 the assessment of the lessons learnt with the Covid-19 large-scale cross-border contact tracing practice at national, EU and international level;

84.2 the assessment of the feasibility of the linkage between the contact tracing applications data with the Early Warning and Response System (EWRS).

85. The study will analyse the benefits, difficulties and legal barriers, the parameters required to support the integration within EWRS and the selective exchange module. It will identify new features and structures to ensure that the different applications for digital contact tracing become interoperable thereby improving the effectiveness of national and international contact tracing efforts.

86. I believe that our Assembly should emphasise the need for developing coordinated solutions at international level to promote safe international travel and global control of the Covid-19 pandemic as well as future threats to public health.

⁷² <u>https://ec.europa.eu/health/sites/health/files/ehealth/docs/contacttracing_mobileapps_guidelines_en.pdf</u>.

⁷³ https://ec.europa.eu/info/live-work-travel-eu/coronavirus-response/travel-during-coronavirus-pandemic/how-tracingand-warning-apps-can-help-during-pandemic_en#latest.

9. Concluding remarks and recommendations

87. CTAs are relatively new and largely untested in many countries. Technology has the power to amplify society's efforts to tackle complex problems. However, governments and private entities are also capable of deploying harmful tracking technologies. The word "crisis" cannot be used to limit people's freedoms through surveillance.

88. The 2020 Data Protection Report also highlighted that by adopting widely diverging systems, countries have limited the efficiency of the measures taken and the influence they could have exercised on actors in the digital market. According to its findings, in 2020 very few applications used in State Parties to Convention 108 stood the lawfulness test.⁷⁴

89. Retrospectively, governments should be encouraged to evaluate the technology and monitor its implementation and compliance with data protection standards. The collection and processing of personal and health data should be justified by legitimate public health objectives and be suitable and proportionate to achieving the intended goal.

90. Users' trust in new technology is instrumental to the level of adoption and adherence, and thus the effectiveness of the system. The lack of citizens' involvement in the debate may explain the ineffectiveness of CTAs and the low adoption rates of the available applications.

91. The further proliferation of data gathered via these applications should not be accessible to third parties that are not involved in public health management, such as other government departments, agencies, private companies, etc. Data collection and processing should be transparent and concise, and reader-friendly information on the purpose of data collection, data storage and sharing should be easily available. Decisions on downloading and using applications should remain voluntary and respect personal autonomy, also to avoid discrimination due to the digital divide.

92. Monitoring and surveillance should be temporary and only be pursued to tackle a crisis. Last but not least, data protection authorities should be involved in the development, oversight, and audit of digital contact tracing systems.

93. At the same time, the ultimate goal of this technology must be to prevent forward transmission and break the chains of infection. Adoption of this technology via smartphones and adherence to its recommendations (such as notifications to others when testing positive or testing after receiving a notification) are essential to its effectiveness and the higher the levels of adoption and adherence, the more effectively CTAs can break the chains of infection.

94. In 2020, the Chairperson of the Committee of Convention 108 and the Data Protection Commissioner of the Council of Europe stressed that large-scale personal data processing can only be performed when, on the basis of scientific evidence, the potential public health benefits of such digital epidemic surveillance override the benefits of alternative solutions.

95. To date, substantial scientific evidence of CTAs' impact and effectiveness remains relatively limited and the point of my report is that strict interpretation of data protection standards could be an obstacle to that aim.

96. CTAs using the GAEN framework are designed in such a way that they do not collect identifiable health data, at least not without explicit consent. On the other hand, manual contact tracing (testing centres, etc.) may lead to the accumulation of sensitive health-related information, which cannot be shared with third parties without consent, including the scientific community, or only in an aggregated, anonymised way. These data are vital for CTA effectiveness analyses.

97. CTAs with limited data collection which are based on decentralised systems to protect privacy, as most European systems are, may hinder the ability of governments to analyse aggregated data, including user demographics or temporal, spatial trends and public health impact of CTA usage and exposure notifications. Contact tracing and testing datasets cannot be processed and combined without citizens' consent.

98. As already stated, effective CTAs are drivers for adoption and adherence. In turn, higher adoption and adherence rates lead to a better performance of CTAs and a timely, honest and accurate assessment of CTAs' public health impact is therefore a key prerequisite of an effective public health policy.

⁷⁴ <u>Report "Digital solutions to fight COVID-19"</u>, Council of Europe, October 2020.

99. A continuous adaptation to changing circumstances and quality improvement of public health processes and interventions are essential to public health. In particular, CTAs must respond to an evolving situation, taking into account the changing transmission and immune-evasion properties of a virus.

100. The tension between data protection standards and health impact assessments can be eased not only to help fight the current pandemic but also to design future technology aimed at tackling other health crises.

101. When technology is designed and implemented under time pressure, without really knowing the realworld effects and the health impact, data protection standards should be considered as an advantage in conditions of uncertainty such as a pandemic. However, those regulations must be interpreted in a way that allows for detailed data collection via the technology itself or via the healthcare system, especially in times of global health crises.

102. Building on these considerations, I elaborated a draft resolution, including a series of actions concerning the use of CTAs or similar future technology which our governments should take. In particular, CTAs should be part of a comprehensive national epidemiologic strategy, remain voluntary and safeguard privacy. Public authorities should be proactive in delivering accurate information and raising citizens' awareness on the benefits of these tools and their proper use, provide strict guarantees to the users' right to privacy, build trust and ensure that the effectiveness of CTAs is properly assessed.

103. Governments have started to turn their attention to medium and longer-term reforms, focusing on building capacity to anticipate and manage current and future crises such as new pandemics or health threats and climate shocks.⁷⁵ This report is meant to be a contribution to the governments' reflection on what could help in preparing a long-term response in the field of CTAs.

⁷⁵ See also OECD, November 2020 <u>The Covid-19 crisis: A catalyst for government transformation? (oecd.org)</u>.