

HEALTH DATA ETHICS IN THE TIME OF COVID-19: A LEGAL PERSPECTIVE

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Abstract: Taking the cue from research on the bioethical and biolegal debate surrounding access to genetic data from the 1990s, this paper explores the implications of the COVID-19 pandemic from a bioethical as well as biolegal point of view. At first, by illustrating some of the risks associated with measures for the containment and contrast of the spread of the coronavirus. Subsequently, by considering the implications of such measures on people as individuals as well as workers, and by discussing the legal implications of a potential sacrifice of privacy for safety, as opposed to necessity and public interest. In this sense, the concept of genetic counseling initially proposed by Sommaggio (2010) is resumed and updated.

Keywords: COVID-19. Genetic counseling. Bioethics. Biolaw. Fundamental rights.

Introduction

Ever since the launch of the Human Genome Project (1990-2003), discussions about the availability and treatment of sensitive health data acquired a central role in the bioethical and biolegal debate³. In particular, in the face of the discovery of a genetic disease in a patient, two different and somewhat opposing interests emerge.

That is to say, on the one hand, the patient's interest in keeping such sensitive health data private; on the other hand, family members' opposing interest in knowing the relative's sensitive health data in order to be able to severely limit or even prevent the appearance of the disease, by knowing one's genetic predisposition⁴.

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³ In this sense, we invite the Reader to see Sommaggio, P. (2010). *La consulenza (gen) etica. Nuovi miti. Nuovi oracoli. Libertà della persona*, Milano: Franco Angeli, and Sommaggio, P. (2010). *La consulenza genetica: Un ponte tra autopoiesi ed auto trascendimento* [Genetic counseling: A bridge between autopoiesis and self-transcendence]. *Tigor*, 2, 155-80.

⁴ By way of example and not limited to, on the uncertainty of genetic prognostic in the predictability of pathologies, see the 2003 Declaration of the European Group on Ethics in Sciences and New Technologies (GEE), retrievable at http://www.europa.eu.int/comm/european_group_ethics/docs/statgentest-en.pdf.

This ongoing debate acquires relevance also in view of the ongoing discussion surrounding Coronavirus tracking apps⁵ as part of a series of COVID-19 containment measures⁶ adopted⁷ (or soon to be⁸) in several States⁹.

In particular, such personal tracking measures would be designed to trace the movements and contacts of subjects infected with the Coronavirus, through the tracking¹⁰ and possible treatment of sensitive data, from a public utility perspective.

In this sense, it may be argued that the same problem that had arisen in extremely narrow terms in the context of the treatment of a patient's medical data in relation to their relatives, is now arising once again, albeit in almost general terms.

In this sense, a problem that once arose for the specific issue of genetic data has now expanded to include epidemiological (as well as location tracking data) in a more general sense.

Therefore, from a situation that saw the contrast between a personal right to privacy and a family right to the sharing of sensitive genetic health data, we seem to have moved on to a

⁵ At the time of writing (June 3, 2020), the totals number of Coronavirus apps is estimated at approximately 70 units.

⁶ When not specified otherwise, we will refer in particular to Italy.

⁷ See TraceTogether, <https://www.tracetgether.gov.sg> (last accessed June 3, 2020), Coronavirus Australia, <https://www.health.gov.au/resources/apps-and-tools/coronavirus-australia-app> (last accessed June 3, 2020), Immuni, <https://www.immuni.italia.it> (last accessed June 3, 2020), Trackcovid-19.org, <https://www.trackcovid-19.org> (last accessed June 3, 2020), Hamagen, <https://govextra.gov.il/ministry-of-health/hamagen-app/download-en/> (last accessed June 3, 2020), Rakning C-19, <https://www.covid.is/app/en> (last accessed June 3, 2020), DOCANDU Covid Checker, <https://www.docandu.com/en> (last accessed June 3, 2020), Stopp Corona, <https://www.rotekreuz.at/site/meet-the-stopp-corona-app/> (last accessed June 3, 2020), eRouška, <https://erouska.cz> (last accessed June 3, 2020), StopCovid, <https://gitlab.inria.fr/stopcovid19> (last accessed June 3, 2020), Stop Covid, <https://novid20.org> (last accessed June 3, 2020),

⁸ See Ketju, <https://ketjusovellus.fi> (last accessed June 3, 2020), OHIOH Framework, <https://ohioh.de> (last accessed June 3, 2020), Ito, <https://www.ito-app.org> (last accessed June 3, 2020), SwissCovid, <https://github.com/DP-3T/dp3t-app-android-ch> (last accessed June 3, 2020), Covid Watch, <https://www.covid-watch.org/> (last accessed June 3, 2020).

⁹ At the time of writing, organisations, companies, universities, NGOs, as well as national governments from more than 30 States are working on or have already released Coronavirus-related apps.

¹⁰ A first significant division has to be made between States in which such measures would use GPS coordinates or anonymous Bluetooth technology. Sometimes, both technologies were considered when first developing the app, see Italian diAry "Digital Arianna" app, Cuno Klopfenstein, L., Delpriori, S., Di Francesco G.M., Maldini, R., Paolini, B.D., Bogliolo, A. (2020) *Digital Ariadne: Citizen Empowerment for Epidemic Control*, in *arXiv: 2004.07717*, which uses a GPS protocol, as well as Immuni, Presidenza del Consiglio dei Ministri (2020) *Immuni Mobile App*, in *Developers Italia*, <https://developers.italia.it/en/software/pcm-immuni-app-immuni> (last accessed June 3, 2020), which uses exposure notification, a privacy-preserving contact tracing system developed by Apple and Google based on a combination of Bluetooth technology and cryptography, Apple and Google (2020) *Privacy-Preserving Contact Tracing*, <https://www.apple.com/covid19/contacttracing/> (last accessed June 3, 2020), Apple and Google (2020) *Contact Tracing: Bluetooth Specifications*, <https://covid19-static.cdn-apple.com/applications/covid19/current/static/contact-tracing/pdf/ContactTracing-BluetoothSpecification.pdf> (last accessed June 3, 2020).

situation in which this contrast has expanded to no longer include just the person's relatives, but the whole national population, thereby potentially leading to a public right to disclose private data.

Such a scenario urges a bioethical reflection on the criteria according to which both the reasonable expectation of privacy and the reasonable compression of the same for reasons of public utility, should be assessed.

Sensitive data and COVID-tracking apps.

The problem that had originally arisen with regard to genetic counseling within the confines of the family has since expanded to the point of acquiring relevance at a community level, as the Coronavirus pandemic has now started to make it more and more necessary, up to a certain extent, for people to share part of one's health data¹¹ (be it one's body temperature, cold symptoms, or more¹²) as well as data on one's movements¹³.

In this sense, it is vital to understand to what extent such compression of privacy¹⁴ could be justified by reasons of utility and public health, as well as to what extent this should be left to the discretion of the individual¹⁵.

¹¹ While several health and fitness apps already ask their users for their consent to access and process their data in order for the customers to avail themselves of the services provided by such applications, it should be noted that this does not equate to a government-supported (let alone promoted) app asking its users to mandatorily share private sensitive data.

¹² See self-diagnostic apps like COVID Symptom Study, <https://covid.joinzoe.com> (last accessed June 3, 2020), CovidSafe, <https://covidsafe.cs.washington.edu> (last accessed June 3, 2020), DOCANDU Covid Checker, <https://www.docandu.com/en> (last accessed June 3, 2020), Self-Diagnosis app, <http://ncov.mohw.go.kr/selfcheck> (last accessed June 3, 2020), Self Shield, <https://sshield.org> (last accessed June 3, 2020).

¹³ See contact-tracing apps like Australia's COVIDSafe, <https://www.covidsafe.gov.au> (last visited June 3, 2020), India's Aarogya Setu, <https://www.mygov.in/aarogya-setu-app/> (last visited June 3, 2020), France's StopCovid, <https://gitlab.inria.fr/stopcovid19> (last visited June 3, 2020), Singapore's TraceTogether, <https://www.tracetoegether.gov.sg> (last visited June 3, 2020), and Italy's SM-COVID-19, <https://smcovid19.org> (last visited June 3, 2020).

¹⁴ It should be clarified that the potential access to an individual's health data will not necessarily translate into the ability of healthcare professionals (as well as other professionals involved in the treatment and usage of such data) to identify the person.

¹⁵ As for Italy's Immuni app, which has been designed to help in quickly identifying new COVID outbreaks in Italy, it will be downloadable on a fully voluntary basis.

Regardless of the path governments will decide to take, it is vital to highlight how nobody should ever be asked to sacrifice their privacy for health. If something of this kind were to happen, this could lead to a dangerous slippery slope¹⁶.

In this sense, it is important that no barter between security and privacy be allowed by the governments/States.

In particular, the main implications of the Covid-19 pandemic in this sense are (at least) twofold, i.e. they concern people as individuals as well as workers.

People as individuals

In the ongoing debate regarding the measures that states should put in place to "flatten the curve" and limit the spread of the pandemic to a minimum, particular attention is given to the so-called *categories at risk*, which include elderly people, (former) cancer patients, immunosuppressed people, pregnant women, people with severe lung or heart conditions, some categories of people affected by rare diseases.

Such individuals are often unable to leave the house¹⁷, and should generally limit their movements to the bare minimum.

In this sense, mechanisms have been set up in many countries to help these people, delegating where possible the tasks not necessarily to be carried out in person.

While it is fundamental that people at higher risk from coronavirus be helped not to have to put themselves in situations of danger of contagion - for example, for carrying out primary activities, such as shopping - it is also clear that such people will often¹⁸ have to disclose their conditions to the authorities, in order to benefit from such services.

Furthermore, the State's need to limit the movements of (young) healthy subjects could be due to their being tested positive for the virus. While positive swabs can be traced back to the individual who had the virus swab, the possibility of ascertaining that a person is positive

¹⁶ Let us just think about the centralisation of health data that is already occurring in the hands of commercial enterprises linked to health and fitness apps as well as genetics; see 23andme <https://www.23andme.com> (last accessed June 3, 2020) and Ancestry.com <https://www.ancestry.com> (last accessed June 3, 2020).

¹⁷ By way of example but not limited to, see some Italian guidelines for people over 65. In particular, the Italian government provided an assistance service for the home delivery of medicines to people at risk and activated a home shopping service for immunosuppressed people and elderly people living alone, <http://www.salute.gov.it/portale/nuovocoronavirus/dettaglioFaqNuovoCoronavirus.jsp?lingua=italiano&id=228#16> (last accessed June 3, 2020).

¹⁸ There are exceptions to this rule, as it is likely for a State to already have access to some of such pieces of information. For instance, it is reasonable to expect a State to be aware of the number, names, and location, of elderly citizens.

to the Coronavirus is not necessarily excluded in the absence of a swab. In fact, it is reasonable to expect a fair degree of plausibility of their own positivity to the virus, from individuals who have been in close contact with one or more subjects who tested positive for the virus, should they later (well within the incubation period) begin to manifest evident symptoms of the Coronavirus themselves.

One would likely argue that such people should also have to disclose their positivity to authorities.

People as workers

Not only did the pandemic have serious repercussions on people's ability to move freely and carry out non-primary activities, it also had a strong impact on individuals as workers.

In particular, a distinction has to be made between employers and employees.

As for the former, the implications of the pandemic in regard to the insurance aspect are extremely relevant¹⁹.

This is due to the fact that companies that had to stay open or had to reopen during the pandemic must also provide insurance coverage, as contracting COVID-19 has not been equated to contracting an illness, but has instead been interpreted as a work accident²⁰ - which implies important consequences for employers²¹. In fact, if it were an illness, the classic insurance mechanisms would be triggered by the actor.

Instead, the Coronavirus being considered a real work accident would mean that it would be subjected to contractual liability by the employer.

Furthermore, this would definitely apply to all employees, but there is no reason to believe one may not try and extend this kind of liability to the customers as well.

¹⁹ In this paper, we will limit ourselves to asking a few questions, without going into detail regarding civil law issues, which concern us only insofar as they are necessary prerequisites for the topic we intend to focus on.

²⁰ According to article 42 ("INAIL provisions") of the D.L. 17/03/2020, no. 18, "Enhancement measures of the National Health Service and economic support for families, workers and businesses connected to the epidemiological emergency from COVID-19", published in the Italian Gazzetta Ufficiale (March 17, 2020, no. 70, Extraordinary edition, effective April 30, 2020): "In ascertained cases of coronavirus infection (SARS-CoV-2) during work, the certifying doctor draws the usual work accident certificate and sends it electronically to INAIL which ensures, in accordance with current provisions, the relative protection of the injured person". See <https://www.gazzettaufficiale.it/eli/id/2020/03/17/20G00034/sg> (last accessed June 8, 2020).

²¹ In a note dated May 15, 2020, Inail (Italian National Institute for Occupational Accident Insurance) intervened on the issue of employers' civil and criminal liability profiles for Covid-19 infections contracted by employees in a professional setting. They clarified that the recognition of the infection as an accident at work does not affect the assessment of (nor does it automatically ascertain) the employer's civil or criminal liability. See <https://www.inail.it/cs/internet/docs/alg-circolare-inail-n-22-del-20-maggio-2020.pdf> (last accessed June 9, 2020)

If that was the case, it would be significantly more difficult to prove how the virus has or has not been contracted while on the company's premises. In fact, there would be an inversion of the burden of proof: in this sense, employers would only have to demonstrate that they adopted all possible measures in order for their customers to be safe and not contract the virus through the fault of the employer.

Even so, what if new scientific evidence were to arise in the upcoming months regarding ulterior means of spread of the virus other than the ones already indicated? Would (and should) the employers be held liable if an employee or customer had contracted the virus for a lack of suitable protection, still unknown at the time? Would that still be classified as a work accident²²?

Moreover, could the employers' need to prove to their insurance provider their full compliance²³ mean that the insurance company itself could ask them to carry out further risk management, up to the point of requesting the employers to test their employees for COVID-19?

In regards to the latter, could employers force employees to undergo a swab or a serological test for COVID-19?

Conclusions

It goes without saying that it is imperative to limit the spread of the virus and to restrict to the bare possible minimum the contact of those who have contracted it²⁴ with those who have not, while also safeguarding those who belong to the categories most at risk.

It is also important not to lose track of fundamental rights and to understand whether a subject's - be it an employer, a company, a research institute, a government - request for someone to disclose sensitive information is valid and supported by serious reasons of necessity and public interest.

²² We are not interested in going into details regarding the effects that the COVID-19 pandemic has and will have in the future in regard to liability and insurance policies between employers and employees. We are perhaps more interested in understanding why that may happen, how that would be possible, and if that would be at all preventable.

²³ The Italian Ministry of labour and Social Policies reminds how it is not possible to expect a completely risk-free workplace. In this sense, they highlight the independence of the insurance profile from that of the judicial assessments. See <https://www.lavoro.gov.it/notizie/Pagine/Coronavirus-e-infortuni-sul-lavoro-pubblicata-la-Circolare-INAIL.aspx> (last accessed June 8, 2020).

²⁴ And are still treated for it, manifest the symptoms, or are asymptomatic.

In this sense, how to balance the different rights and interests at stake? To what extent is it reasonable to loosen one's right to privacy in order to protect health and when does it begin to compromise the person's right of free determination?

Referring to what was said before, with regard to the danger of partially renouncing the protection of one's privacy for health reasons, a potentially effective methodology could be based on the determination of the primary interest determining one's choice to disclose sensitive data.

In particular, if the individual were to decide to do so in order to limit other people's risk of contracting the virus, we argue that this would not necessarily imply serious and disproportionate negative repercussions on their part²⁵.

Conversely, if the subject were to choose to disclose sensitive information for safety reasons, thereby renouncing part of their right to privacy in order to feel safer, we argue this should not be allowed lightly, by any means.

Instead, in addition to ensuring that individuals should not be in positions where they are asked to sacrifice their privacy for safety, states should provide free consultancy services²⁶ to ensure that individuals be aware of their rights, to allow them to make informed decisions.

²⁵ Note how there have been cases of people who resulted positive to COVID-19 and refused to comply with health measures required by attending physicians. As such measures were aimed at limiting the risk of contagion for anyone who could otherwise come in contact with the COVID-positive subject, we argue that such behavior is not justifiable by reasons of individual rights and freedom of self-determination.

²⁶ For reference, see Italy's psychological support counter for the coronavirus emergency. <http://www.salute.gov.it/portale/nuovocoronavirus/dettaglioContenutiNuovoCoronavirus.jsp?lingua=italiano&id=5395&area=nuovoCoronavirus&menu=vuoto> (Last accessed June 3, 2020).