Informed consent, clinical research, Covid-19 and contact tracing apps: some neuroethical concerns

Mirko Daniel Garasic*

ABSTRACT: The explosion of the Covid-19 pandemic has led us to introduce numerous states of exception in our everyday lives, sparking debates about their appropriateness at various levels. Among other changes we have adopted, there has been an increase of apps supporting our fight against Covid-19 all over the world. From apps helping us to join and coordinate clinical trials to contact tracing apps, various are the instances in which digital technology has -at least attempted to- come to rescue to the scientific, public policy and political realms during the challenging times we are currently living in. Particularly in relation to contact tracing apps, ethical concerns have been raised over the level of transparency that they can guarantee, often stressing how the State needs to ensure a number of variables to be granted to citizens: from privacy to fairness of access and distribution through their compulsory status or not. In Western liberal democracies, the assumption has been that all risks associated with this digital technology would have to be dealt with by the State hence making its misuse "only" public, albeit authoritarian in their most dystopian versions. Here, the intention is to stress some of the overlooked dimensions of the use of different types of Covid-19 related apps. More specifically, this paper takes issue with the secondary use of data that various private companies engaged in the fight against Covid-19 could make -with an unclear role for informed consent. Especially when in the hands of private, for profit, companies, attention should abound on what states of exceptions we are allowing to slip through our ethical supervision -and to what we are actually giving consent to when downloading these apps.

KEYWORDS: Big data; contact tracing apps; Covid-19; informed consent; neuroethics

SUMMARY: 1. Clinical trials in relation to Covid-19 - 2. Contact tracing apps across the globe - 3. Behaviour and private companies - 4. Predicting or designing? - 5. Stimulating the brain while ensuring informed consent - 6. Determining who buys what? - 7. Concluding remarks.

^{*} ETHOS – LUISS. Mail: <u>mgarasic@luiss.it</u>. This essay is developed within the European project "Improving the guidelines for Informed Consent, including vulnerable populations, under a gender perspective" (i-CONSENT), funded by the European Union framework program H2020 (Grant Agreement n. 741856). The article was subject to a double-blind peer review process. The author wants to thank the blind reviewers for the useful comments provided.



Downloaded from www.biodiritto.org. ISSN 2284-4503



1. Clinical trials in relation to Covid-19

side from the centrality of the notion on informed consent highlighted by recent projects¹, clinical trials are historically conceived to be carried out in predefined and restricted settings (a decisive component for both constant supervision and scientific methodology), yet the advent of digital technology might have changed this paradigm quite substantially². Contact tracing apps might have opened the Pandora box of a not-so-subtle revolution that occurred through the digitalization of clinical trials and data. To understand better the meaning of this affirmation, let us take an extract of the definition given of clinical trials by the US National Institute of Health on their website:

"Clinical trials are research studies performed in people that are aimed at evaluating a medical, surgical, or *behavioral* intervention."³

The interesting aspect highlighted here is that behaviour itself could be both the subject of the study and the goal of the trial. As it will explained more in details in the following sections of the paper, not only that behaviour has a very broad definition that encompasses many layers of individual and societal variables for which technology could represent an unprecedented tool to quantify and address them, but we also know that, through neuromarketing, the private sector has been studying for years now how to influence and reshape our behaviour. Covid-19 related apps could surely work towards a virtuous direction, raising hopes but also concerns of the appropriateness of certain collections of data -and the risk of polarizing us towards less noble behaviours.

Let us remember that, aside from being one of the two main types of clinical studies, a clinical trial can be interventional, where it is supposed to try out a possible intervention on the population -and this could include a medical device, a drug or, more relevantly here, a procedure. A clinical study can otherwise be "only" observational, where subjects are scrutinized in the light of a theory. Notably, these types of studies do not necessarily need to provide a treatment but are used to observe the theory in action and possibly readdress some deficiencies erupted by the implementation of a certain drug, treatment and so on. They are, by definition, less invasive both in terms of physical e psychological burden and people can be involved in more than one of them at the same time precisely for those reasons.

The need for enrolling patients during a pandemic has added additional layers of difficulty, but the response has been equally vigorous: from the Israeli *PI-Enroll* app (available for free to Covid-19 trials conducted in Asia, Europe and North America) to the pre-Covid-19 *CUREITT* US app the intention of scientists was that of speeding up the recruitment process.

By helping to find and enrol Covid-19 positive patients, these and other apps can accelerate the completion of clinical trials for new drugs and vaccines. Physiologically, the pandemic has also

¹ <u>https://i-consentproject.eu/</u> (last visited 31/05/2021).

² L. PALAZZANI, Consenso informato alla ricerca clinica nell'ambito della pandemia CoViD-19: tra bioetica e biodiritto, in Biolaw Journal – Rivista di Biodiritto, 2020, 3, 323-335.

³ <u>https://www.nia.nih.gov/health/what-are-clinical-trials-and-studies (last visited 31/05/2021)</u> My emphasis.

pushed Big Tech companies such as Google⁴) to somehow contribute to making the use of the digital tools in our hands -especially in a situation where time is key- as efficient as possible. This commitment to the usage of our digital footprints has quickly moved into the evolution of the pandemic: restriction of movement and the introduction of contact tracing apps. We will look into those next.

2. Contact tracing apps across the globe

Plenty has been written on the ethics of contact tracing apps in the past year⁵ as well as various documents have been published⁶ but, due to space limits, this work will be only tangent to the central concerns highlighted in those enquiries. There have been different types of contact tracing apps across the world, with very different rates of success. While in Asia (from South Korea to Singapore, Taiwan and China) the implementation of this technology was rapid and useful⁷ in other parts of the globe such as the Old Continent, the various national apps provided to the population was not successful at all.

This result was due to a number of variables spanning from the technical realm (low levels of digital literacy are widespread in Southern Europe for instance) to a cultural realm – especially in Western liberal democracies, the idea of having a too intrusive State minding our business was subject to a lot of scepticism⁸.

Examples such as that of Singapore -where the Government passed on the data collected by the *TraceTogether* app to the police- has come to prove that such prejudice might have been well posed in many instances. These concerns became even more pressing when the data are delegated to a private company that could "misuse" them. After all, while a police department could be using our data to enforce law (even if at times unlawfully), what exactly is the "misuse" that a private company such as Amazon⁹, that has profit as a mission, could apply to our data? One of the most immediate



⁴ Fierce Biotech, <u>https://www.fiercebiotech.com/medtech/google-launches-virtual-medical-research-app-starting-studies-flu-and-covid-19</u> (last visited 31/05/2021).

⁵ R. RANISCH, N. NUSINGH, A. BALLANTYNE, ET AL. *Digital contact tracing and exposure notification: ethical guidance for trustworthy pandemic management*, in *Ethics Inf Technol*, 2020 <u>https://doi.org/10.1007/s10676-020-09566-</u><u>8</u> (last visited 31/05/2021); R. KLAR, D. LANZERATH, *The ethics of COVID-19 tracking apps – challenges and volun-tariness*, in *Research Ethics*, 16(3-4), 2020, 1-9; M. KLENK, H. DUUF, *Ethics of digital contact tracing and COVID-19: who is (not) free to go?*, in *Ethics Inf Technol*, 2020 <u>https://doi.org/10.1007/s10676-020-09544-0</u>; A. DUBOV, S. SHOPTAWB, *The Value and Ethics of Using Technology to Contain the COVID-19 Epidemic*, in *The American Journal of Bioethics*, 20(7), 2020, W7-W11.

⁶ Austrian Bioethics Commission <u>https://www.bundeskanzleramt.gv.at/dam/jcr:ef931182-2a1f-4d8f-aebc-72557b9f2438/Covid ContactTracing en.pdf</u> (last visited 31/05/2021); The Nuffield Council on Bioethics <u>https://www.nuffieldbioethics.org/news/guide-to-the-ethics-of-surveillance-and-quarantine-for-novel-</u>coronavirus (last visited 31/05/2021).

⁷ Y. HUANG, M. SUN, Y. SUI, *How Digital Contact Tracing Slowed Covid-19 in East Asia*, in *Harvard Business Review*, April 15 2020 <u>https://hbr.org/2020/04/how-digital-contact-tracing-slowed-covid-19-in-east-asia</u> (last visited 31/05/2021).

⁸ W. JONKER, *Covid-19 - why didn't Europe's tracing apps work?*, in *EUObserver*, 5 February 2021 <u>https://euobserver.com/opinion/150813</u> (last visited 31/05/2021).

⁹ J. TAYLOR, Questions remain over whether data collected by Covidsafe app could be accessed by US law enforcement, in The Guardian, 14 May 2020 <u>https://www.theguardian.com/law/2020/may/14/questions-remain-</u>

issue is that of the jurisdiction of these data, but many other ethical and political concerns are surely to be taken into account – not last our behavioural habits.

Hence, aside from crucial questions such as: "Should the apps in question should be mandatory to download and use or not?" "Where will the data be stored and by who?" "Will or should a refusal to download the app automatically result in a limitation of our freedom of movement?" the intention of this paper is to make more evident the threats that might arise from the discoveries in neurosciences and their implementation by private actors (and their extensions through apps) in this pandemic. With this questioning spirit in mind, we shall move our analysis to the way behavioural analysis is more intertwined with technology next.

3. Behaviour and private companies

Scientific breakthroughs have been always thrilling our society. Nowadays, we might be facing a new stage of technological development and its impact can be compared with the Industrial Revolution of the past centuries¹⁰. Disruptive innovations of this technological transformation, inventions and other advances of science are not only expanding our degree of knowledge, but also provide with an opportunity to enhance mental and physical capabilities we own.

One of the most promising and fast-growing branches of the tech advances is Cognitive Technology (CT). CT or cognition-related technology is a term covering wide subset of technologies that assist, augment or simulate cognitive processes or that can be used to achieve some cognitive aims¹¹. It includes two major sub-groups: neurotechnologies and Artificial Intelligent (AI) systems. The former is the set of tools that reveals human nervous system and allows to monitor and assist natural cognitive processes through the neural connections. The latter are any computer systems that are taught to mimic human intellectual patterns. It can be anything from planning and reasoning to voice and image processing as well as the interaction with the objects in a physical space. The difference between these types of the cognitive technologies is that neurotechnologies are mostly used to interact or influence "internal information processing systems", whereas AI is referred to the "external processing systems" and use external cognitive resources for supporting or enhancing human intellectual functioning.

This work wants to examine the ways current neurotechnologies are implemented into such field of human behaviour studies as marketing. By looking into which tools and methods have been already used and can be theoretically applied in the future, we will hopefully come back to the discussion on contact tracing apps with more ethical awareness regarding the potential threats of neuro and digital technologies' usage in marketing. Including of course, the dynamics currently in place in the midst of the Covid-19 pandemic.

Past decades have been marked by an extreme growth in consumption. Since shopping has switched from merely purchasing essentials to the constant evaluation of price-quality-design-ratio of all those

over-whether-data-collected-by-covidsafe-app-could-be-accessed-by-us-law-enforcement (last visited 31/05/2021).

¹⁰ L. FLORIDI, *The Fourth Revolution: How the Infosphere is Reshaping Human Reality*, Oxford, 2014.

¹¹ M. IENCA, E. VAYENA, Direct-to-Consumer Neurotechnology: What Is It and What Is It for?, in AJOB Neuroscience, 10(4), 2019, 149-151.





billions of goods and services offered to us every day, the necessity to understand what drives consumers' behaviour has become vital and urgent for producers. Marketing is a field of study that is trying to cope with this difficult question: "how does consumer's brain work?".

However, the more supply is there, the higher the complexity of the decision-making process becomes - and more efforts market researchers have to put into their studies. Once the "technological revolution" we are facing now has made it possible to glimpse into the black box navigating consumers through their shopping path, academics and self-labelled companies promptly started using the advances in neurosciences that offered powerful insights into the human brain's responses to marketing stimuli. Synergy of marketing research and neurosciences has laid the path to the development of neuromarketing.

The goals of neuromarketing are to observe objective information of the inner processes in consumers' brains that reflect their preferences and behaviour. Such research includes the use of neurotechnological applications and allow to conduct in-moment measures of the brain and body activity while making purchase decision, watching advertisement, and participating in other consumption-related processes. Neuromarketing tools' specification allows to target different experiments to the question of interest.

The most common brain-based methods are functional magnetic resonance imaging (fMRI) and electroencephalography (EEG). fMRI helps to measure blood oxygen level dependent (BOLD) and can produce data about the neural processes that can occur depending on a different consumption experience.

For instance, recent studies conducted with fMRI showed that people are more likely to buy a product if the price was viewed first. BOLD signal that appears in the part of the brain that controls decision-making processes has been detected immediately after a purchase was made in the case where the price was shown first. On the contrary, if a person was not able to evaluate price before looking at the product BOLD signal was not marked. This discovery can affect the principles of merchandising as once people see the price and then a product itself, the assessment of the good is held with the price worthiness prevailing over the quality's estimation.

Another example is a study ran at Harvard University. It was stated that fans of a TV show "South Park" experienced changes of the BOLD signal listening to the intro music, comparing to the nonfans whose brain activity in the same area remained unchanged. Particularly this reaction was seen in the part controlling reward processing. This means that fans of the "South Park" are more vulnerable as a target group as they may be pushed towards purchasing goods or services on a subconscious level if they hear favourite music during shopping.

4. Predicting or designing?

EEG can measure arousal and even directly predict consumer behaviour even before the actual decision is made. Electrical activity of the brain that is tracked by sensors attached to the head can be highly representative when the preferences or the immediate reactions have to be observed. For example, during the experiment a focus-group was shown a trailer of an unreleased movie and the outcome has indicated that data on the participants' brain activity was correlated with the results of

Downloaded from www.biodiritto.org.

SSN 2284-4503



Greenial issue

a U.S. Box office for this movie after it was offered in the cinema. Similar results were stated by the research on the correlation of brain activity and future success of a particular song. Brain activity of those participants who had listened to the songs was found to be a significant predictor of the song's success three years later, whereas the survey responds of the same members were negatively correlated with the actual sales¹².

These techniques (fMRI and EEG) allow to predict decisions of a broad part of audience based on the observations of the smaller sample of participants. Along with the brain-centred methods neuromarketing applies biometrics as a measurement of a physiological responses which often can supplement each other. Eye-tracking points where the participants of the study fixated their attention or how long they were gazing at the given material. Moreover, consumers pupils' can indicate a certain extent of arousal or their interest in the product, as well as the level of hormones can reflect one's risk preferences or predict a decision. Even skin conductance observed by hand sweating can serve as an indicator of a potential customer's reaction. Neuromarketing can go beyond solely measurement and in case of a lab-conducted experiment researchers can test how direct actions affect brain or physiological activity. One of such in-lab research showed that if participants consume particular protein shake the level of serotonin in their brains, neurotransmitters that are crucial for the mood formation, can significantly decrease.

5. Stimulating the brain while ensuring informed consent

Another technique impacting natural functioning is transcranial magnetic stimulation (TMS). This method allows to brake or enhance local brain function. Magnetic fields can incapacitate one of the brain's areas, therefore reducing person's ability to engage this "knocked out" part. After researchers switch off brain region controlling certain processes, changes in a participant's behaviour can be observed. One of the discovered consequences of the TMS effect is the decreased consumer value for food. Participants of the experiment had to starve for 3 hours and then were asked to set prices for some usual products. Two groups, one that was influenced by TMS and the other that was not, showed different results. Non-stimulated people priced the food by 65% higher than those who were affected by the stimulation¹³. All these results prove that some approaches that not only "measure" consumers' reactions and behaviour but also affect them in a different way can make it possible to deplete of specific physiological reactions. Aggregation of biometrics and brain-activity measurements can allow establishing causal relationships that in the future may be used as a guidance for marketers how to build their campaigns or for producers to be precise in the product promotion as they will be sure in the effects followed by the consumption of their goods. This can lead to the significant increase in consumption which is already one of the debating issues nowadays. It seems clear that neuromarketing generates undeniable advantages over usual marketing methods and tools in terms of better prediction of success, suitability and personalization of goods and

¹² S.J. STANTON, W. SINNOTT-ARMSTRONG, S.A. HUETTEL, *Neuromarketing: Ethical Implications of its Use and Potential Misuse*, in *Journal of Business Ethics*, 144(4), 2016, 799-811.

¹³ M.C. CAMUS, N. HALELAMIEN, H. PLASSMANN, ET AL., *Repetitive transcranial magnetic stimulation over the right dorsolateral preforntal cortex decreases valuations during food choices*, in *European Journal of Neuroscience*, 30, 2009, 1980-1988.

services. New data can make it possible to segment market in a more comprehensive way altering brain differences, instead of demographics or psychographics. However, for all the benefits both producers and consumers can take from the deepen understanding of the brain functioning it is crucial to have systematic and extensive data collection processes – research and experiments. This requires people to submit their informed consent after being explained all the procedure and the steps they will go through participating in one of these processes.

The most common issue with the clinical research is raised because it is hard to evaluate if a person is able to understand all the phases and potential risks of the research or not. Meanwhile, ethical concerns about the submitted consents in neuromarketing can slightly differ. It might be so because future participants cannot know beforehand all the details of the experiments – whether it is persuasive techniques or brain tricks that will be used, unawareness is often the initial premise and a necessary aspect for the representative results. Subsequently, if the tested methods of neuromarketing will be implemented as the regular means of persuading customers, people may also be not aware of undergoing any extraneous effects. To address this worry, in 2019 the Neuromarketing vendors have to provide those who actively consent to research participation with the explanation of the stages of the process and the used tools, intentions of the study and their right to withdraw at any time, as well as the assurance of the personal data protection and easy access for participants to the contents of the regulations.

Moreover, ongoing studies should not discredit the profession and the field of neuromarketing research, back all analysis and results provided to the clients by a solid scientific ground and disclose protocols in case of incidental findings during tests applying fMRI data capture. Nonetheless, this code is a first step on the way to the ethical neuromarketing implementation and there is still high variability in benefits to participants and neuromarketing firms across different protocols used in the industry¹⁴. Other ethical concerns are raising due to the passive data acquisition that is frequently occurring nowadays (especially in the present circumstances of the Covid-19 outbreak and ubiquitous placement of the protective technologies).

6. Determining who buys what?

Thermal cameras, video-based face recognition or emotion detection – these technologies are widely spreading, especially in contexts where authorities see public safety as superior to privacy or individual freedoms. For instance, the Chinese government is using video-based face recognition to identify and test citizens who have been previously accused of the drug possession¹⁵. Another type of technologies - emotion detection - can describe facial expressions, which then can be analysed by AI and be assessed to one of the 7 universal groups (anger, contempt, disgust, enjoyment, fear,

¹⁵ J. GOLDKORN, *Drug users nabbed by facial recognition system at beer festival—China's latest top news*, in *Sup-China*, September 1 2017 <u>https://supchina.com/2017/09/01/drug-users-nabbed-facial-recognitionsystem-beer-festival-chinas-latest-top-news/</u> (last visited 31/05/2021).



¹⁴ K.R. CLARK, A field with a view: Ethical considerations for the fields of consumer neuroscience and neuromarketing. Ethical Dimensions of Commercial and DIY Neurotechnologies Developments, in Neuroethics and Bioethics, 2020, 23-61.

sadness, surprise)¹⁶. The spin-offs of the ethical concerns related to such invasive use of technology cannot be analysed more in details here.

Currently, due to the active development of the Web and social media usage, where content is created and shared based on an open-access concept (Facebook, Instagram, Twitter, Snapchat and so on) the application of CT has boomed. It has become the standard that for-profit companies can play on our emotions, having access to these media-based technologies and targeting us according to the mood we are in (generating at times dependence from this very toxic stimulating system). Shoshana Zuboff has recently shed light¹⁷ on how surveillance has changed in the internet era. Not only we can be screened by cameras in the streets, but our digital footprint can feed algorithms and machines with our data, generating more personalized and precise marketing approaches. Messages we text, photos and videos that are post or sent – all these can trigger an immediate offer from those who are able to process our biological data and classify as an angry or happy potential customer. Taking as an example the dystopian movie Minority Report where advertisements in the shopping centre were adopting according to whom technologies were recognizing and which emotions and desires a person possessed. This idea of "bioscanning" from the 2002 sci-fi movie is turning into 2021 everyday reality -with some shopping malls already capable to tailor the ads on a specific customer. Unprotected personal information that can flow from one company to another while being processed multiple times on the way makes it possible to apply neuromarketing tools to a large number of people even without direct brain scanning. For instance, after our own faces and emotions are identified and analysed by modern technologies and algorithms, they can be stored and recovered once new technologies are available - so to have a new special type of advertisements.

One of the ways companies may play with our brains could be based on the results of the research showing that people are more attracted by those who are physically resembling themselves¹⁸. Even political and social campaigns can undergo some conceptual changes: during the study, participants were shown two photos of unfamiliar political candidates. One of them had some artificially added elements in their physical appearance taken from the very voter or extracted from the other participants with similar looks. It was noted a very strong correlation between the preferences and the familiarity of the face chosen¹⁹. Tricks like this one are invisible to the users' eyes, but if potential customers or voters get personalized advertisement or political campaigns can hide subconscious leverages, it will be hard not talk about brainwashing -making it really complicated to distinguish decisions reflecting free will of a person from those that were imposed from outside.



¹⁶ P. EKMAN, *The argument and evidence about universals in facial expressions of emotion* in H. WAGNER, A. MAN-STEAD (Eds.), *Wiley handbooks of psychophysiology. Handbook of social psychophysiology*, Chichester, 1989, 143-164.

¹⁷ S. ZUBOFF, The Age of Surveillance Capitalism: The Fight for a Human Future at the New Frontier of Power, New York, 2019.

¹⁸ L.M. DEBRUINE, *Resemblance to self increases the appeal of child faces to both men and women*, in *Evolution and Human Behavior*, 25, 2004, 142-154; M.I. GOBBINI, J.D. GORS, Y.O. HALCHENKO, ET AL., *Prioritized detection of personally familiar faces*, in *PLoS One*, 8(6), 2013, e66620.

¹⁹ J.N. BAILENSON, S. IYENGAR, N. YEE, N.A. COLLINS, *Facial similarity between voters and candidates causes influence*, in *Public Opinion Quarterly*, 72(5), 2008, 935-961.

Regarding users' protection in the digital space, GDPR is the main regulator for organizations using personal data. Privacy policy should be clearly explained and provided directly to everyone whose data can be processed while online -or at times even without even being online (e.g. being recorded by a Google car while cutting one's garden). In practice, many of the users are not able to competently agree on consent asked to them or clearly understand the terms and conditions they encounter when accessing a website or an app, because these documents are often extremely long, at times unclear and require a certain digital literacy. That is why, in theory, sites and companies are obtaining users' informed consent on the Internet, whereas, in practice, once a person is asked to explain what exactly he or she allows to do with the personal information that was allowed to be aggregated during the search – only few would be able to respond in the way their consent can be counted.

We make our everyday decisions basing on conscious and unconscious processes instantly going on inside the brain. This black box is driving us through millions of choices we have to take every day. The rise of purchasing power of a large part of the population has boosted up the demand which in turn has affected the supply side. We often hear the phrase "we have an opportunity to buy anything we want from anyone we want". However, the limits of our will are becoming blurrier. Which "part" of us is really being determined? Is it consciousness that gives a right answer to the question on whether it is worth doing something or we are driven by one of those neural impulses inside the brain? The development of CT has lifted the veil of some of the brain's secrets. It is beyond the scope of this work to engage with a philosophical discussion on determinism, but in this context suffice to say that marketers are eager to implement CT into their field and lay the path for the neuromarketing progress. It has become clearer that subconscious plays a significant role in the decision-making processes.

EEG, fMRI, biometrics' trackers and stimulators have made it possible to understand and even affect brain processes - regulating consumer behavioural patterns inside this subconscious layer. Digital technologies (and apps) have taken and are taking advantage of these findings in marketing especially when connected to companies that are, after all, in the game for profit. From what highlighted here, it seems crucial to raise the level of consumers' awareness about methods and means that are used and can be used in the future by neuro and digital marketers -because this could quite directly affect their willingness to give consent (or not) to the use of a certain app or the extraction and (future) storage of their data.

If we combine what just highlighted with the increase use of "data extractors" such as Palantir, it should become even more apparent that we are at risk of being pushed towards a certain commercial direction without even knowing about it

On its website, Palantir -a gigantic private company on which secret services and powerful sovereign states, but also commercial companies, have increasingly relied upon in the last decade- states: "we build software that lets organizations integrate their data, their decisions, and their operations into one platform. Our software empowers entire organizations to answer complex questions quickly by bringing the *right* data to the people who *need* it."²⁰

Downloaded from www.biodiritto.org.

ISSN 2284-4503

1.5.11e

²⁰ https://www.palantir.com/ (last visited 31/05/2021).

Grecial issue

What is the right data though? And who needs what? Palantir continues by explaining how they preserve our [mental?] privacy by affirming: "from our roots in counterterrorism to our current work spanning the public, private, and non-profit sectors, we've delivered software that incorporates principles of privacy by design." Yet, their immense power might derive precisely from being able to gather data from the loopholes that do not define an infringement of one's privacy extracting data from an app, neural activity or website only because the design is such that our privacy is not "encrypted". That is far from a satisfactory answer to the ethical concerned raised by these technologies, and the Covid-19 pandemic might have helped us realize how murky some dynamics really are.

7. Concluding remarks

The Covid-19 pandemic has brought forward many unforeseen scenarios and many of those have been directly related to the unprecedented level of technological advancement that is currently in our hands. Especially in the beginning of the pandemic, one of the most evident implementations of digital technology aimed at fighting against Covid-19 have been contact tracing apps and, to a lesser extent, other apps related to the pandemic (such as those helping recruiting people for clinical trials). Many countries have successfully used (in more or less liberal terms) these apps, whereas Western realities have struggled much more to implement them in a way that produced an impact. While the ethical debate concerning apps developed to contrast the pandemic has mostly focused on how the State should protect its citizens from the dark side of this intrusive technologies, this paper has addressed the commercial dynamics behind the private, non-state control usage of the technology - and the pandemic. By focusing on the developments of neuromarketing, business strategies increasingly connected with the exploitation of our data and the unclarity that still is connected with some private project -even more so than with already controversial results run by the State such *TraceTogether-* the suggestion here is to enlarge our scanning of the ethical soundness of certain apps also to the private sector.

As we are entering another emotionally charged phase of debates over the use of apps connected to Covid-19, it is important to increase -and not jeopardize further- trust in authorities. It is the only way in which global tracing apps (such as those called by some "vaccine passport apps")²¹ could have a chance to not exacerbate further some of the concerns already raised across the European Union when discussing other contact tracing apps²². If privacy is power, as Carissa Véliz convincingly argues in her recent book²³, more attention should be given to the use of our data by a private company in a state of emergency such as the one we are living in. Examples of private empires such as Palantir (able to provide services related to the usage of data to various countries across the globe in the form of assistance for police departments and secret services) exemplify the dominance of expertise



²¹ S.M. KELLY, Vaccine passport apps could help us return to normal. First they need to solve the trust problem, in CNN Business, 29 March 2021 <u>https://edition.cnn.com/2021/03/29/tech/vaccine-passport-app-privacy/index.html</u> (last visited 31/05/2021).

 ²² C. GOUJARD, Europe risks another tech tangle with vaccine passports, In Politico, 13 April 2021 <u>https://www.politico.eu/article/vaccine-passports-echo-coronavirus-app-failures/</u> (last visited 31/05/2021).
²³ C. VÉLIZ, Privacy is Power, London, 2020.

of the private sector over the public in (mis)using our data. If we feel already uncomfortable with the State knowing *too much* about us, should we not be even more concerned to give consent to a "private" app that will structurally entail a direct profit for someone (moreover, inevitably based on

Jecual issue



us in some ways)?