

**NATIONALISM AS IT
AFFECTS THE COVID-19
PANDEMIC**

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Relevant Information

This document summarises the key point of one of the round tables held at the [Fide Foundation 2nd International Congress at Oxford, on Nationalism, Populism and Identities: Contemporary Challenges](#). The key topic was the Impact of nationalism and populism at the national level.

The panel was comprised of **Senén Barro**, Scientific Director of the CiTIUS-Research Centre in Intelligent Technologies of the University of Santiago de Compostela, **Rosario Cospedal García**, COO at Blue Healthcare Group. Former General director of Genómica. Member of Fide's International Academic Council. (*Constructive friend of the Working Group*), **Daniel Innerarity**, Professor of political philosophy, IKERBASQUE researcher at the University of the Basque Country. Chair Artificial Intelligence and Democracy at the European University Institute of Florence, **Gabriel López Serrano**, Director of Regulatory Affairs for Microsoft Ibérica. Academic Advisor to Fide, **Federico de Montalvo**, Professor of Constitutional Law, Law School-ICADE, and Vice-Rector and Registrar, Comillas Pontifical University of Madrid (*Leader of the Working Group*), also as a contributor: **Concha Serrano**, Director of Institutional Relations, Pfizer S.L.U.

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About the Fide Foundation

The Fide Foundation is a legal-economic think-tank based in Spain, committed to involving the civil society in all major legal and economic developments in Spain, the EU and abroad.

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L. NATIONALISM AS IT AFFECTS THE COVID-19 PANDEMIC

Nationalism, EU, and health: from common framework to language through the experience of the pandemic, and Knowledge, science, and data in times of Coronavirus

ABSTRACT:

The current Pandemic has showed the convenience of having a common framework for public health and healthcare at EU level. The different common decisions and measures adopted during these difficult times by the EU institutions, such as the Covid EU card or central purchases of vaccines, have been the proper way to try to solve the dramatic situation we were living under.

These common actions and decisions of EU in health are important not only for the proper area of health, but for democracy. A common policy not only strengthens the EU itself and its institutions, but also could allow for certain populist and nationalist movements to be silenced. A common policy and framework for relevant decisions in health would strengthen the adherence of EU citizens to its institutions, and to the project. Given the direct link between populism and nationalism and a fear for the future, a fear of losing everything, such a common policy would also help to assuage one of the key motivating factors behind the support for such movements.

In the first part of this paper, we analyse the convenience of a common framework from different perspectives and the main problems for such proposal, where the lack of a common healthcare model in the State members is relevant.

In the second part, we analyse the lack of a common ethical proposal for the vaccination campaign against Covid at EU level. A common framework in health means also sharing not only models and structures, but ethical and legal values and principles.

The challenge we are addressing in our paper is not easy and because of it we finally propose a sort of harmonisation through EU minimum standards, not the implementation of a full harmonised

system. We are not calling for wholesale change, but rather a step-by-step approach to a new common health policy framework.

The availability of data in sufficient quantity and quality is now the basis for much of Artificial Intelligence and its applications. Its impact on all kinds of fields is being very great, and among them there are some from which we will benefit especially if we do things right.

The field of health is paradigmatic in this regard. If there was any doubt about this, COVID-19 has removed it. But not everything is a smooth ride, and this has also manifested itself during the pandemic. We have faced many difficulties in obtaining data. They are apparently within reach of our computers, but only apparently. The difficulty of sharing this kind of highly sensitive data, and the general lack of interest in it by companies and even public organisations and even governments, makes almost impossible gathering sufficient and good quality data to tackle complex health problems. Just as we cannot navigate thousands of small streams, no matter how much water they may together contain, there is little we can do when the data is siloed.

Beyond the data, there have also been serious difficulties in accurately conveying to society the course of the pandemic and the decisions that have been taken along the way. We tend to take it for granted that what has scientific support does not need to be explained in a special way, nor will it be controversial, let alone rejected. But once again this has happened.

It is clear that there has been ignorance, disagreement and even negation about the causes of the pandemic and about its very existence. Also, about the usefulness of vaccines and even their purpose, among a long list of other nonsense, at least for those of us who believe we are well informed and give science and scientific and technological advances decisive weight in the search for solutions to the problems that afflict us. But neither can we fall into the error of ignoring the existence of this type of unfounded or clearly mistaken opinions, which are nevertheless held by a significant part of society.

In this paper we look at these and other issues of particular relevance and, more importantly, try to provide some keys to making things better. Machines and people need abundant, quality data and information to make the best decisions. Ensuring that this happens is everyone's responsibility, and that of governments in particular.



Nationalism, EU, and health: from common framework to language through the experience of the pandemic

Citizens across Europe are pessimistic and anxious about the future, and a significant minority of people feel 'left behind' by the current system. National and EU-level governments need to promote policies and political discourses that seek to allay fears, address concrete concerns, and more proactively foster social cohesion. This requires moral and principled leadership on the part of political leaders, and targeted policy interventions to address the economic, social, and cultural factors driving insecurity and dislocation

Nothing to fear but fear itself, DEMOS Report, p. 424.

“We cannot wait for the end of the pandemic to repair and prepare for the future. We will build the foundations of a stronger European Health Union in which 27 countries work together to detect, prepare, and respond collectively”

Ursula von der Leyen, President of the European Commission, speaking at the World Health Summit (25 October 2020)

“We are more united than ever, and we will stand up in this war, that is for sure that we will overcome, and we will prevail. We are united and we stay united”

Ursula von der Leyen, President of the European Commission, speaking at the European Parliament Plenary on the Russian aggression against Ukraine (1 March 2022)

The construction of common health policies as the “vaccine” against populism and nationalism

- i. Directive 2011/24/EU, of the European Parliament and of the Council of March 9, 2011, on the application of patients' rights in cross-border healthcare represented a very important advance in the development of a common healthcare framework in the European Union so that the principle of free circulation does not only apply to medicines and medical devices and health professionals, but also to the patients themselves.

- ii. There are some specific risks and difficulties for the development of this common framework in the specific area of health. However, it is not easy to imagine a European Union that proclaims freedom of movement as a founding principle without this principle being developed in the sphere of citizens as patients. This has been proclaimed by the Court of Justice of the European Union in a well-established jurisprudential doctrine, which has been, precisely, the one that determined the enactment of the Directive (cases Kohll, Decker, Kroll, Geraets-Smits and Peer booms, Ioannidis and Descamps, Inizan and Keller).
- iii. The Court of Justice has considered that the development of common health policies constitutes one of the aims of the European Union that is not limited to a mere single economic market. It recognizes this at *United Kingdom v. Commission*: "furthermore, none of the documents before the court supports the argument that the commission's exclusive or main purpose was of an economic nature rather than to protect health". It can therefore be said that for the Court, the promotion of common policies in the field of health protection and health care would constitute a true expression of European citizenship.
- iv. On the other hand, it is difficult to promote true an EU citizenship without having a common policy in the field of health, and this, beyond the recent experience of the Covid-19 pandemic, which is still present. European citizens consider health protection to be one of the most important public policies for their own well-being and safety. If there is a public benefit that citizens have assumed as inalienable, once the welfare state has been developed, this is precisely the protection of health. The European Union itself must be aware that its progress towards a more homogeneous political and economic framework passes, inexorably, through health policies.
- v. Even a common policy not only strengthens the EU itself and its institutions, as we have been shown, for example, by the centralized purchase and proportional distribution of vaccines against Covid-19, but also allows certain populist and nationalist movements to be silenced. A common policy and framework for relevant decisions in the area of health would strengthen the adherence of EU citizens to its institutions and to the project. There is a direct link between populism and nationalism and fear of the future, fear of losing everything.

- vi. In our opinion, the main problem is not about that the national healthcare systems of the Member States are failing or falling short, but to strengthen the cooperation and collaboration among Member States and EU Institutions as a way to show that health for the EU Institutions matters. On the other hand, a common market and freedom of circulation of citizens and companies are not really understandable without a common framework in the area of health.
- vii. The phenomenon of globalization brings with it the fear of losing one's identity, one's own culture, but above all, of losing everything. Globalization moves the elements of production, not its products, beyond our borders. Capital has become extraordinarily mobile, organizing production globally. And this generates distortions and difficulties in the solvency of our robust social States and the effect of what have been called, metaphorically, Left Behinds. The report of the British Institute Demos, under the title, nothing to fear but fear itself? which incorporates and explains in detail this concept of those left behind, points out that the problem of the crisis of our contemporary democracies essentially lies in the fact that the citizens of all over Europe are pessimistic and anxious about the future, and a significant minority of people feel "abandoned" by the current system. National and EU governments need to promote social cohesion, and, among these policies, health occupies a leading role.
- viii. As the German philosopher, Markus Gabriel, reminds us, the problem is deeper and affects the ethical behaviour of individuals, since moral demands can only be satisfied when we create the necessary economic conditions for this purpose. We cannot start from the premise that all people will behave as moral heroes in all circumstances. It is the task of the economy to create the necessary conditions to act morally without heroism.
- ix. As Norman Daniels and other authors explain following the John Rawls ideas about justice, right to healthcare is not only related to Social State, as one of the main social rights, but to democracy. The principle of democratic State requires the active participation of all citizens. Therefore, they should enjoy a minimum of living conditions that make such participation feasible. If the notion of procedural democracy requires respect for the effective political participation of all members of the body politic, they must be in material conditions exercise

that right. So, the constitutional proclamation and guarantee of a first level of social rights, such as right to healthcare, is a premise of the democratic process. Citizens should enjoy a vital minimum that preserves their dignity and allows them to participate at the democratic framework. Those who have less opportunities to overcome a disease, groups in worse economic condition, usually have less opportunities for a real political participation. Guaranteeing certain material preconditions, and among them, healthcare, supposes, also, to protect the right for political participation¹.

- x. This objective of a common European framework is not easy to be developed, even, considering the robust doctrine of the EU Court, mainly, because, organization and management of health care systems is a responsibility of the Member States, as it is recognized in the founding Treaties, limiting the powers of the Union in this matter to mere coordination and cooperation (art. 168 Treaty of the European Union).
- xi. However, the principle of sincere cooperation, as enshrined in Article 4(3) TEU, and which entails solidarity, to which the Commission refers, constitutes, together with the principle of unity, the cornerstone of European integration; or the 'pillar of our Union'².
- xii. Therefore, we are calling for a sort of harmonization through EU minimum standards, not a full harmonized system. We are not calling for wholesale change, but rather a step-by-step approach to a new common health policy framework.

¹ L. Morales, *Derechos sociales constitucionales y democracia*, Marcial Pons, Madrid, 2015, p. 303; and Ponce Solé, «Reforma constitucional y derechos sociales: La necesidad de un nuevo paradigma en el Derecho público español», *Revista Española de Derecho Constitucional*, n.o 111, 2017, p. 70.

² See Professor Neergaard's Paper on 'EU, Covid-19 and Nationalism: Legal Aspects' starting on page 155

Towards a common bioethical framework in the EU: the missed opportunity of prioritizing access to vaccines by citizens of the Member States

- i. The common purchase and distribution of vaccines against Covid disease by the EU, avoiding situations such as those experienced at the beginning of the pandemic with the shortage in international markets of certain health resources (masks, diagnostic tests, respirators, means of life support, ...), constitute, perhaps, the greatest success of the EU institutions in recent decades. This makes possible to mitigate certain criticisms of EU project. All EU citizens felt equally protected by EU.
- ii. However, it has not been accompanied by a common framework for prioritizing vaccines at the internal level, which would have made it possible to further complete that achievement. The context in the different Member States is, certainly, not identical. But it is also true that the characteristics of the European population are not so unequal. In addition, the Member States have a common ethical-legal framework for decision-making in the field of health through the Convention of Oviedo of Council of Europe, ratified by all of them, and the rights enshrined in the EU Rights Charter. However, these regulations contained in the Convention and the Charter were not developed for a specific situation of health catastrophe.
- iii. In a context of "catastrophe medicine" such as the one we have experienced during this pandemic, the use of resources must be planned, based not only on scientific criteria, but also on ethical principles and the rule of law, avoiding utilitarian decision-making, where the most vulnerable are the ones who usually end up losing. This has, also, a direct impact on criticizing the EU from a populist and nationalist perspective. Utilitarianism is insufficient for the solution of complex ethical issues related to right to life and healthcare. For the utilitarian perspective, human dignity is not a relevant value for the decision-making process. Jeremy Bentham stated that "natural rights is simple nonsense: natural and imprescriptible rights, rhetorical nonsense-nonsense upon stilts". It is a mere pragmatic solution that would allow quantify numerically, based on empirical data, with the plausible aspiration of achieving the greatest happiness and well-being for the greatest number of citizens. Utilitarianism offers a pragmatic and procedural solution where ontological value of the human being has been

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removed. A space in which an ethics without truth is promoted. As professor Gustavo Zagrebelsky says principle of justice speaks, fundamentally, not of the greatest benefit for the greatest number of people, but rather the least number of those excluded from happiness. The utilitarian approach falls into the fallacy of the absence of moral separability of people, that is, it assumes that the moral value of people is interchangeable: the health that some gain compensates for the health that others lose, as long as the result is a positive sum. The interpersonal compensation of human lives against each other, in order to maximize presumed collective benefits, is incompatible with the primacy of human dignity.

- iv.** As the German Ethical Council pointed out at the beginning of the current pandemic, the State has the moral and legal duty not only to save as many human lives as possible, but also, and above all, to safeguard the foundations of the legal system, and this is key if we want the EU project to move forward.
- v.** This pandemic has offered us the opportunity to continue advancing in the EU project in a robust manner, silencing the criticisms against it coming from populist and nationalist movements. Opportunity achieved with the centralized purchase and distribution of vaccines, but not with the determination of common ethical criteria in prioritizing access to vaccines by citizens of the Member States. Moving towards an EU with shared ethics in a field as sensitive as health is moving towards an EU with “good health”. Subsidiarity principle usually plays a relevant role in such difficult cases of scarcity, but the EU vaccines experience during the pandemic offers the opportunities of working together in the area of public health and healthcare, beyond that principle.
- vi.** Finally, it is also important to broaden the focus and to consider prioritization not only for EU citizens but the World, specially, developing countries. To develop an EU model based on bioethics and human rights should also mean to attend the needs of the world and not only Europe. Experiences such as COVAX have been very stimulating but not enough.

A short comment about science and language and communication as an introduction for the following chapter

- i. The pandemic has showed also that we are not living under a framework of rationality as many of us expected. The proper concept of sentimental democracy, developed by Manuel Arias Maldonado in Spain, is a good example of this trends. The rational interpretation and explication of reality has been substituted by emotions. The example of vaccines against Covid-19 and anti-vaccination movement is a good example of this. The more effective and safety those vaccines are, the more the anti-vaccination movement question them. Following the explanation of Arias Maldonado about this concept, it seems desirable that democratic government now be based on affective seduction and not on rational persuasion.
- ii. And perhaps, one of the problems comes from using the same language that we were using for a rational dialogue and debate, instead of adding emotions to the messages. It is not about transforming the scientific language in a merely emotional one, which goes against the proper concept of science. It is about considering the characteristics of scientific message when it is addressed to common people, to establishes a link between the people to whom the message is addressed and the content of it.
- iii. The pandemic has showed everywhere and, mainly, in Europe that we need to reconsider the way and the form we express our scientific messages in a context of emotions, nationalism and populism.

CONCLUSIONS OF THIS CHAPTER:

1st There is a closed link between nationalism and populism and healthcare as a social right (Brexit Campaign is an example of it)

2nd There is a need to develop a common framework for healthcare at EU

3rd If we consider the concept of the left behinds and the need to develop a new social agenda for the EU as a real way to maintain our democracies, we should achieve it through a common healthcare system or, at least, an increase of the common policies in the area of health

4th This common framework should consider the differences among State members, such as the proper characteristics of the healthcare system (Beveridge, Bismarck, etc.)

5th The experience of the pandemic has showed us the opportunity and possibilities to achieve it

6th We should think about the form and ways to communicate scientific conclusions or recommendations when the messages are not addressed to the scientific community, but to the common people. Now emotions play an important role

Knowledge, science, and data in times of Coronavirus

Knowledge and technology society

- i. The pandemic has highlighted the importance of science and the technological development that emanates from it. Where else have the vaccines come from that allow us to face it with more hope than fear? At the same time, we have seen the importance of collaboration in addressing solutions to our most complex and pressing problems. Having shared the genetic information of SARS-CoV-2 from the beginning allowed us to detect it and fight it with unusual speed. Having quality data, sharing it and having the ability to properly compute it is increasingly important even for the progress of science and technology.
- ii. The world can never protect itself completely from a pandemic, any more than from a hurricane or cyclone. COVID-19 has taught the global healthcare community priceless lessons. It is our responsibility to use them to make our defences against the next pandemic more nimble, more robust, and more equitable.
- iii. One of the first weaknesses identified during the pandemic was the shortage of some raw materials, finished products and even scarcity of certain technologies. In the biopharma industry this was translated in the need to supply unprecedented large quantities of some products that were needed during the pandemic. This put a lot of pressure in Eu countries and companies to supply the essential required products. Spain and Europe have lost part of their biopharma production capacity in favour of third countries where manufacturing costs are much lower. Both Europe and Spain should support biopharma companies and promote the manufacturing of essential drugs in our territories.
- iv. Another important factor was the fact that shortages of raw materials and intermediate products were made worse by trade restrictions and competition for and among vendors which resulted in inefficient allocation of available supply, leaving most developers less capable of rapidly testing, manufacturing, and

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delivering COVID-19 vaccines and therapeutics. Proposed investments to expand manufacturing capacity must also build capacity for sufficient and rapid supply of critical commodities and raw materials.

- v. Paradoxically, at the same time that we are heirs and beneficiaries of centuries of scientific advances, we are also witnessing an increase not only in scepticism around certain advances in science but even in their denial. The so-called negationist not only appears in areas where there is still some scientific controversy, such as climate change, but also in issues where there is no possible discussion, such as the existence of covid-19 or the AIDS virus, which has been with us for decades. Negationist is dogmatic, not scientific. Paradoxically, it is even possible that it will find some oxygen to develop in the caution with which scientists present and defend scientific knowledge, considering it potentially falsifiable, to use the words of Karl Popper.
- vi. Without going to the extreme of the negationist, there is also a growing disaffection with science and technological development in a significant part of European society. The number of anti-scientists also seems to be increasing. The causes are manifold: information saturation, lack of education, failures in the communication and dissemination of science and technological advances, perceived abuses of power by governments and companies. The often-inadequate communication of scientific and technological advances, together with an information overload, which saturates us and often prevents us from separating dust from straw, undoubtedly contributes to this.
- vii. We should not confuse these phenomena, in any case, with the reasonable questioning of the intrinsic value of any technological progress. We have known since the origin of the first tools that the axe used to defend against a predator can be used to kill another human being.
- viii. Perhaps as never before, Artificial Intelligence, and in particular big data to learn how to solve a myriad of problems, embodies this ambivalence between the

potential benefits and harms of technology. In 2013 David Brooks coined the term *dataism* to great acclaim,³ and since then this phenomenon has gone from strength to strength, to the point where we can think of data as both the Oracle of Delphi of the 21st century and Pandora's box.

- ix. Indeed, the future of Europe, or any other country or region of the world, cannot be good unless it is fundamentally underpinned by progress in science and technological development, and the innovation that flows from it. These, moreover, are increasingly data-dependent, as we have already indicated. However, while there is some consensus on this, doing so requires political decisions on what and how to invest, an equitable distribution of wealth, and a commitment to social, economic, and environmental sustainability. It also depends on overcoming many inertias and barriers, not least local visions, and interests, fostered by nationalism and corporatism.

The paradoxical coexistence of reverence for knowledge and technological development and the rejection and denial of both

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- i. European societies are facing problems and crises that will require a great mobilization of knowledge and a great technological impulse. We need the best knowledge and technology to be used to make the appropriate collective decisions. This reality introduces us to the debate about what is the correct relationship between science and people, between knowledge and power, between experts and politicians. This debate does not take place with all the time in the world and in the midst of a stable reality, but in the face of the urgency of very serious problems, with sometimes contradictory requirements of the different social subsystems and conflicting visions of what is at stake.

³ Brooks, David (4 de febrero de 2013). «The Philosophy of Data». The New York Times. ISSN 0362-4331.

- ii. As if that were not enough, there is the circumstance that this enhancement of knowledge must be carried out at a time when science is also the object of distrust and controversy. It is a problem that cannot simply be explained as irrational ways of thinking but is telling us something about the nature of our societies. Only by understanding those who distrust science can we understand the society in which we live and the role that knowledge plays in it. Understanding does not mean here to give reason to those who seem to lack it, but to explain the circumstances from which this resistance arises because then we will have a more precise idea of the rationality they reject.
- iii. Our chaotic digital environment has, from the outset, objective causes. It is true that disinformation often has specific responsibilities that can be identified. But it is not this intentional disinformation that should concern us the most but that ignorance that has no guilty subjects but objective circumstances that make it inevitable, in whole or in part.
- iv. The greatest complexity in the world, the mistakes of scientists and experts, the accelerated technology that creates new areas of ignorance, all produce perplexity and bewilderment. Complexity here means disconnection with immediate evidence, unintelligibility, information that disorients. There are also causes that refer to an overloaded subjectivity, which can be relieved by a conspiracy theory or by the denials that arise in a context of fear, anxiety, distrust and feeling of helplessness. For those who feel that everything is out of control, a narrative that explains their feelings and enrols them in a safe community of believers becomes a reassuring relief.
- v. Since the mid-twentieth century various analyses of this dialectic have been formulated, but almost always as if ignorance were the opposite of rationality; we have hardly reflected on the mix of knowledge and ignorance that characterizes us. In the coming years, with great probability, we will witness great scientific discoveries and we will see how some technologies will develop that will radically modify our environment. All this will imply new ignorance (about, for example, the

side effects of certain technologies or the regulatory uncertainty they generate) and will set in motion intense debates, since discussing is what we humans do in democratic societies when we ignore something and want to generate the corresponding knowledge about it. As always, the advancement of knowledge makes us both wiser and more ignorant. There is no scientific discovery or technological invention that does not carry, like its own shadow, a new ignorance.

- vi. At the same time, we are aware that the most important political and social problems require a great deal of scientific knowledge and those who lead political institutions do not have it, so they have to be advised appropriately. Politics is not practicable today without a continuous recourse to expert knowledge.
- vii. We need to think about the conditions under which knowledge can and should be present in the political process. The dissent of experts, the questionable scientific assessment of the risks and the threatening potential of some scientific innovations, have contributed to questioning the traditional image of science as an instance that provided objective, safe and universally valid knowledge. Faced with the technocratic dream, the truth is that science is one more voice in the concert and political, ethical, or ideological logics are also asserted as legitimate points of view when making decisions. Science advises, but it does not replace politics.
- viii. We should think of the relationship between science and politics not as submission from one to the other but as an argumentative process. Political problems must be translated into the language of science, but in turn the answers of scientists are not applicable to politics as long as they have not been poured into the format of political decisions. There is no immediate translation of scientific judgments into political decisions, nor is there a scientific justification for previously taken decisions.
- ix. Final decisions on issues beyond the local level, such as vaccination, although to be taken by the national competent authorities in each country, must not only take into account scientific advice, but also the interests beyond their borders, including

those of the world population. For example, not to cooperate with vaccination at the global level, also in the interest of national health, would be another form of self-limiting nationalism

- x. An important positive advance coming from the pandemic was the cooperation and sharing of data y scientists, academia, start-ups, biotech, and traditional pharma of data on the virus and on the vaccines and therapeutics. Chinese scientists⁴ quickly posted the genomic sequence of the SARS-CoV-2 virus on GISAID (2), a widely available data-sharing platform: this should be both the scientific norm and the legally binding obligation that every nation owes to every other nation. The approval of the first vaccine in just 326 days after that genome was published was an unthinkable feat and it was based in R&D previous years, decades of robust research and the cooperation of all public and private sector agents involved.
- xi. As well we have seen work done by the world's healthcare regulators during the pandemic, which saved millions of lives. Regulatory flexibility and collaboration among the leading agencies proved invaluable, from fast-tracked approvals and e-signature authorizations to expedited scientific guidance and rolling review processes. The EU has a new programme that will support all areas of research and innovation, based in excellent science and we need voluntary partnerships to continue of all parties involved in R&D, face global challenges and industrial competitiveness, increase manufacturing capacity, facilitate technology and knowledge transfer, and drive rapid R&D. Governments priority is to ensure the safety of their people. But narrow understandings of that duty have led to the rise of "vaccine nationalism." Policies like export restrictions and vaccine hoarding, regardless of global public health need, have intensified and likely prolonged the

⁴ See <https://www.science.org/content/article/chinese-researchers-reveal-draft-genome-virus>

COVID-19 pandemic. Refining the concept of "national health security" in a global context will be essential to build a different framework to be prepared for a new pandemic

The omnipresence of data: opportunities and threats in times of pandemic

- i. Turning back to the pandemic, it is necessary to consider some of the issues that the pandemic has brought to light and others that it has changed or helped to change in an accelerated way. Among the first is Europe's dependence on the outside world, particularly in certain critical industrial sectors: from chips to masks, respirators, and diagnostic tests. For its part, everything that has to do with the digital economy and society has accelerated enormously during the pandemic: Automation, teleworking, telemedicine, tele-education, digital transformation in general.
- ii. During the pandemic, it has become clear how the collaboration of EU Member States is essential. For example, we have seen it in the purchase and distribution of vaccines.
- iii. The importance of data to face the pandemic has also been highlighted, both in epidemiological analyses, as well as in the processes of diagnosis and contact tracing, or even in the planning of the necessary economic recovery. In fact, the large quantity of data generated and analysed about the virus and its effects make this crisis the first "data-driven pandemic", as Daniel Innerarity points out.⁵ This collaboration has not been frictionless, at some instances politicians have suggested to exacerbate nationalisms over collaboration that have had an impact in how institutions have managed the pandemic⁶.

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⁵ Daniel Innerarity, "The Data-Driven Pandemic: A New Conceptualization of the Data Society," May 2021.

⁶ <https://www.bbc.com/news/health-60259302>

- iv. It is not an exaggeration to talk about the data economy and society, and if Europe wants to occupy vanguard positions in it, it must avoid hyper-protectionist policies, often fostered, or supported by nationalisms. In this line, the European Commission presented in March 2020 the "Digital compass for 2030: the European way for the digital decade" that forms the roadmap for the digital transformation of the European Union⁷ until 2030. Its objectives include the reference to European digital sovereignty and the need to reduce its dependence on other countries outside the European framework.
- v. The phenomenon of Digital Sovereignty and its regulatory derivatives represent one of the greatest challenges for the European Union, since the approach to technologies such as Artificial Intelligence or even cloud computing, are often perceived as negative, showing them as technologies that should be feared and, therefore, subject to restrictions, instead of promoting their adoption and development. The most recent examples of such protectionist measures are those implemented by France's NISSA (Cybersecurity Agency) in SecNumCloud (National Certification for public cloud services) and Germany's BSI agency on C5 (National Certification for public cloud services), which, based on their interpretation of the current international data transfer regime, have decided to impose sovereign models for their public sector data (which may include health care data). These initiatives will clearly have an immediate effect on the transatlantic relations and are likely to lead to further fragmentation in the region.
- vi. Obviously, the risks posed by the inappropriate use of technologies should not be ignored, as we have already said. The fact that negative prejudices about technological developments and their applications are installed in society can bring us many problems as well. These include the erosion of the European single

⁷ https://ec.europa.eu/info/sites/default/files/communication-digital-compass-2030_en.pdf

market and the dissonance of policies and regulatory frameworks, the impact of which is felt from universities to the market.

- vii. Perhaps the paradigm of what we are saying is in the realm of medicine and health. The report of the [Centre for Data Innovation](#) called "Who is winning the AI Race", analyses the evolution of this technology in the United States, China and Europe. In the case of health data, the report states that more and more researchers are using this type of data in the design of AI systems to help identify, prevent, and predict the development of diseases. In fact, one of the indicators being analysed is the capacity of each region to collect and exchange health data. ⁸ In this sense, at the European level the health sector faces a high level of fragmentation, which includes the different ways of interpreting and applying the General Data Protection Regulation or GDPR. Issues as basic as the ownership of health data have different solutions in countries such as Finland, Denmark, The Netherlands, Spain, and Italy.
- viii. Fragmentation remains in many areas that are critical for data-based research, and that concern the sharing and use of data, as well as data governance and ownership and the responsibilities arising from its misuse. A recent study by ICLG comparing regulatory frameworks in different EU countries clearly shows the need for greater harmonisation around data in the region⁹. Ways of dealing with this data fragmentation at EU level are being explored, such as the application of federated learning models, which avoid data sharing, or data anonymisation techniques. But these are not definitive solutions, and, in the meantime, they risk stifling innovation and delaying or preventing applications that can save lives and improve people's lives. Indeed, many research projects in critical areas have been discontinued or

⁸ <https://www2.datainnovation.org/2021-china-eu-us-ai.pdf>

⁹ <https://iclg.com/practice-areas/digital-health-laws-and-regulations>

abandoned, as highlighted by Professor Heidi Beate Bentzen and other researchers who are assessing the barriers to data sharing and their consequences¹⁰.

- ix. This situation that we have been commenting on has at least a triple effect. First, researchers must comply with the requirements established by national regulations. Secondly, if it is a project involving other countries in the European environment, then you will need to add to your analysis the regulatory requirements that come from those countries. Finally, if the project has implications beyond the European Union, then it will have to consider everything related to international transfers. While it is logical and desirable that there are controls that guarantee the prevalence of fundamental rights in the face of the undesirable consequences of an inappropriate use of technology, the truth is that it is necessary to reflect on a fragmentation that may be unnecessary and, of course, is certainly limiting.
- x. As can be seen, achieving true integration and a single European digital market is a major and extraordinarily complex challenge, and even more so if we introduce into the equation issues related to the possible nationalisms and claims of digital sovereignty of the different countries of the Union.
- xi. Of course, we are not suggesting an unregulated or uncontrolled use of data, particularly data that directly affects people, such as health data. Indeed, there are many regulatory measures that can be taken, such as the European Commission's recent proposal on the AI Act. But it is necessary to distinguish the essential from the recommendable or even from the ancillary. Regulations "just in case" may particularly affect pan-European and transatlantic research, with clearly undesirable consequences.

¹⁰ <https://www.nature.com/articles/s41591-021-01460-0>

- xii. Data, especially personal data, must be protected by privacy and security laws and practices. No one disputes this. But taking this to the extreme and keeping data in silos, which cannot be expanded either in space (sharing data across organisations and countries) or in time (using data for new purposes), undermines its public, not just private, value.
- xiii. In any case, the pandemic has made more evident what we already knew: we need more science and technological development, but at the service of the common good. We need more and better data and information, and this will not be achieved without sharing it efficiently and effectively. The pandemic is not the only global problem we face. Climate change is in the medium term something that can have even more serious and even irreversible consequences, at least if action is not taken in time. Once again, we have to recall the Lisbon European Council in 2000, where it was set as a strategic objective to turn the Union's economy into 'the most competitive and dynamic knowledge-based economy in the world, by 2010, capable of lasting economic growth accompanied by a quantitative and qualitative improvement in employment and greater social cohesion'. It is obvious that we did not achieve that task in 2010, and neither have we achieved it in the present. If we do not want to give up on achieving it in the more or less near future, it is absolutely necessary to understand and cooperate between the countries of the Union, also in everything that is relevant in the so-called data economy, where there is no room for nationalisms and digital sovereignties at all costs or paralysis due to analysis.
- xiv. We are living through the first "data-intensive pandemic", and it is further highlighting the dichotomy between the protection of individual data and the potential collective benefit of having it available, particularly in the field of health. Failure to properly resolve this dichotomy may affect scientific progress and technological development. This situation may also be worsened if countries go to extremes in defending the sovereignty of "their data", preventing them from being used even for the general interest. In the case of Europe, in particular, if this leads to data being isolated in isolated compartments or silos, within each country of the union, we may put a significant part of our competitiveness and our future at risk.

Secondary use of health data: should EU change the Helsinki paradigm in the area of research through data

- i. Big Data offers new opportunities for the development of our societies and for solving many of our current economic and social problems in general, but most specifically in the field of health research. The extensive use of conventional health data and even their interlinking with non-traditional data shall help to fight against many diseases and to develop new treatments which is a new hope for patients and for all the community. The results extracted from data use took decades to obtain only a few years ago. Currently, because Big Data and AI, it can be revealed within months, even days, and, above all, at a very affordable cost. Algorithms enable the comparison of a large number of healthcare processes, thus offering accurate conclusions, in terms of volume, on the most acute diagnosis and the best treatment for many diseases.
- ii. The context is, therefore, unique from an historical perspective and not taking advantage of it could be seem as a not very ethical option, above all, if we consider the opportunities offered for the prediction, prevention, or healing of many diseases.
- iii. As the German Ethics Council (*Deutscher Ethikrat*) pointed out, in biomedical research, the analysis of large volumes of health data should provide a better understanding of important scientific processes and their connections. Among the most data-intensive applications are modern imaging and molecular biological procedures, such as those employed in what we call 'omics' (e.g., genomics or proteomics).
- iv. This opportunity has even more value and projection for the future in those States, such many of the EU Member States, which have implemented a public healthcare system where there is a correlation among millions of medical records and health data. On the other hand, these new opportunities of the development of new technologies, Big Data or AI pose some ethical and legal conflicts and dilemmas. Health data is one with a strict regulation and legal

protection considering the impact of their revelation in individuals' privacy. There are risks to personal rights, as there are opportunities.

- v. **Is my health data mine anymore?** This question could be seen as a strong one or, at least, a tricky one. New technologies and mainly Big Data offer a great number of new opportunities in the area of health where we have a huge amount of data coming from medical records, clinical trials protocols, internet consultations, etc. Consequently, it can be stated that clinical data are no longer a mere reminder of the healthcare process, but rather the main source of knowledge and progress in Medicine and Biology. Health data can already be considered as the true treasure of biomedical research, as many said that biological samples were the treasure of the previous decade.
- vi. From an ethical perspective, as the Spanish Bioethics Committee said on its Report on the ethical legal requirements in research with health data and biological samples in the framework of the Covid-19 pandemic, 2020, maintaining the postulate that the disease and the data generated by its treatment only belong to those who suffer it is not only to ignore reality, but also to ignore the existence of conflicting values and rights and the correct way in which they should be reconciled. Data protection is not, nor has it ever been, an end in itself, but rather serves to protect the person in their privacy, both in their private sphere and in the public sphere. However, it is also important to remember that this right to privacy, like other rights, plays in a social environment of interrelations, in which it is as relevant to recognize the autonomy of the individual as the solidarity of the citizen.
- vii. A similar position is supported by Barbara J Evans: those who invoke their right not to share their data in any circumstance, even when the health of third parties may depend on them, may be blurring the line between individual autonomy and narcissism. A position that ignores the common good and prioritizes not only autonomy but even selfishness and narcissism does not seem acceptable from an ethical-legal perspective. Also, for Ricard

Martínez, there is a change of paradigm towards a new one based on efficient control by the authorities of the use of data from an initial consent.

- viii. The International Bioethics Committee, IBC-UNESCO, pointed out in its 2017 Report on Big Data in health, that Big Data can already be considered a common good of humanity (literally, “Big Data can be framed as a common good of humankind”). Science and technology in the field of Big Data can help reduce the inequalities that prevent many human beings from enjoying the highest possible level of health, both nationally and internationally. Therefore, it can be said that health data, in the Big Data stage, is a true heritage of humanity, even if it is in merely metaphorical terms. However, the provision of this Big Data cannot be carried out at the cost of violating the right that each individual has.
- ix. The new EU regulation, while not specifically addressing the particular dilemmas and conflicts of Big Data, does contain specific references to health data and, more specifically, to the requirements for their secondary use for research purposes. We may say that the Regulation opens up a new era or even a new paradigm in this field. In fact, it replaces the model based on the alternative between informed consent and anonymization, with one based on informed consent or pseudonymization that would enable a more flexible use of health data in the interest of the community and everyone’s good health.
- x. What is relevant in this new model is not so much an individual’s prior consent to the new purpose for which data are intended or strict data anonymization. In fact, what matters is the legitimate origin of the data, the great importance of their secondary use for community health and the adoption of sufficient measures to prevent non-authorized third parties from gaining access to an individual’s identity through the data, without necessarily demanding any strict anonymization. This seems to be legally achievable through what is commonly named pseudonymisation, defined by the EU Regulation as the processing of personal data in such a way that they can no longer be attributed to a specific individual without the use of

additional information, as long as that such additional information is kept separately and subject to technical and organisational measures of non- attribution to an identified or identifiable individual.

- xi. The advantages of pseudonymization over traditional, strict anonymization are clear from the standpoint of community health. In fact, interlinking the data to the person, even when it is extraordinarily difficult for a third party to decode them, means not only to broaden the data used in research to include other initially insignificant data (data enhancement), but also to corroborate the results of data use with the patients' real progress (results verification), for example. And this is very relevant in today's Big Data science. Pseudonymisation is, in the end, the only guarantee against the previously mentioned misleading causalities that are one of the main risks of Big Data.
- xii. Therefore, we can affirm that what is relevant in this new model will not be that the individual has given their prior consent for the new purpose to which the data is intended to be used, but a) the legitimate origin of data, b) the relevance for the general interest of the secondary use, c) and the implementation of enough guarantees to protect the individual's identity from whose data come from. And it seems that, legally, it can be achieved through what is now called pseudonymization, understood, in the words of the EU Regulation, as the processing of personal data in such a way that they can no longer be attributed to an interested party without using information additional information, provided that such additional information appears separately and is subject to technical and organizational measures designed to ensure that personal data is not attributed to an identified or identifiable natural person.
- xiii. The virtues offered by pseudonymization compared to the traditional strict anonymization are evident from the perspective of the interest of the health of the community, since, by maintaining the link between the data and the person, when it is extraordinarily difficult for a

third party to decode it, it is allowed not only to expand the data used in the research to others that initially could not be considered transcendent (data expansion) but, which is very important in the current state of Big Data science, to contrast the results of the exploitation of data with, for example, the true evolution of the patients (verification of results).

Pseudonymization is, in the end, the only guarantee against the spurious causalities which is one of the main risks of Big Data at its current stage of evolution.

- xiv. In this new framework of great opportunities to fight against diseases and improve people's health, it is important to promote new paradigms which do not forget that there is a very different context from the existing one a few years ago. The great advantages offered by massive data processing should determine a vision not only based on individual interest with a clear detriment of the common good. A balance between both positions seems to show itself, as it happens in many other areas, as true virtue.
- xv. Furthermore, the debate must be framed in terms where the context is also considered. In the models of healthcare developed in Western Europe after the Second World War and, above all, in those based on the more social democratic formula such as Beveridge model, it is a contradiction to maintain a position that only addresses the individual dimension, when the model has essential features of communitarianism.
- xvi. In any case, this new paradigm also needs the development of a real governance of health data to correctly support it. So, accepting a new model based on pseudonymization means to put all our efforts in that target, a new model of co-governance where all the benefits from the massive exploitation of millions of health data should redound to the benefit not of the industry nor the specific individuals from which these data come from, but to all the community.

xvii. There is also a second question about the new paradigm: should we apply it for all kind of health data or only for some of them, mainly, the traditional health data, such as those coming from medical records or telemedicine, for instance. We pose this question because currently under the term health there are a lot of instrument and tools which produce a great amount of data, but where the fiduciary relationship is not so clear (for instance, apps, wearables, etc.).

Finally, we should remember that developing a new paradigm in the area of health data research means improving healthcare of EU citizens and it will play a main role of satisfaction about the EU project and a great vaccine against nationalism and populism

CONCLUSIONS OF THIS CHAPTER

1st There has been a growing disaffection with science and technological development in a significant part of European society and the causes are manifold. The often-inadequate communication of scientific and technological advances, together with an information overload, which saturates us undoubtedly contributes to this. Therefore, this reality obliges us to address the debate about what is the correct relationship between science and people, between knowledge and power, between experts and politicians.

2nd The most important political and social problems require a great deal of scientific knowledge and those who lead political institutions do not have it, so they have to be advised appropriately. Politics is not practicable today without a continuous recourse to expert knowledge, but we should think of the relationship between science and politics not as submission from one to the other but as an argumentative process.

3rd We also need more and better data and information, and this will not be achieved without sharing it efficiently and effectively. Fragmentation remains in many areas that are critical for data-based research, and that concern the sharing and use of data, as well as data governance and ownership and the responsibilities arising from its misuse. We must deal with this data fragmentation at EU level.

4th It is absolutely necessary to understand and cooperate between the countries of the Union, also in everything that is relevant in the so-called data economy, where there is no room for nationalisms and digital sovereignties at all costs or paralysis due to analysis.

5th Refining the concept of "national health security" in a global context will be essential to build a different framework to be prepared for a new pandemic.

6th We should develop a new paradigm in the area of health data research based on a moral duty of sharing those data

7th This new paradigm based on a moral duty of sharing health data could act as a way to promote innovation in EU and, therefore, to guarantee healthcare as a social right

8th This new paradigm has been, in some sense, included at the EU regulation on data protection

9th We should distinguish between traditional health data from the health system in a holistic way (coming from medical records, telemedicine, ..., for instance) and new health data from new agents and products (wearables, apps, ...)

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**NATIONALISM, POPULISM,
AND IDENTITIES:**

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