



REPORT ON THE STATE OF APPLICATION OF NEW TECHNOLOGIES TO HUMAN LIFE

PANDEMIC-DRIVEN TECHNOLOGIES

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For The Life Sciences

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CNECV Annual Report to the Portuguese Parliament on The State of Application
of New Technologies to Human Life 2021
Pandemic-driven Technologies

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CNECV ANNUAL REPORT TO THE PORTUGUESE PARLIAMENT ON THE STATE OF APPLICATION OF NEW TECHNOLOGIES TO HUMAN LIFE 2021 Pandemic-Driven Technologies

Executive Summary

FOREWORD

The VI mandate of the National Council of Ethics for the Life Sciences (CNECV), which took office in July 2021, presents its first Report on the State of Application of New Technologies to Human Life, in compliance with the provisions of paragraph c) of Article 3.1 of Law No. 24/2009 of 29 May 2009, which established the CNECV as an advisory body functioning adjunct to the Portuguese Parliament. In addition to the formal fulfilment of what is legally established, the Report's main objective is to contribute to an ethical reflection that accompanies some of the most recent scientific-technological advances in their human implications, highlighting the positive impacts to be implemented and the negative impacts to be safeguarded.

In the broad field of life sciences, the past two years have been indelibly marked by the still current COVID-19 pandemic (coronavirus disease 2019), declared as such on 20 March 2020 by the World Health Organization (WHO), caused by the SARS-CoV-2 virus (severe acute respiratory syndrome coronavirus 2) and which has extended through successive variants of the virus, affecting the world dramatically. It has given rise to the most serious global health crisis since the 1918 influenza pandemic and has triggered an economic and social crisis whose heavy consequences have been accumulating and are likely to persist for a long time, with effects that are still largely unpredictable.

The CNECV issued two Statements on the main ethical issues in the context of social isolation and compulsory confinement and in a scenario of potential unavailability of resources, arising from the covid-19 pandemic: on 1 April 2020, with the position statement "Public health emergency situation by the Covid-19 pandemic: relevant ethical aspects". Subsequently, and in view of some technological solutions, created to respond globally to the spread of contagions, through an ecosystem of shared data of individual location, it decided to issue a position statement on "Digital mobile applications to control the transmission of covid-19: relevant ethical aspects", on 29 June 2020.



The Covid-19 pandemic has also been the most prominent stage for the development of various technologies, which, although not effectively unprecedented, have been driven in this context of health crisis, with strong impact on human life. This Report on the State of Application of New Technologies to Human Life focuses, therefore, on the technologies driven by the pandemic. The CNECV, true to its nature and the exercise of its specific mission, necessarily focuses on human issues arising from the progress of technologies and assessed from an ethical perspective, which is also the scope and approach of technologies driven by the pandemic.

In this context, the CNECV has tried to select some of the aspects of intervention of technologies in human life that have been particularly developed, discussed and applied during this time of pandemic, briefly describing the evolving reality and focusing on new paradigms in formation. Recommendations will also be proposed as contributions to future public policies that refer to the highlighted themes.

Maria do Céu Patrão Neves
President, CNECV



RECOMMENDATIONS

At the end of the present reflection on the Technologies driven by the Pandemic, the National Council of Ethics for the Life Sciences highlights

- **the drama unleashed by the pandemic**, at the health, economic and social levels, leading to an exacerbation of vulnerabilities and the worsening of inequalities and, simultaneously, calling for **the imperative for greater social justice**;

- **the opportunity for scientific-technological development** through the urgency of effective actions, either by accelerating the innovation already underway, or by intensifying international cooperation, with the availability of substantial funding for the discovery of new therapeutic resources and, at the same time, calling for **the imperative of sharing its benefits**;

- **the probability of the emergence of other public health emergencies**, it being important to learn from the experiences of the current pandemic, for national preparation for other health crises and, simultaneously, calling for **the imperative of assuming a duty of protection**;

- **the requirement to assume technological innovation in its instrumental dimension**, as a means of personal fulfilment and social development and to appreciate in advance its social impacts and, simultaneously, calling for **the imperative to respect humanity as the ultimate goal of human action**;

And, therefore, recommends that

1. at the level of scientific and technological development

- not only in this time of pandemic, but in our contemporaneity, when the most serious human problems are global, **multidisciplinary and international scientific cooperation should be stimulated**, in order to produce more and better knowledge, and the development of its ethically oriented application, in a shorter period of time and with an optimised management of human, technical and financial resources, **requiring, at national level, more attractive institutional and professional conditions**

- **public funding for scientific research be strengthened, in recognition of its useful social impact, ensuring that the resulting benefits are also in the public interest** and promoting the widest possible equity; particularly in the area of private research, the importance of respect for patents for scientific and technological progress be recognised, as well as the obligation of the pharmaceutical industry to produce the necessary goods in sufficient quantity, at widely accessible costs, and also to contribute to global solidarity;

- at times when science may tend to unfold in real time and live, there is **continued investment in the scientific literacy of the population and in science communication**,



requiring government and regulatory bodies to communicate in a clear, objective and coherent manner; researchers to strictly observe scientific integrity (in the dissemination of robust results) health professionals, the faithful compliance with professional ethics (in the disclosure of proven realities), when they reach a media status, and always in observance of their social responsibility, to which other protagonists of scientific communication such as politicians, journalists and commentators are also obliged;

2. at the level of data management

- given the exponential production of useful data for scientific research, the advantages of collecting relevant pharmacovigilance and clinical data in real time, particularly in the evolution of life sciences and the progressive digitalisation of human activities, **its quality, protection** (e. g. pseudo-anonymization, not ignoring the possibility of re-identification of data), **accessibility** in order to enable the ability to replicate (within the legal framework in force) are assured according to the principles of Open Science, also contributing to more informed decision-making in the interest of the public;

- the technologies destined for individual surveillance **are designed involving the populations for which they are intended and** subsequently **integrated into an ecosystem of intervention in public health, whose regulations unequivocally explain the data to be collected and its purpose, the description of the procedures relating to collection, storage and duration, as well as the security, retention and destruction measures**, which prevent the commercial use of the data for purposes other than those explained, and that there are expiry clauses, guaranteeing privacy, the transparency of the procedures and accountability for any breach of what is stipulated. Digital tools that enable symptom and contact tracing should be accompanied by rapid testing, isolation and quarantine measures, treatment and remote monitoring.

3. at the level of digital health

- health authorities can **develop appropriate national and internationally coordinated strategies for the prevention and early detection of new infectious agents** that pose a risk to public health (in wild animals, open markets, farms, etc.); **the holistic perspective expressed by the One Health concept should be adopted** in addressing human health in its relationship with animal health and the environment;

- **given the broad, diverse and accelerated application of digital technologies in health during the pandemic**, with obvious benefits in surveillance, diagnosis, **therapy and health monitoring, attention should be paid to their real impact** (duly measured) on health care provision, whether in terms of remote assistance or access to information, in order to enhance the advantages of greater proximity and cost-effectiveness of health care, while also ensuring its reliability in terms of quality and privacy, **with the priority being not to neglect any citizen or pathology**;



- attention should be paid to the reconfiguration of the relationship between health professional and user through the intermediation of new information technologies, in order to **preserve the balance between the exercise of the user's autonomy and the principle of beneficence that identifies the health professions, in the promotion of a relationship of trust on which shared decisions are based;**

4. at the level of mRNA technology

- the new paradigm for the discovery and validation of vaccines that has been created and is to be maintained, characterized by the scientifically sustained acceleration of their development, **does not create increased risks for participants in clinical trials, nor does it affect the highest levels of quality, safety and effectiveness that are currently required;**

- **the obligation to disclose pharmacovigilance results in real time** and in a transparent manner is established by international legal norms and/or agreements signed with manufacturers of vaccines and other medicines, **in order to protect public health and citizens' trust in science;**

- **the asymmetry in the levels of vaccination against COVID-19 that still exist in different countries be rapidly resolved**, requiring the international community (UN, EU, national governments and international organisations) to adopt cooperation mechanisms and develop efforts at different levels (monitoring/inspection/surveillance/verification) through the COVAX programme (COVID-19 Vaccines Global Access), to ensure that all people, everywhere are reached by vaccination, **and also to replicate, adapt and improve solidarity mechanisms for the promotion of global health for other diseases;**

- **fundamental scientific research**, which creates valuable foundations for applied research, **should be valued and the new therapeutic opportunities arising from the extension of technologies that use RNA**, both for the discovery of new vaccines for known pathologies and for the treatment of various pathologies, should be developed, and **the inclusion of this new therapeutic approach in the NHS should be openly discussed;**

- in cases of medicines with added therapeutic value, particularly in areas where there are still unmet therapeutic needs, **the rapid access of the population to the medicine be guaranteed**, through mechanisms similar to those adopted for COVID-19 vaccines.

Approved at the 265th Plenary Meeting on 25 May 2022.

Maria do Céu Patrão Neves

President, National Council of Ethics for the Life Sciences



RAPORTEURS

This Report was drafted, in its initial version, by

Maria do Céu Patrão Neves, Rosalvo Almeida, Boaventura de Sousa Santos, Luís Duarte Madeira, Jorge Soares, João Ramalho-Santos, Carlos Maurício Barbosa and **Ana Paula Martins**, and is presented in its final version as a text that brings together both the contributions of the 24 personalities and of the plenary of the Council.

EXPERT HEARINGS AND PUBLIC DEBATE

The Report on Pandemic-Driven Technologies was presented in four public sessions, during which experts of different academic, scientific and professional backgrounds and from different institutions and geographical areas were heard, followed by a debate open to the public:

28 January 2022, Porto, with the following experts:

- **Fernando Araújo**, MD, Chair of the Board of Directors of the Centro Hospitalar Universitário São João and Professor at the Faculty of Medicine of the University of Porto.
- **Filipa Calvão**, PhD, President of the National Commission for Data Protection, Portugal (CNPD), Associate Professor at the Faculty of Law (Porto), Universidade Católica Portuguesa.
- **António Fontainhas Fernandes**, degree in Pharmaceutical Sciences, Full Professor of Environmental Biochemistry, Rector of the University of Trás-os-Montes e Alto Douro.
- **Isabel Soares**, clinical psychologist and psychotherapist, Full Professor at the University of Minho, director of the Department of Applied Psychology.
- **Luís Portela**, graduate in Medicine, President of the Bial Foundation.
- **Maria Manuel Jorge**, PhD in Philosophy, retired, was a professor at the Faculty of Letters of the University of Porto.

10 February 2022, Coimbra, with the following experts:

- **Carlos Robalo Cordeiro**, pneumologist, Full Professor, director of the Faculty of Medicine, University of Coimbra, director of the Pneumology Service of the Coimbra Hospital and University Centre.



- **Filomena Gaspar**, psychologist, investigator, doctorate in Educational Psychology, Professor at the Faculty of Psychology and Educational Sciences, University of Coimbra.

- **Henrique Martins**, physician, PhD in Management Studies, invited assistant professor at the Faculty of Health Sciences, UBI - University of Beira Interior.

- **Lina Ramos**, physician, CHUC, coordinator Neurogenetics, Hepatic Diseases, Immunohemotherapy/Coagulopathies, Dep. Genética Médica, Hosp. Pediátrico Coimbra, President of the Portuguese Society of Human Genetics.

- **Luís Pereira de Almeida**, Professor of the Faculty of Pharmacy, University of Coimbra, coordinating researcher of the Centre for Neurosciences and Cell Biology and the Centre for Biomedicine and Innovative Biotechnology;

- **Manuel Santos**, professor at the Department of Medical Sciences, University of Aveiro, Director of iBiMED.

11 March 2022, Lisbon, with the following experts:

- **Henrique Barros**, MD, Full Professor at the Faculty of Medicine of the University of Porto, President of the Institute of Public Health of the University of Porto (ISPUP) and of the National Health Council;

- **Baltazar Nunes**, assistant researcher at the Epidemiology Department, National Institute of Health Dr. Ricardo Jorge (INSA);

- **Maria da Glória Garcia**, retired Full Professor of Law, current Vice-President of the Class of Letters of the Lisbon Academy of Sciences;

- **Manuel Carmo Gomes**, PhD in Biology, MSc in Probabilities and Statistics, teacher, researcher and epidemiologist, Faculty of Sciences of the University of Lisbon;

- **Cecília Arraiano**, graduated in Biology from the University of Lisbon, with a PhD in Genetics, coordinating researcher at ITQB - Univ. NOVA of Lisbon;

- **Luísa Vicente**, medical specialist in Psychiatry and Child Psychiatry, PhD in Psychiatry and Mental Health, President of the Portuguese Psychoanalysis Society.

7 April 2022, Évora, with the following experts:

- **João Figueiredo**, PhD in Mechanical Engineering - IST Lisbon (Robotics and Control), Director of the Department of Mechatronic Engineering, University of Évora.

- **Dulce Gomes**, PhD in Mathematics, BSc and MSc in Probabilities and Statistics, Assistant Professor of the Department of Mathematics, University of Évora;



- **Clévio Nóbrega**, researcher, PhD in Molecular Biology and Cytogenetics, Director of the Algarve Biomedical Center Research Institute (ABC-RI), Univ. of Algarve;

- **Carlos Alberto Silva**, PhD in Sociology, Full Professor at the University of Évora (Sociology of Organizations and Health, Sustainable Development);

- **Constança Biscaia**, clinical psychologist, psychotherapist and psychoanalyst, associate professor at the Psychology Department, University of Évora;

- **Fernanda Henriques**, PhD in Philosophy, Emeritus Professor at the University of Évora, was a Councillor of the CNECV from 2003 to 2008.

The National Ethics Council for Life Sciences would like to thank all the experts who made themselves available to reflect on the themes selected for the report, thus sharing their knowledge, experiences and interpretations, as well as the other participants who gave their contribution, resulting in a wide and stimulating debate.