

EU Health Policy Platform Thematic Network 2022-23: Navigating Health Inequalities in the EU through Artificial Intelligence\*

### The Impact of Artificial Intelligence on Health Outcomes for Key Populations: Navigating Health Inequalities in the EU

### Background

The use of Artificial Intelligence (AI) in the health sector is rapidly growing. Whilst the use of AI in health has shown some demonstrable benefits and improvements in specific healthcare areas, such as health data management, diagnosis in cardiovascular diseases, and certain types of cancer, there is growing evidence of the potential risks of AI for patients' health, wellbeing, and fundamental rights in the absence of an appropriate legislative or governance framework. AI especially poses risks to key populations,<sup>1</sup> who may face specific vulnerabilities and multiple, layering patterns of inequalities, related to age, gender identity, sexual orientation, cultural identity, ethnicity, and race, (digital) literacy, disability and (mental) health status, residence status, and who may already face barriers and inequalities in accessing healthcare<sup>2</sup>, potentially increasing health inequities in the European Union (EU). This Joint Statement focuses on actions needed to benefit from the potential of AI in health while protecting key populations from the risk of harmful effects with the main objective of preventing AI algorithmic tools from deepening health inequalities in the EU while reinforcing patterns of bias and discrimination. Simultaneously, the Joint Statement, in its recommendations, aims to direct the use of AI in health in responsible, participatory, ethical, and equitable ways, exploring how its use and deployment could have the potential to close the chasm of health inequalities for key populations.

<sup>\*</sup> This Thematic Network is jointly led/coordinated by Dr. Pin Lean Lau (Brunel Centre for AI) and Hannah van Kolfschooten and Janneke van Oirschot (Health Action International). The Joint Statement is drafted by the joint leaders of this Thematic Network, with feedback and input from network partners, stakeholders of the Thematic Network roundtable webinar, and other relevant stakeholders.

<sup>&</sup>lt;sup>1</sup> 'Key populations' referred to in this Joint State include but are not limited to: persons with disabilities, persons with rare diseases, older persons, racial and ethnic minorities such as the Roma and Travellers, undocumented people or people with insecure residence status, persons experiencing mental health problems, and members of the LGBTQI community, amongst others.
<sup>2</sup> EU Fundamental Rights Agency (2011) Fundamental rights of migrants in an irregular situation in the European Union. & WHO Europe. Report on Childhood Cancer Inequalities in Europe.

In concert with the GENERAL MEASURES stipulated below, this Joint Statement calls for a renewal of EU commitments and coordination of efforts of all EU institutions, Member States, and relevant stakeholders, with existing strategies, plans, and directives/guidelines/legislation, *including but not limited to* the following:

- 1. The European AI Strategy
- 2. The Coordinated Plan on AI
- 3. The Artificial Intelligence Act
- 4. The Product Liability Directive
- 5. The AI Liability Directive
- 6. The Medical Devices Regulations
- 7. The In-Vitro Diagnostic Medical Devices Regulations
- 8. The European Health Data Space Regulation
- 9. The General Data Protection Regulation
- 10. The Data Governance Act

In particular, as the above all have a common approach to ensure excellence and trustworthiness of AI systems in the EU, including those used in the health sector, this collective effort should be particularly extended to recognise and address health inequalities and inequities of underrepresented and marginalised voices; to align with the Charter of Fundamental Rights of the European Union, the Race Equality Directive 2000/43/EC, and the UN Convention on the Rights of Persons with Disabilities ratified by the EU and all its Member States; and pursue complementary advocacy with the European Commission for Standardisation (CEN), the European Commission for Electrotechnical Standardisation (CENELEC) and the European Telecommunications Standards Institute (ETSI) to ensure that the technical standards, legislative and regulatory frameworks for AI promote transparency, counter bias and racism, and protect the health and rights of key populations.

### This Joint Statement emphasises the following concerns about health AI:

- 1. AI used in healthcare deserves special consideration because personal and public health is at stake and individuals are in a vulnerable position when in need of healthcare.
- 2. AI systems in healthcare may be trained with sub-optimal-quality health data, as high-quality health data for some types of medical conditions are sometimes difficult to obtain.<sup>3</sup> Health data are often scattered in different institutions, unstructured, incomplete (e.g. due to measurement errors in self-reported health or medical records), nonrepresentative and non-generalisable (e.g. because of lack of inclusive clinical data, underrepresentation of minorities, and differential approaches that may exists in some healthcare settings). There is a lack of guidelines and scientific standards to use health data as training data.
- 3. AI is increasingly developed by private, profit-driven companies, which currently far outweighs public investment in AI.<sup>4</sup> It is critical to develop regulatory mechanisms that foster patient need-driven innovation, e.g. in rare or neglected areas of healthcare and for the needs of populations who have historically been overlooked and may be deemed commercially 'less profitable'.
- 4. AI used in healthcare has potential for life-saving innovation but may pose health risks, especially for key populations, because AI models are often trained with unrepresentative datasets, and systems thus may function based on racist, sexist, or ableist patterns and other types of biases leading to discrimination and inequality in healthcare, eventually causing/worsening health problems for some people, and result in individual injury or even death<sup>5</sup>, when medical treatment recommendations are incorrect because they do not recognise individual characteristics. For example, AI software used to predict individual cardiovascular risks may perform better for men than women because women have been underrepresented in the training dataset, which may lead to underdiagnosis of women. The risk of misdiagnosis

<sup>&</sup>lt;sup>3</sup> Genevieve Smith and Ishita Rustagi, 'When Good Algorithms Go Sexist: Why and How to Advance AI Gender Equity (SSIR)' (*Stanford Social Innovation Review*, 31 March 2021)

<sup>&</sup>lt;https://ssir.org/articles/entry/when\_good\_algorithms\_go\_sexist\_why\_and\_how\_to\_advance\_ai\_gender\_equity> accessed 10 May 2022.

<sup>&</sup>lt;sup>4</sup> Cindy Gordon, 'How the Private Sector Can Help Close The Public Sector AI Knowledge Gap' (*Forbes*, 30 November 2022)

<sup>&</sup>lt;https://www.forbes.com/sites/cindygordon/2022/11/30/how-the-private-sector-can-help-close-the-public-sector-knowledge-gap-in-sustainable-ai/> accessed 7 April 2023.

<sup>5</sup> Richmond Alake, 'Algorithm Bias In Artificial Intelligence Needs To Be Discussed (And Addressed)' (*Medium*, 28 April 2020) <a href="https://towardsdatascience.com/algorithm-bias-in-artificial-intelligence-needs-to-be-discussed-and-addressed-8d369d675a70">https://towardsdatascience.com/algorithm-bias-in-artificial-intelligence-needs-to-be-discussed-and-addressed-8d369d675a70</a> accessed 14 December 2021.

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<sup>&#</sup>x27;Algorithmic Bias in Health Care Exacerbates Social Inequities — How to Prevent It | Executive and Continuing Professional Education | Harvard T.H. Chan School of Public Health' <a href="https://www.hsph.harvard.edu/ecpe/how-to-prevent-algorithmic-bias-in-health-care/">https://www.hsph.harvard.edu/ecpe/how-to-prevent-algorithmic-bias-in-health-care/</a> accessed 15 December 2021.

is also true for underrepresented minorities, for example, as shown in the underperformance of AI tools for skin cancer diagnosis for people of colour.<sup>6</sup>

- 5. In the absence of strong safeguards, AI used in healthcare may pose risks for erosion of privacy and data protection rights of patients. The development of AI leads to an increased collection, processing, exchange, and transfers of data, often beyond the health system and for purposes not initially known to the individuals. This may encourage actors to indirectly or unintentionally pressure individuals to provide personal sensitive data. The known opaque nature of some AI applications further challenges patients' access, use and control of personal data.
- 6. **AI used in healthcare may pose risks for autonomy of patients,** because AI systems often lack transparency on how they come to decisions/outputs. This may also impair the ability to explain results or conclusions arising from algorithms. This forms a threat to patients' rights to information and informed consent to medical treatment, with vulnerable groups having potentially higher risk of harm as a result.
- 7. AI used in healthcare has the potential to address differential access to health but may also pose risks for furthering healthcare inequalities, as certain key populations who are either excluded or have limited access to the healthcare system in the first place, are not included in the training data and are thus excluded from adequate care, may not have access to expensive AI tools, or may not have adequate internet access. In addition, AI tools may not account for people's digital skills and -literacy or accessibility requirements (for example in case of persons with disabilities).<sup>7</sup>
- 8. Possible lack of transparency of AI in healthcare could further exacerbate unethical practices, as data is collected in low and middle-income countries with less strict regimes on personal data protection in order to develop AI technologies to be used in the EU. In addition, these datasets might not be representative of the EU population.

<sup>&</sup>lt;sup>6</sup> 'Research Shows AI Is Often Biased. Here's How to Make Algorithms Work for All of Us' (*World Economic Forum*) <<u>https://www.weforum.org/agenda/2021/07/ai-machine-learning-bias-discrimination/> accessed 14 December 2021.</u>

<sup>&</sup>lt;sup>7</sup> Pin Lean Lau, 'Addressing Cognitive Vulnerabilities through Genome and Epigenome Editing: Techno-Legal Adaptations for Persons with Intellectual Disabilities' [2022] European Journal of Health Law 1

<sup>&</sup>lt;https://brill.com/view/journals/ejhl/aop/article-10.1163-15718093-bja10085/article-10.1163-15718093-bja10085.xml> accessed 24 July 2022.

We call for attention to both the positive and potential negative effects of health AI on key populations, including, but not limited to, the aging population, undocumented people or people with insecure residence status<sup>8</sup>, persons experiencing mental health problems, persons with rare diseases and disabilities, members of the LGBTQI community, and racial and ethnic minorities such as Roma people, Travellers, and the Sami, and draw attention to intersecting systems of oppression, such as gender inequalities, anti-Roma racism, and other patterns of discrimination, which may ultimately feed into AI systems unless an appropriate governance/legislative framework is in place.

Despite the promise and opportunity AI holds in some contexts, such as assistive technologies for persons with rare diseases and disabilities for communication and enhancing access to information, it is not a neutral technology. On a societal level, AI is exacerbating structural inequalities and health inequalities due to existing historical, social, and cultural patterns of discrimination and systems of oppression, which most key populations have extensively experienced.<sup>9</sup> The below provides a short overview of particularly marginalised groups which should inform the development of AI in healthcare:

• **Persons with disabilities** have long been subject to ableism narratives and with their lives not being perceived as equally valuable as persons without disabilities. The outdated medical model of disability viewed disabilities as problems that needed to be fixed; instead of reflecting on how barriers faced by persons with disabilities are in fact socially constructed. During the COVID-19 pandemic, for example, procedures for the rationing of access to healthcare discriminated against people with disabilities simply by virtue of a presumed triage that undervalued their disabilities. In the UK, this led to a horrifying statistic of 60% of mortalities<sup>10</sup> during the pandemic being among persons with disabilities. Persons with disabilities have also been historically subject to patterns of coercion,

<sup>&</sup>lt;sup>8</sup> 'Undocumented people' or 'undocumented migrants' are people whose residence is not recognised by the country they live in. They are unable to obtain a residence permit or citizenship because of restrictive migration and residence policies. Many have had residence permissions linked to employment, study, family, or international protection, but those permits were either temporary or very precarious and their validity expired. There are also children who are born to undocumented parents and inherit this precarious residence status. Gianco, M. and Kanics, J. (2022). <u>Resilience and resistance in defiance of the criminalisation of</u> <u>solidarity across Europe</u>

<sup>&</sup>lt;sup>9</sup> Nature Editorial, 'Henrietta Lacks: Science Must Right a Historical Wrong' (2020) 585 Nature 7.

<sup>&</sup>lt;sup>10</sup> Edward Scott, 'Covid-19 Pandemic: Impact on People with Disabilities' <a href="https://lordslibrary.parliament.uk/covid-19-pandemic-impact-on-people-with-disabilities/">https://lordslibrary.parliament.uk/covid-19-pandemic-impact-on-people-with-disabilities/</a> accessed 11 April 2023.

segregation, institutionalisation, forced treatment or forced 'care' in their so-called "best interests". Further, many persons with disabilities living under guardianship have no legal voice and personal autonomy to make decisions relating to their own lives and bodies.<sup>11</sup>

- Older persons are most likely to face ageist stereotypes and infantilising or surveillant technologies which attempt to mimic social interactions as part of care for older persons. These technologies may have the reverse effect of infringing privacy rights, and the resultant behavioural adaptations can impact on their human dignity and agency. In many narratives, older adults are perceived as a burden to society without recognition of their contributions, and further face infringement of their autonomy as decisions are made on their behalf. The way healthcare and treatment are rendered to older persons are also often problematic and do not always adhere to the cardinal principles of informed consent.<sup>12</sup>
- Undocumented people or people with insecure residence status experience significant difficulties in exercising the universal right to health both legally and in practice<sup>13</sup>. Many people are denied access to essential health services simply because they do not have regular migration status in the country they live in. Even in countries where health services are available as a matter of law, there are many administrative and other practical barriers that can prevent people who are undocumented from receiving the care they are entitled to. Because irregular entry and stay are often criminalised, people who are undocumented face the risk that the use of services will expose them to immigration enforcement<sup>14</sup>. Explicit data-sharing arrangements between health or social services and immigration services exist in some Member States, which has the effect of discouraging health-seeking behaviour and undermining the right to health. Even where such formal arrangements don't exist, there is often no protection against ad hoc incidents of reporting by medical staff or administrators. Outside of the health sector, AI systems are increasingly developed and deployed for purposes related to migration, asylum, and border control<sup>15</sup>.

<sup>&</sup>lt;sup>11</sup> Robert D Dinerstein, 'Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road From Guardianship to Supported Decision-Making' 19.

 <sup>&</sup>lt;sup>12</sup> College of Sport and Exercise Science, Victoria University, PO Box 14428, Melbourne, Vic 8001, Australia and Terence Seedsman, 'Aging, Informed Consent and Autonomy: Ethical Issues and Challenges Surrounding Research and Long-Term Care' (2019) 3 OBM Geriatrics 1 <a href="https://www.lidsen.com/journals/geriatrics/geriatrics-03-02-055">https://www.lidsen.com/journals/geriatrics/geriatrics-03-02-055</a>> accessed 7 April 2023.
 <sup>13</sup> PICUM (2022) The Right to Health for Undocumented Migrants.

<sup>&</sup>lt;sup>14</sup> PICUM (2020) Data Protection and the "Firewall": Advancing the Right to Health for People in an Irregular Situation.

<sup>&</sup>lt;sup>15</sup> PICUM (2022) Digital technology, policing and migration – what does it mean for undocumented migrants?

While the uptake of AI is promoted as a policy goal by EU institutions, in the migration context, AI technologies fit into a wider system of over-surveillance, discrimination and violence<sup>16</sup>. Increasingly, racialised people and migrants are over-surveilled, targeted, detained and criminalised through EU and national policies, with technology (including AI) forming part of those infrastructures of control.<sup>17</sup> It is essential that the use of AI in the health system is not used to replicate these patterns of human rights violations.

- Racial and ethnic minorities, including Roma people and Travellers, also experience lower and discriminatory access to care and higher mortality rates, and face longstanding institutional, interpersonal, and societal anti-Roma racism, discriminatory attitudes and views, which sometimes materialise and are reinforced through highly unethical and racist research, including genetic research practices.<sup>18</sup> It is also critical to recognise that technologies working outside the health sphere can still have a major impact on health and health inequities. For example, these may include policing systems that disproportionately affect racial or ethnic minorities due to existing human discrimination or biases. Additionally, numerous studies have shown that digital technologies, whilst improving many facets of life, can also advance xenophobic and racist ideologies, and can be subject to misuse for nefarious purposes. It is important that for AI to deliver a full spectrum of benefits, fair representation (in data, design, research, and technological development), trust, human rights, and anti-racism must be treated as equal pillars of importance.
- Persons experiencing mental health problems can increasingly rely on algorithmic and data driven technologies in the mental health care field. If digital mental health care technologies do not respond to high quality standard, then this can have serious consequences (and jeopardise the trust of the persons experiencing mental health problems and preventing them from seeking help altogether). Most algorithmic and data driven technologies in the mental health sector is directed at detection and diagnosis, with a focus on the individual in distress, who appears as the one to be fixed. Technology offers what might seem an easy fix. This way of considering mental health an individual issue disregards

<sup>&</sup>lt;sup>16</sup> <u>www.protectnotsurveil.eu</u>

<sup>&</sup>lt;sup>17</sup> Sarah Chander, as a member of the Migration and AI coalition, 9 May 2022, "<u>Regulating migration text: How the EU's AI act</u> <u>can better protect people on the move</u>".

<sup>&</sup>lt;sup>18</sup> Veronika Lipphardt and others, 'Europe's Roma People Are Vulnerable to Poor Practice in Genetics' (2021) 599 Nature 368 <a href="https://www.nature.com/articles/d41586-021-03416-3">https://www.nature.com/articles/d41586-021-03416-3</a> accessed 11 April 2023.

and makes invisible the broader factors that shape mental health. In actuality, socioeconomic determinants and other forms of structural and systemic barriers are important contributors to the complexities of mental health.<sup>19</sup>

• Members of the LGBTI community: Gender and sexual minorities face unique health challenges not experienced by cisgender and heterosexual people and face a disproportionate burden of physical and mental health issues, as well as sexual violence.<sup>20</sup> For example, the provision of sexual health and care is different for transgender people and men who have sex with men (MSM) as they may be at a higher risk of HIV. Women who have sex with women are also marginalised in terms of response to their specific health needs, precisely due to the biased assumption that none is needed. In addition, these individuals experience unique access barriers due to stigmatisation and discrimination<sup>21</sup>. Also, the health needs of LGBTI older persons differ greatly from the older persons who are not part of the community. AI trained on health datasets of cisgender and heterosexual people could not be applicable for use on LGBTI patients.

The above examples are a mere partial illustration of the injustices faced by key population groups. Due to these patterns, many key populations face reduced access to healthcare and/or discrimination in provision of healthcare, which results in unrepresentative health and medical data in the long term. When unrepresentative datasets are being used to train algorithms in machine learning tools used in healthcare, the outcomes of the algorithmic tools will also present discriminatory predictions and outcomes based on gender, race, age, disability, (mental) health status and the like. This has the effect of subjecting key populations to additional layers of intersecting discrimination. In addition, exclusionary development, and design, not considering digital literacy, diverse needs, technological use implications and risks, and accessibility requirements can cause further discrimination and increase health inequalities.

<sup>&</sup>lt;sup>19</sup> Mental Health Europe, 'Mental Health in the Digital Age: Applying a Human Rights Based, Psychosocial Approach as Compass' (Mental Health Europe 2023) <a href="https://www.mhe-sme.org/wp-content/uploads/2023/04/Mental-health-in-the-digital-age-Applying-a-human-rights-based-psychosocial-approach-as-compass.pdf">https://www.mhe-sme.org/wp-content/uploads/2023/04/Mental-health-in-the-digital-age-Applying-a-human-rights-based-psychosocial-approach-as-compass.pdf</a>> accessed 7 April 2023.

 $<sup>^{20}\</sup> https://www.who.int/activities/improving-the-health-and-well-being-of-lgbtqi-people$ 

#### Therefore, we want to draw attention to:

The important potential of AI systems coupled with its often **subjective and value-based nature**. We want to emphasise that AI is a technical tool, which cannot solve complex and multi-faceted issues of societal, cultural, and environmental origin (including chronic conditions and rare diseases) and may inadvertently pose the risk of replicating and aggravating such issues.<sup>22</sup> If we are not consciously and cautiously investigating the way in which these issues can be mirrored, the issues of systemic inequalities will continue to persist, and AI, the tool that can lead to important gains in many disease areas, may exacerbate those in the absence of an appropriate legal/governance framework. Techno-solutionist narratives which claim to have technical solutions for societal problems should be profoundly scepticised. If we truly want to develop AI to reduce health inequalities, this can only happen in a community-based and radically co-creational way. Otherwise, it will simply be another tool which may bring health benefits to some at the exclusion of others; particularly those who are, and have been, traditionally excluded and remain in the fringes of society, often referred to as the "dead spaces" of society.<sup>23</sup>

# This Joint Statement calls for GENERAL MEASURES for health AI by EU institutions, Member States, and relevant stakeholders:

- 1. Recognising the risk of overestimating AI's benefits and underestimating its limitations and detriments, in health care as well as more generally, in light of the over-representation of commercial interests in influencing policymaking and the under-representation of those most likely to experience its harms; and therefore, the need for approaches that centre the perspectives and experiences of those most likely to be adversely affected by certain uses and their fundamental rights.
- 2. Acknowledging the need for special attention for the effects of AI used in healthcare for human health, wellbeing, and fundamental rights.
- 3. **Recognising** the existing inequalities in access to healthcare and the potential detrimental effects of AI used in healthcare, on health inequalities and inequities in the EU.
- 4. **Recognising** the differences in health outcomes between specific populations in the EU, AI posing additional risks for already vulnerable and racialised key populations.

<sup>&</sup>lt;sup>22</sup> Eleanor Beard and others, 'Ethnicity and Socioeconomic Status: Missing in Research Means Missing in Clinical Guidance' (2021) 5 BJGP Open <a href="https://bjgpopen.org/content/5/3/BJGPO.2021.0034">https://bjgpopen.org/content/5/3/BJGPO.2021.0034</a>> accessed 13 April 2023.

<sup>&</sup>lt;sup>23</sup> Achille Mbembe, Necropolitics (Duke University Press 2019).

- 5. Introducing safeguards against unethical uses of AI in healthcare, such as the commercial exploitation by third parties of personal health data to target vulnerable and racialised key populations.
- 6. Ensuring robust protection of personal data and confidentiality to ensure that personal data obtained in the context of receiving care is not further shared or in particular, for secondary uses outside the provision of healthcare.
- 7. **Setting up effective redress mechanisms** allowing patients to contest the application of the AI system or challenge the decisions made by the AI systems.
- 8. **Setting up a public EU-wide system to** record the relevant usage of health AI systems and communicate its use to the patients concerned.
- 9. Strengthening the market approval procedure for medical devices using AI, by including a fundamental rights assessment in the Medical Devices Regulation for AI assisted medical devices and providing the Notified Bodies with guidelines to assess the effects of AI used in healthcare, including specifically for key populations.
- 10. Introducing a separate category for medical devices using AI in the EUDAMED database to create more awareness about the use of AI in medical devices and improve transparency.
- 11. Require all health AI systems used in the EU, not merely high-risk systems, to be registered in the EU public database which will be developed under the European AI Act to increase transparency and include information on the users of the system (institutions which use a particular system e.g., a specific hospital) and any impact assessments carried out.
- 12. Require all health AI systems to undergo an impact and ethical assessment and be subject to oversight, basic regulatory requirements, and external audit to verify whether claims made are accurate and to ensure the systems' safety and effectiveness, and compliance with fundamental rights.
- 13. Strengthening the protection of personal health data in the EU by further harmonising implementation and interpretation of the GDPR's special protection regime<sup>24</sup> for personal health data across all EU Member States and within institutions in the same country, including clarity on the definition of the legal basis for data sharing in academic research as public interest, and issuing consensus/consultation-based guidelines and tools on health data processing for AI used in healthcare.

<sup>&</sup>lt;sup>24</sup> Gilles Vassal and others, 'The Impact of the EU General Data Protection Regulation on Childhood Cancer Research in Europe' (2022) 23 The Lancet Oncology 974 <a href="https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(22)00287-X/fulltext">https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(22)00287-X/fulltext</a> accessed 12 April 2023.

- 14. Ensuring a Trustworthy European Health Data Space which upholds, through robust processes, privacy, principles of informed consent, data minimisation and puts balanced criteria on secondary uses of health data, which excludes purposes that have commercial interests. Secondary uses of personal health data for innovation or research must require consent. In case of purpose that is limited, such limitation criteria should be reasonably crafted, and other uses of secondary data should be properly and expressly clarified.
- 15. Investing in the development of education in digital literacy, including specifically for children, older persons, other high-need key populations, and foster knowledge exchange amongst vested stakeholders in the health ecosystem, emphasising and recognising the importance of equality, diversity, and inclusion (EDI) and intersectionality. It is also important to hold these efforts to internationally recognised standards of excellence and stewardship, for example, using the United Nations Sustainable Development Goals (UN SDGs) as a benchmark (particularly SDG3 on health and wellbeing, and SDG10 on reduced inequalities).
- 16. Education and training in the field of health AI, for all health professionals (including clinicians) must also be robustly implemented, where the risks regarding health inequalities that are linked to AI systems, are highlighted, and emphasised to create awareness of this issue. Culminating hereon, a training guide may be established, based on a flexible checklist of key considerations to tackle health inequalities resulting from the use of AI systems.
- 17. Fostering potential ways for minimising risks of discrimination and bias such as: i) requiring transparency and disclosure about how algorithms were built to enable detection and eventual rectification of discriminatory applications; ii) assessing the impact of potential biases and abuses resulting from algorithms; iii) assessing the quality of all data collected (including how the data was collected, labelled and used) ; iv) ensuring algorithms can be meaningfully explained to allow informed decisions.
- 18. Emphasising and embedding EU values and biomedical ethical principles into the design and lifecycle of AI-driven healthcare processes and products.
- 19. Enhancing legal and ethical accountability (including medical liability attributed to failures in AI decision making, and other liability that can be attributable to different stakeholders in the lifecycle of an AI system) and work with AI developers to embed tracing of processes and procedures in systems and impose obligations to report on the steps taken in the model development process, including how stakeholders were involved at each stage.

## This Joint Statement calls for SPECIFIC MEASURES for health AI for key populations by EU institutions, Member States, and relevant stakeholders:

- 1. Improving infrastructure, opportunity, means, access and services to innovative treatments and therapies for all those who need them across Europe, with specific attention to key populations, including biomedical, digital, eHealth and mHealth services, and the IoMT (Internet of Medical Things).
- 2. Creating awareness and implementing professional training among duty-bearers and health practitioners on the risk of bias of training data and the dangers for key populations; and ensure this bias is considered in current regulation on medical technology.
- 3. Furthering specific measures to ensure unbiased and unadulterated information on evidence-based public health and healthcare needs (especially for key populations), as a means of studying the saturation of inequalities that exist and convey this to inform policy makers and relevant stakeholders to take further concrete action. One way in which this could be explored, is to investigate how we might reduce already prevalent health inequalities by pursuing and promoting the use of AI that is just, transparent, fair, and ethical.
- 4. Improving breadth and quality of datasets for AI in healthcare to counter algorithm bias and under-representation of especially intersectional key population groups in research literature and data, whilst also acknowledging that risks can still occur in datasets of people with unique and rare conditions.
- 5. **Promote inclusion by design as well as ethical principles** among public as well as private AI developing organisations in alignment with a regulatory framework.
- 6. **Involve people with lived experience** in all stages of the development of AI, using a community centred approach and guaranteeing representation of key populations not only in datasets but also in developer teams.
- 7. Acknowledge that also the use of AI in fields other than healthcare can impact the health of people, for example when AI is used for predictive policing.
- 8. Introducing a 'firewall', by creating legal, technical, and organisational separation between public immigration enforcement activities targeted at people who are undocumented and service provision to the same individuals, in the areas of health care, social services, education and access to the justice system. The same applies for the use of health data for law enforcement without a specific court or magistrate order and without fulfilling the established requirements (principle of legality). In some cases, the interest of society and the establishment

of safeguards could outset the privacy invasion, but not the use of health data (e.g. genetic information) by default and without judicial authorisation.

### This Joint Statement is endorsed by the following individuals/organisations:

- 1. Associate Professor Ana Nordberg, Faculty of Law, Lund University, Sweden
- 2. Brunel University London Centre for Artificial Intelligence: Social & Digital Innovations
- 3. Brunel Law School, Brunel University London
- 4. Central European University
- 5. Centre for Ethics and Law in Biomedicine (CELAB)
- 6. Digestive Cancers Europe (DiCE)
- 7. EKPIZO (Consumer Association the Quality of Life)
- 8. European Association of Health Law
- 9. European Federation of Psychologists' Association (EFPA)
- 10. European Forum for Primary Care (EFPC)
- 11. European Health Management Association
- 12. EuroHealthNet
- 13. European Liver Patients' Association
- 14. European Network Against Racism (ENAR)
- 15. European Public Health Alliance
- 16. European Sex Workers' Rights Alliance
- 17. Fundacja Moje Państwo
- 18. Global Health Advocates
- 19. Health Action International
- 20. HealthNet TPO
- 21. Hope European Hospital and Healthcare Federation
- 22. Institute of Digital Futures
- 23. Instituto de Investigación Sanitaria IDIVAL
- 24. Interest Group on Supranational Bio-Law of the European Association of Health Law
- 25. International Diabetes Federation Europe
- 26. Irish Council for Civil Liberties
- 27. Italian League for Fighting AIDS (LILA)
- 28. Mental Health Europe (MHE)
- 29. Platform for International Cooperation on Undocumented Migrants (PICUM)
- 30. Professor Judit Sandor, Central European University
- 31. Professor Timo Minssen, University of Copenhagen
- 32. Validity Foundation





This Thematic Network & Joint Statement is coordinated by the Brunel University London Centre for Artificial Intelligence: Social & Digital Innovations, and Health Action International – together with network partners from the European Association of Health Law – Interest Group on Supranational Biolaw and the Validity Foundation.

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Margareta Matache, Director of the Roma Program, FXB Centre for Health and Human Rights, Harvard University | Lecturer on Social and Behavioural Sciences, Harvard T.H. Chan School of Public Health

Raymond Gemen, Senior Policy Manager for Health Inequalities, European Public Health Alliance (EPHA) | Leader of the 2022 Thematic Network, '*Tackling Health Inequalities through Mainstreaming Anti-Racism and Anti-Discrimination Policy*' (*DisQo*)

Francesca Centola, Policy and Knowledge Officer, Mental Health Europe | Leader of the 2022 Thematic Network '*Mental Health in All Policies*'

Michele LeVoy, Director, Platform for International Cooperation on Undocumented Migrants (PICUM)

Louise Bonneau, Advocacy Officer, Access to Justice, Racial Equality and Health, Platform for International Cooperation on Undocumented Migrants (PICUM)

Laurence Meyer, Racial and Social Justice Lead, Digital Freedom Fund

The European Society for Paediatric Oncology (SIOPE)