Concept Note

WHO & University of Miami
International Ethics consultation
Big Data and AI for achieving UHC
Miami, USA
October 12-13, 2017

Background
The Department of Information, Evidence and Research (IER) is part of the Health Systems and Innovation (HIS) Cluster and aims to strengthen the availability, accessibility, quality, reliability and use of health information and public health research among Member States and health development partners. This should result in improved data for evidence-informed decision-making, allowing better public health services in the context of universal health coverage (UHC), and contributions to the UN SDGs. WHO's Member States face large and interesting challenges related to the acquisition, analysis, governance and sharing of health data and information. These challenges are especially difficult, if not vexing, given recent and rapid improvements in and availability of data mining software, and in the size and scope of data sets.

The promise of big data emanates from the ability of current technologies to collect data from various websites, online databases, confidential records available with various agencies (such as the health systems, the insurance agencies, the road vehicle safety agency and so on), data held by super-markets, credit card vendors, bank accounts, personal e-mails, data on social networks and so on, and link the data for various purposes. For exam ple, this allows researchers to estimate disease prevalence, changes in consumption pattern s and lifestyle that can lead to changes in disease patterns, correlations of changes in habitat to disease patterns. Much of this information is very valuable for policy making, and taking action at the population level at an early stage. However the risk to individuals to communities, to populations and to countries by the way this type of data is handled and used is not well analysed and documented. For example there is a risk that this type of analysis also has the potential to stigmatize groups of individuals or increase vulnerabilities of groups if not handled with care. Depending upon the algorithms used, and the assumptions made in estimating, this type of analysis can also be hugely misleading. Finally this type of analysis has the potential to identify individuals, even though the individual databases themselves include only coded data. Therefore any assurances in relation to privacy and confidentiality given to people when their data is collected for any purposes is largely irrelevant. And a thorough analysis of the risks and benefits from the use of these technologies needs to be made, and made available in the public domain.

Ethical Issues
Among the most difficult challenges raised by Big Data for health and analytic software are those regarding the ethical collection, analysis and sharing of health data and information. These issues – perhaps best framed as ethical, legal and social issues (ELSI) – include (i) the need for and scope of valid consent to acquire the data, (ii) privacy, confidentiality and

security protections, (iii) problems related to sharing or publication of data and information given needs and sometimes requirements of Member State sources, (iv) appropriate uses and users of WHO-controlled or stewarded data and information and (v) ethical difficulties in making decisions and policy recommendations based on probabilistic, imperfect and even flawed data, including reliance on decision-support software.

Objectives
In order to address these issues, the University of Miami – a WHO Collaborating Center and WHO propose to jointly organize an International ethics consultation on Big Data and AI for achieving UHC. The scoping meeting aims to identify the ethical challenges that arise through the use/management etc. of Big Data and AI for UHC, and develop principles for use by various stakeholders.

Outcomes
- WHO meeting report on Ethics & Big Data for health
- Scientific publication