

THE USE OF BIG DATA IN HEALTH-RELATED QUESTIONS: UNESCO AND APEC PERSPECTIVES

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► SOME ASPECTS TO BE CONSIDERED

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INTRODUCTION

- Big Data as a global challenge.
 - There is no uniform regulation of them.
 - A useful definition of Big Data: “the treatment of large volumes of data through mathematical algorithms in order to establish correlations among the data, predict trends and make decisions”.
 - International Organizations (universal and regional) have analyzed the consequences of the use of Big Data and Health.
 - Special attention will be paid to the activities of UNESCO and APEC.
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A REVOLUTION: THE USE OF BIG DATA ON HEALTH (DATIFICATION)

One example: apps related to Health.

Pros: direct relation with the medical practitioner.

Cons: Personal data included in these platforms (and reused or ceded by “other purposes”).



THE NUMBER OF APPS RELATED TO HEALTH IS NOT TRIVIAL...


...more than 165.000 apps related to health (and more than 500 million people as users).

HAVE INTERNATIONAL ORGANIZATIONS BECOME AWARE ABOUT THE USE OF BIG DATA AND THEIR SPECIAL CONSEQUENCES ON THE FIELD OF HEALTH?


A question to be solved, because Big Data on Health are Highly Sensitive



BIG DATA AND HEALTH: SOME PROS

- Produce new approaches to disease, diagnosis and treatment, public health, medical research and innovation.
 - Datasets may be useful to prevent or eradicate certain maladies.
 - Personalized medicine and treatments (including preventive uses).
 - Epidemiology and response to disease.
 - Big Data may be reused indefinitely in other contexts, linked, combined or analysed together with data from different sources.
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BIG DATA AND HEALTH: SOME NEGATIVE OR LESS BENEFICIAL DEVELOPMENTS

- Privacy may be infringed.
 - Inaccuracy and mistakes in the collection and analysis may have adverse implications.
 - Data protection of information collected by apps.
 - Commercial use of big data.
 - Social media producing a “fake news ecosystem” on health questions.
 - The need to protect genomic data: a challenge.
 - More transparent individuals against more opaque data.
 - Saving the gap: developing countries and health benefits.
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BIG DILEMMAS SURROUNDING BIG DATA

- Science needs information provided by patients.
- Is this a part of “our social responsibility” as citizens?



UNESCO PERSPECTIVE: THE ANALYSIS OF THE DOCUMENT ADOPTED IN 2017

After three years of debate in the International Bioethics Committee of UNESCO, in September 2017 was adopted a Report on Big Data and Health (Doc. SHS/YES/IBC-24/17/3 REV.2). [See the Report](#)

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MAIN IDEAS OF THE REPORT

-The need to regulate the use of big data and health, due to its implications on the domain of human rights protection.

-Examples:

- UNGA's Guidelines for the Regulation of Computerized Personal Data Files (1990).
- Declaration of Helsinki (2013).
- UNCTAD's data Protection regulations and international data flows (2016).
- World Medical Association's Declaration of Taipei on Ethical Considerations Regarding Health Databases and Biobanks (2016).



TOGETHER WITH
REGIONAL EFFORTS...

OECD

- Guidelines governing the Protection of Privacy and Transborder Flow of Personal Data (2013).
- Recommendation on Health Data Governance (January 2017)[Click here](#).

...IN THE EUROPEAN SPHERE (I)

COUNCIL OF EUROPE

- ETS no. 108. Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (28 January 1981), with Amendments (1999). A new Protocol is under discussion.
- Guidelines on the protection of individuals with regard to the processing of personal data in a world of Big Data (2017).


IN THE EUROPEAN SPHERE (II)

European Union

- Article 8 of the Charter of Fundamental Rights of the EU recognizes “the protection of personal data”.
- General Data Protection Regulation (GDPR): Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC, effective since 25 May 2018.

AFRICAN CONTEXT

-The African Union Convention on Cybersecurity and Personal Data Protection (2014).

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APEC (ASIA-PACIFIC ECONOMIC COOPERATION)

APEC updated Privacy Framework
(2015).

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THE UNESCO PERSPECTIVE ABOUT BIG DATA AND HEALTH

It is described as **“a comprehensive and evidence-based personalized, stratified or so-called precision medicine, which combines the best available scientific knowledge with professional experience of health professionals for the benefit of the individual patient”**.

Four paradigms: from disease orientation to health orientation; from focus on therapy to prevention; from health to life style counselling; from the role of a patient to the role of a user, customer or digital citizen.

Consent, transparency, privacy and confidentiality must be taken into account.




IT IS AN OPPORTUNITY TO REVISIT THE TRADITIONAL VISION ON BIG DATA

And reconcile all the rights and interests which overlap in this field, such as those of the person from whom the data derives, those of the researcher, those of the companies and organizations who use the data and those of society in general who may benefit from such use.


- It is necessary a multi-tiered governance structure, for responsible use of data.

- Together with this, the adoption of an international legal instrument on Data Protection in Health Care and Health Research.





THE APEC POSITION ON THIS SUBJECT

- It is necessary to move towards a culture of privacy.
 - The New APEC Privacy Framework (2015) amends the previous 2005 legal regime.
 - There is a Health APEC Working Group.
 - Cooperation with the EU must be enhanced.
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BIG DATA PROTECTION: A CHALLENGE FOR STATES AND INTERNATIONAL ORGANIZATIONS

Questions related to health are considered as sensitive information by the Philippines Data Privacy Act 2012.

Technologies and human rights have opened new windows of knowledge and legal systems must be adapted to this new reality.

An example of this is the Framework Agreement on Colaboration and Cooperation between the EU and their member States and the Republic of the Philippines, done in Phnom Penh, 11 July 2012 (art. 24 referred to data protection).





SALAMAT