

# Big Data in Health Care: new ethical challenges

## 5 (Vs) Dimensions:

- volume* - amount generated
- velocity* - speed of flow
- variety* - types used
- veracity* - level of trust
- value* - rate of return

## New opportunities for treatment, improving:

- *diagnosis* (faster and more accurate)
- *therapies* (more efficient, contributing to save money)
- *prognosis* (maximizing good outcomes)

## and becoming part of clinical practice and changing it:

- *through a digital assistant*
- *leading to a personalized medicine* (designing a customized treatment for an individual patient)
- *and also to a precision medicine* (designed to optimize efficiency or therapeutic benefit for particular groups of patients)

## Major issues:

- *privacy* (data collection, use and retention)
- *sharing* (lack of distinction of private and public sphere)
- *transparency* (secondary uses of data sets)

## Due to

- *procedures of data collecting*
  - *algorithmic organization*
  - *pattern of presentation for decision making*
- ought to be addressed at 3 levels of governance where core ethical principles are at stake**

## economic and political

e.g. automatic indexation of data; concentration of economic and political power; deepening the gap between powerful and powerless; access to healthcare not guaranteed; lack of awareness about the volume of information produced and transferred; issues of ownership, patenting and commercialization; anonymization of personal information does not guarantee confidentiality; no incentives for international cooperation and the obligation of benefit sharing.

## Justice

*Fair distribution of benefits and burdens among all stakeholders, guaranteeing equal opportunities, is compromised, because Big Data grows outside adequate worldwide regulations, and without legal counterparts.*

## scientific and professional

e.g. creativity, imagination, freedom of thought, possibility to make mistakes are overridden by AI; human decisions are converted into algorithmic decisions; accountability becomes ambiguous, and liability ever more difficult to pursue by plaintiffs; patient's participation in the therapeutics process is eliminated; informed consent loses pertinence, no justification for a second opinion.

## Autonomy

*Capability to decide by and for oneself or the power of self-determination, of the researcher, of the healthcare professional and of the patient is compromised, because Big Data grows relying on statistics and patterns to deliver the best decision.*

## individual and societal

e.g. translation of human features into numbers/statistics, dilutes singularity into the homogeneity of patterns; diseases are more important than the uniqueness of sick people; unicity of psychosomatic interactions are neglect; a holistic medicine put aside; people and groups are reduced to profiles and patterns behavior, classified into categories, which can lead to individual functionalization, and social discrimination, stigmatization.

## Human Dignity

*Absolute and equal value of each and all of the patients, in their uniqueness, vanishes diluted in a numerical language, statistical grammar and patterned discourse, in a growing homogenization.*