Presidenza del Consiglio dei Ministri

COMITATO NAZIONALE
PER LA BIOETICA

ABSTRACT

INFORMATION AND COMMUNICATION TECHNOLOGIES AND *BIG DATA*: BIOETHICAL ISSUES

25 November 2016

The advancement of information and communication technologies and the development of informatics are paving the way to new possibilities of knowledge, use and application in different fields, including healthcare. The expression big data refers to a massive volume of digital data constituted by the traces of personal information released into the environment through the use of information technology: this huge amount of data, coming from heterogeneous sources, is generated at great speed with pervasiveness.

The document discusses the enormous opportunities for development now opening up, especially in healthcare, with telemedicine, precision medicine, and the development of healthcare policies. The Committee also outlines some critical issues regarding the difficulty in governing the huge amount of data in the collection, analysis and use of data, particularly when it is used and applied differently from initial collection or without user awareness. Information technologies can present challenges regarding primarily processing and protection of private life and personal data, transparency, quality of information, addiction, the principle of participatory justice and governance.

The CNB, in view of an "appropriate" use of data, respectful of fundamental human rights, makes some recommendations: defining the responsibility of providers; verifying data quality and transparency of algorithms; identifying efficient instruments to request user consent or dissent to the processing of data; implementing an effective recognition of the right to be forgotten; involving citizens in emerging ethical issues, with special attention to young people, calling for the development of guidelines for the proper use of social technologies; promoting research for innovation of the ethical approach to the design of social technologies; guaranteeing all those who are willing to make use of new technologies conditions for access.

The Opinion calls for the development of legislation for the protection of personal data and the safeguarding of citizens/users against the social risks of misuse of data.

The annex includes a legal note retracing synthetically and in a critical manner the current situation of European and national regulation.

The subject and original draft of the Opinion was brought to the attention of the Committee by Prof. Rosaria Conte in April 2015.

Prof. Rosaria Conte presented in an internal consultation session the state of scientific and ethical discussion.

The group met twice in 2015. The preparation of the Opinion was interrupted because of Rosaria's ill health and death in the summer of 2016, which has left a great void.

Profs. Antonio Da Re, Lorenzo d'Avack, Laura Palazzani and Carlo Petrini have supplemented and completed the Opinion.