Digital and Health

propositions of the

French National Consultative Ethics Committee for Health and Life Sciences

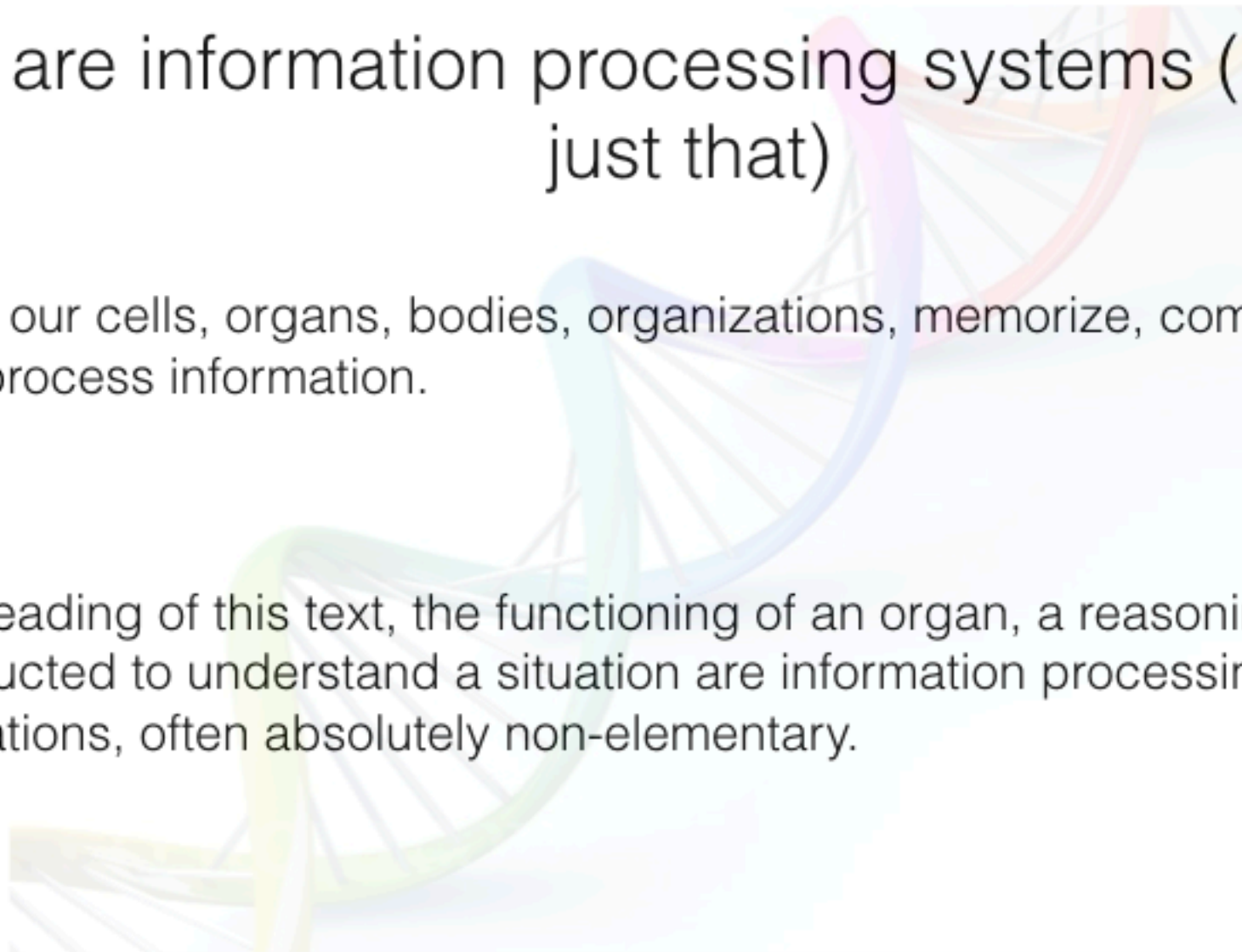Claude Kirchner

informatiques *mathématiques*
Ínría

RÉPUBLIQUE FRANÇAISE

Tokyo, October 31, 2018

DIGITAL SCIENCES AND TECHNOLOGIES

Why to they have such an impact on human and society ?

We are information processing systems (and not just that)

DNA, our cells, organs, bodies, organizations, memorize, communicate and process information.

The reading of this text, the functioning of an organ, a reasoning conducted to understand a situation are information processing operations, often absolutely non-elementary.

These two types of information processing systems, the Human and the Digital

◈ complement each other

◈ interact

◈ collaborate

◈ combine

with profound consequences for and on the human being

This induces profond consequences on all topics of Health and Life Sciences with pressing ethical issues.

The president of CCNE decided to setup a working group to:

- analyse the situation and

- make propositions to prepare CCNE's opinion

GW Composition

CCNE members
- Gilles Adda
- Cynthia Fleury
- Claude Kirchner (co-chair)

CERNA members
- Gilles Dowek
- Christine Froidevaux
- Catherine Tessier
- Célia Zolynski

Associated
- Julia Petreluzzi
- Vincent Puybasset

Other personalities
- Agnès Bocognano
- Christian-Claude Colas
- Anastasia Colosimo
- Jacques Demotes-Mainard
- Alain Fontaine
- David Gruson (co-chair)
- Clothilde Huyghe
- Benoit Le Blanc
- François Lemoine
- Jacques Lucas
- Marie Martin
- Frédéric Séval
- Stéphanie Seydoux

1. The very fast diffusion of the digital in Health

Examples in all domains

Signal processing, machine learning and health

Telemedecine

Digitisation of surgery rooms

Digital research for health

Institutional management

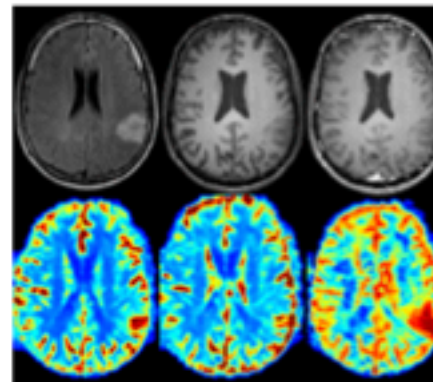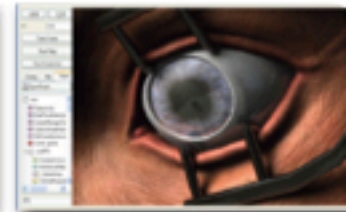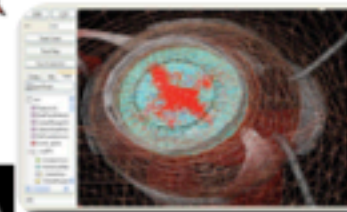Diagnostic assistance

Genomics and genomics

Medical education

The empowerment of people

Clinical research

Public health research

Detection and control of epidemics

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GW findings

- **The rapid rate of digital diffusion within the health system is a major, irreversible fact**.

- The available evidence shows how **digital sciences and technology is a source of major advances in strengthening the quality and efficiency** of our health system.

- **Mobilization of this potential is only at its beginning**. It is essential to be accompanied by a continuous analysis of the ethical issues associated with these technologies and their future development.

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- **The organization and governance of the entire health system**, from research to the clinic, from the individual to the doctors, from the office to the largest institutions, **will be profoundly impacted.**

- From today and much more so in the future, **profound changes will take place in the professions, roles, functions and responsibilities of the actors in the health system**. The consequences on the training of all actors will be multiple.

- The **fundamental role of data.**

2. Major ethical issues

Examples in all domains

I have a rare disease and provide my personal data for research purposes....

I am a doctor and I use gmail and dropbox to exchange information about patients...

I am patient and I am asked to give my free and informed consent....

I am an engineer and I develop pollution control software...

I am a doctor and I get digital help in my diagnosis....

I am the director of a health facility....

I am a citizen and I could be "increased" by placing connected objects....

I am a caregiver of elderly people who use a PDA....

I am a researcher in the field of public health....

I am a medical student, and my training is adapted to digital practice....

I am a genomics scientist and do research in bioinformatics....

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GW findings

The insufficient use of digital technology in patient care, for research or to support the development of data-driven management **leads**, on a large scale, **to unethical situations** within our health system.

The resolution of these problems is a priority issue and involves public policy levers that are not mainly related to normative creation in the future bioethics law.

An ethical path must be found between the need to protect health data and the need to share it in order to strengthen the quality and efficiency of our health system.

The dissemination of digital health services can have potentially significant effects on health inequalities, in terms of their reduction but, in some cases, their expansion.

Two major ethical issues associated with the spread of algorithmic medicine have been identified and must be the subject of regulatory mechanisms:

- The risk of depriving the patient of a large part of his capacity to participate in the construction of his management process in the face of proposed decisions provided by an algorithm;

- The danger of a reduction in the consideration of individual situations.

Digital technology, as a means of avoiding traditional channels of access to healthcare or assessing the intervention of professionals, is both a factor of freedom and transparency for citizens and a vector for destabilising our healthcare system and professionals.

Sharing research data according to the FAIR principles (findable, accessible, interoperable, reusable) is a crucial element for the development of scientific health research at the highest international level and contributes to ensuring the reproducibility of results. It is also important to provide the scientific, technical and regulatory means to control the risks of re-identifying unidentified data.

3. CCNE opinion

CCNE

1. considers the dissemination of digital health technology to be a priority, and hopes that, given the current state of research and development of these technologies, the use of opposable law will be limited to a maximum.

Given the margins for quality and efficiency gains allowed by the wider use of digital technology in our health care system, implementing a blocking regulatory logic would not be ethical.

Proposes that in the coming months, consideration be given to the creation of "flexible right" regulatory instruments applicable to the dissemination of digital technology within our health system, with a general supervisory role that could be assigned to the High Authority for Health. Such a framework would strengthen the effectiveness and efficiency of our health system, while maintaining the operational flexibility necessary to support innovation.

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CCNE

2. **Proposes to enshrined in legislation the fundamental principle of a human guarantee of the digital in health.** i.e. the guarantee of human supervision of all use of the digital in health, and the obligation to establish for any person wishing to do so and at any time, the possibility of human contact able to transmit to him all information concerning the modalities of use of the digital as part of his care journey,

3. Considers it necessary that any person possibly using artificial intelligence as part of his or her care pathway to be informed in advance so that he or she can give a free and informed consent.

CCNE

4.   **Proposes that a secure national platform for the collection and processing of health data be created** to link the various ethical issues related to health data.

5.   **Does not consider it necessary to build, in the immediate future, a general framework for compensation for damage** caused by digital objects and proposes that this reflection be carried out on a European scale.

6. **Proposes to fully engage in ethical reflections relating to the field of digital technology and health**; and on the other hand, to help in the pre-configuration of an ethics committee specialized in the challenges of digital science and technology.

メルキ, Thank you
Merci!

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