

Personalized medicine, CARPEM & Ethics research

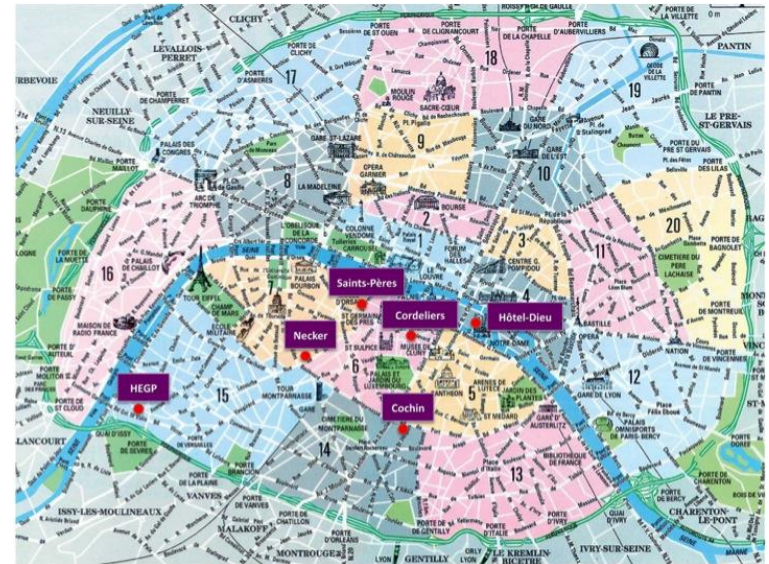
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What is CARPEM?

- CARPEM for « CANcer Research and Personalized Medicine»
- Two Paris-based hospitals (HEGP and Cochin/Hôtel-Dieu) and one University (Paris Descartes)



What about Ethics and Social Science?

- LEM for « Laboratoire d’Ethique Médicale (EA4569) »
- Ethics, Philosophy, Epistemology and Politics.
- A translational social science and humanities research program



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Initial action plan (1)

- 1) To conduct modern and efficient clinical and translational research.
- 2) To deliver the benefits of this to patients.

Initial action plan (2)

- a) Creation of two distinct committees.
- b) Identification of the main sensitive issues and organization of specific research plans.
- c) Organization of public conferences and proceedings.
- d) My dissertation.

Achievements



- **The Joint Committee (JC)**
- **The Patient Committee (PC)**

How to better inform patients?

Develop interfaces between all the components of the process:

Patients - Practitioners - Researchers

How to ethically collect samples for retrospective studies?

- Reorganization of the collection of tumors.
- A new consent form.
- (Systematic) approval from the Ethics Committee (CPP Ile-de-France).

How to improve patient care by a holistic approach in precision medicine in cancer care?

- What kind of information is available and how is it circulating between the different stakeholders in patient care? Does the information provided to patients and practitioners help them to make informed decisions?
- How to explain to patients that they could be ineligible to receive innovative treatments, without making them think that they have been excluded or that the doctors have given up?
- How to explain to patients that the non-sustainability of some therapeutic targets may lead to discontinuation of treatment?
- How to manage the adverse effects of targeted therapies given the multitude of caregivers in different situations?

Genetic and personal data in Care and Research (1)

- Non-participant observation of multidisciplinary consultation meetings (“RCP moléculaire”).
- Non-participant observation of oncogenetic consultations.
- Semi -structured interviews of researchers and clinicians.

Genetic and personal data in Care and Research (2)

- 1) How and why genetic data are obtained and used?
- 2) Are we in the Care? Are we in Research? Are we in an "in-between"?
- 3) Is the information transmitted to the patient ensures a patient's autonomous choice?

Conclusion

Develop an anticipatory ethical reflection.



Thank you