



Institut du cancer  
**PARIS CARPEM**  
CANCER RESEARCH FOR PERSONALIZED MEDICINE  
AP-HP.Centre-Université Paris Cité



# Setting up a patient committee dedicated to oncology in a university hospital: benefits and perspectives

Alexandre Brutti  
Marie-France Mamzer  
Pascale Finkelstein



# PARIS CARPEM CANCER INSTITUT - PERIMETER



**3** hospitals with a high expertise in oncology grouped in 2019



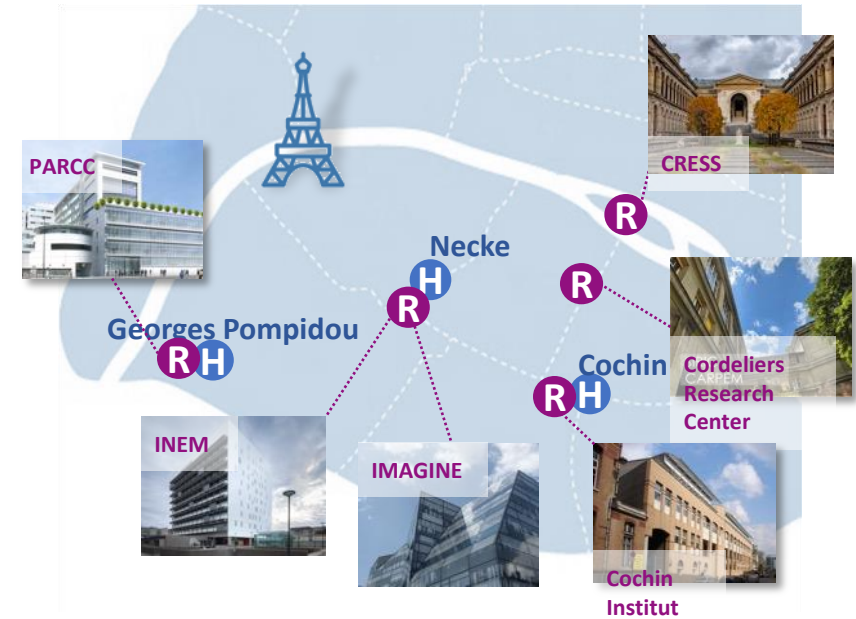
**> 35** services that take care of adult cancer patients

- hospitalization sectors
- biological departments
- imaging departments

Who are we?

**22** research teams addressing:

- tumoral heterogeneity
- metabolism
- health democracy / ethics





# A NEW COMPREHENSIVE CANCER CENTER



## 1) Defining the Quality Policy

**25** Teams with self assessments based on 85 standards

## 2) Defining the scientific strategy with programs linking strongly research to care

**28 PROGRAMMES**  
**Describe** our activities breakdown through themes

**A functional cartography** addressing interactions between the various actors

**Focus set to** interactions between care and research

Who are we?

## 3) Integrating the « patient » dimension into every « atomic » parcells of the Institute

1 out of the 28 programs is centered on **Patient experience and ethics in oncology**

Pr Marie-France Mamzer  
Mrs Pascale Finkelstein  
Mrs Aude Chaboissier  
A group of patients



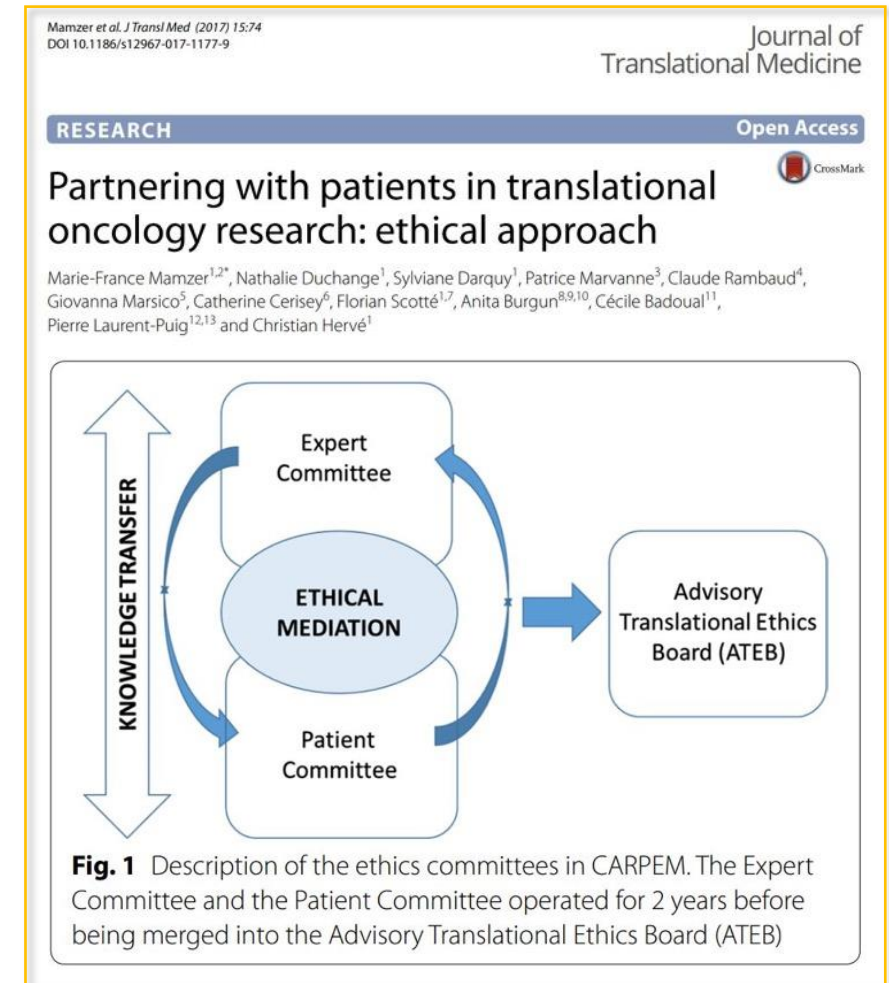
# A LONG-STANDING CULTURE OF PARTNERSHIP WITH PATIENTS THANKS TO THE TRANSLATIONAL RESEARCH PROGRAM CARPEM



## A PATIENT COMMITTEE, clearly identified as a need by the Institute :

- Since 10 years, the translational research team involved a small group of patients in its multidisciplinary research practices
- As the new project started, the Steering Committee confirmed the great interest to have a wider patient/care givers presence throughout our organization and pathways :
  - Every action, initiative and/or process involves the patient/user at a point in time.
  - Users and/or Patients are the keystone of the process.

Where do we come from?





# A PERSPECTIVE FACILITATED BY A VERY STRONG, LONG-STANDING QUALITY CULTURE



2022

**OECD accreditation**  
« standards for high  
qualitative  
**cancer care** »



« Promoting innovation  
and quality for patients »



HAUTE AUTORITÉ DE SANTÉ

2023 - 2024

**HAS Certification**  
preparation in progress  
« High quality of care »,  
**whatever**  
**the area of care**

**Making patient experience a priority  
to improve healthcare pathways  
and quality of care**

Where do we  
come from?



# THE PATIENTS' COMMITTEE IS BORN OF AN AMBITION TO FOCUS ON PATIENTS AND THEIR FAMILIES



The program «Experience patient and ethics in oncology » integrates the « patient » dimension into all the institute's components, aiming at:

- **Understanding collectively** that each patient's experience is singular, complex and chaotic
- **Documenting, analyzing et co-constructing** with patients and users more suited practices and organizations
- **Putting the experience of the patient at the center of the care services**

Where do we come from?

- ✓ An obvious choice for the steering committee that wants patients and their representatives to be at the heart of the system
- ✓ A long term priority project, part of the Hospital master plan





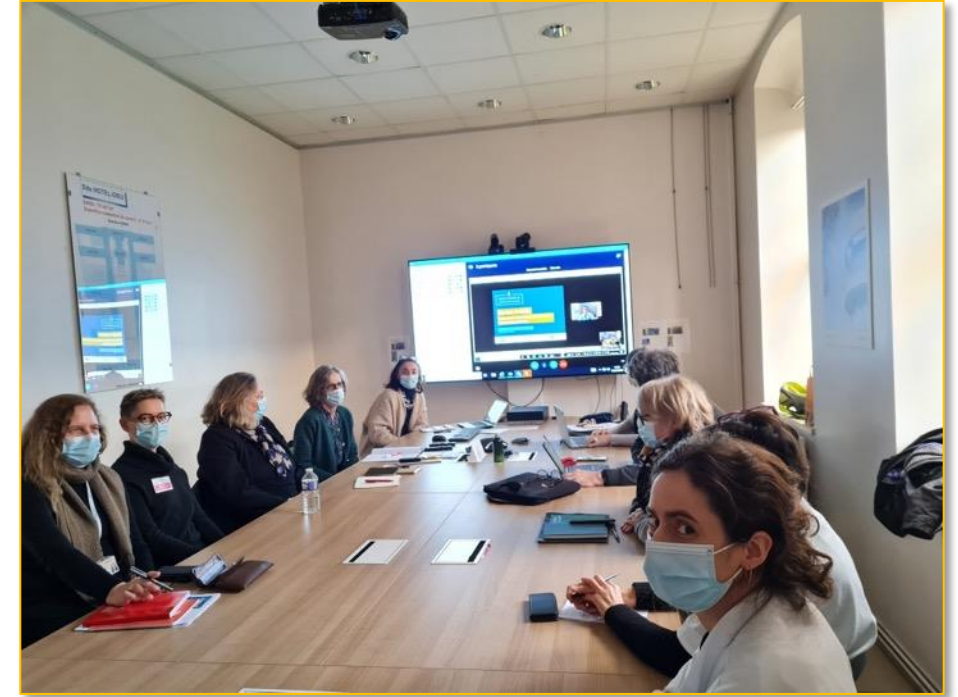
# THE PATIENTS COMMITTEE IMPLEMENTATION



**A mixed committee** gathering engaged healthcare professionals together with cancer patients and family caregivers

**Strongly supported** by the general direction of the University Hospital Group, through the implication of 3 departments:

- Care, communication, and quality and user relations departments
- Linked to the medical ethics functional unit



The  
setting up

=> A wide project across all sites, involving health care services and several hospital departments aiming to involve users in the process of improving our organizations through partnerships focusing on specific themes.



# PATIENT'S RECRUITMENT



- ✓ In association with care departments
- ✓ Through patients involved in associations
- ✓ Through Patient Care Satisfaction Committee:
  - received claims/praises can help in recruiting people
- ✓ Through flyers advertising
  - Patients may send unsolicited applications

The  
setting up

INFORMER

REJOIGNEZ LE COMITÉ DE PATIENTS

Le Comité de Patients est un collectif qui valorise l'émergence d'idées sur des projets pour l'amélioration de la qualité de la prise en charge et du vécu des patients et de leurs proches

VOTRE EXPÉRIENCE NOUS INTÉRESSE !

Pour plus d'information, contactez-nous : [comite-patients.aphp-centre@aphp.fr](mailto:comite-patients.aphp-centre@aphp.fr)

AP-HR, Centre Université de Paris

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# DEONTOLOGY CHARTER & FORMS

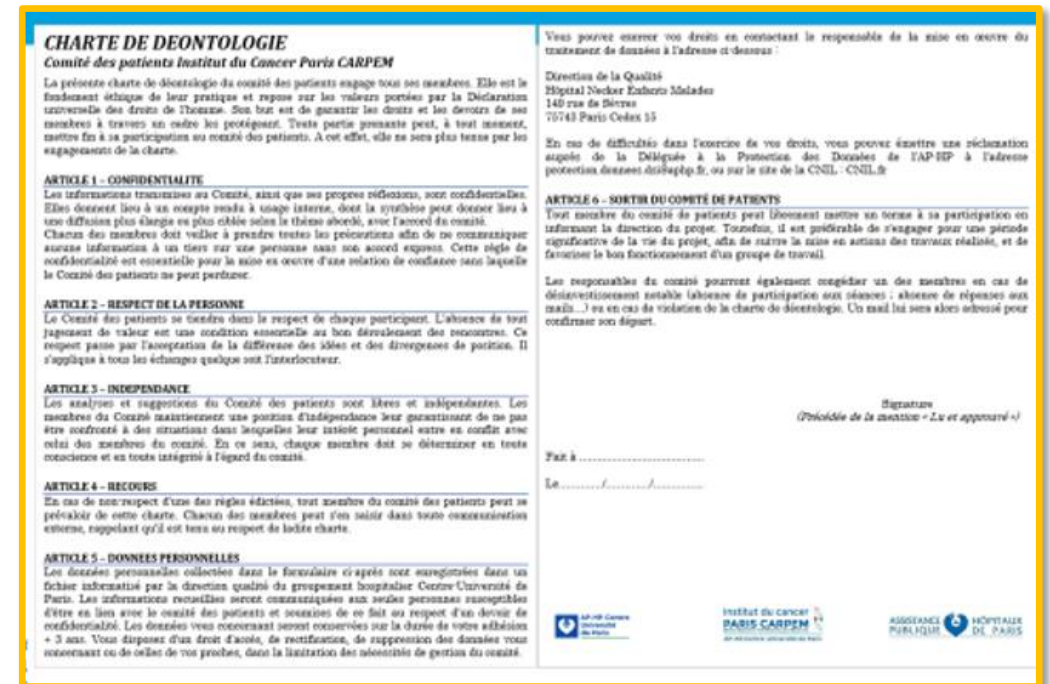


Each member of the Patient Committee agrees on the below, by signing the Deontology Chart:

## 6 main rules

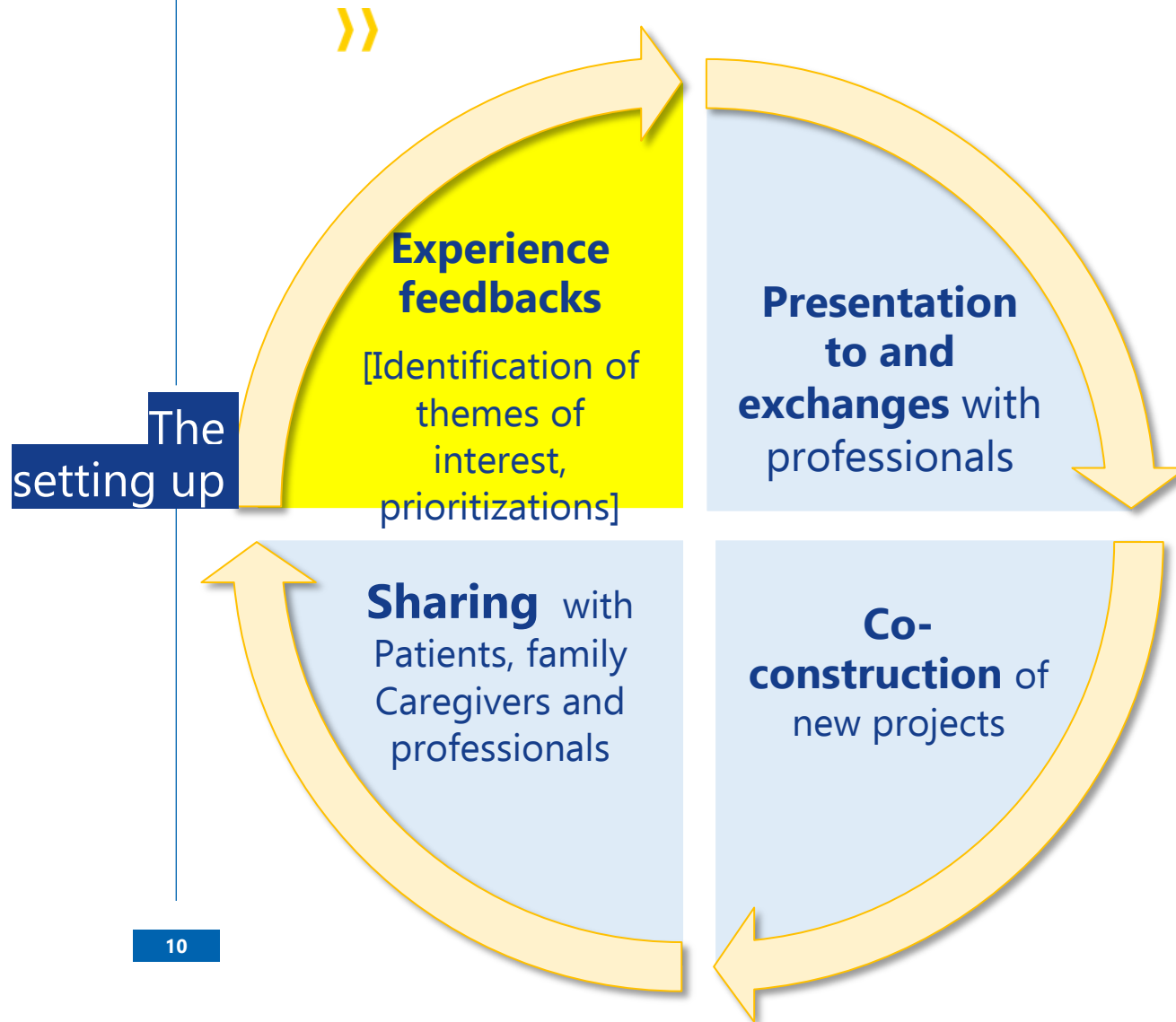
The setting up

- Confidentiality,
- Respect for the individual,
- Independence,
- Call for recourses,
- Privacy & Personal Data (compliant with GDPR)
- Free termination of membership.





# ORGANISATION ASSESSMENT AFTER 2 YEARS



Committee started June 2021

15 meetings to date

✓ 13 permanent members :

- 7 patients and family caregivers
- 6 professionnels

✓ **Outstanding Dynamics**

Active participation to transversal activities held by the Institut

(attendance to ethical reflection-groups, strategical committees, Panel Discussion, Podcasts & Videos presenting the structure)



# MAIN ACHIEVEMENTS

## » (1) *implication in the clinical setting*

- ✓ Strong implication in the **spreading of a « CARPEM cancer Institute Identity »**, *through the 3 sites of the Institute*

- ✓ Implication in the **strategic/and or architectural projects:**
  - New dedicated website
  - New hematological Clinic

- ✓ Implication in the **quality of care,**
  - Active attendance to the OECI certification
  - Promotion of the implementation of PROMS
  - High support for opening the doors to a Patient – Partner (PP)



What we do?



# MAIN ACHIEVEMENTS

## » (2) Partnering in Education & Research

- ✓ Executive task force ensuring patients and relatives' **engagement in the agenda of the SIRIC CARPEM Research program**
  - *Engagement of patients and relatives in the Research Program dedicated to Health democracy and Ethics*
    - *Steering Committee for the whole research program*
    - *Direct participation in a research action to create specific PREMS for Research*
  - *Direct contribution to empowerment of patients and relatives in translational research*
    - *Building specific tools*
    - *Recruitment assistance (PP)*
- ✓ Joint presentations in **scientific congresses**
- ✓ Participation to programs of **training for Health students:**
  - Medicine
  - Master students in Ethics and Bioethics

What  
we do?



# MEDIUM/LONG-TERM PROJECTS



## To develop the Patient's committee

- Increasing the number of patients & relatives
- Proposing an institutional training program for pro. & patients

## To take better into account the place of relatives and family caregivers

- Creation and distribution of a dedicated welcome booklet

## To recruit patient-partners

## To empower patients and enhance the experience centered approach

- Improvement of tools of communication
- Adapted satisfaction surveys
- Implementation of PROMS and PREMS in clinics

Perspectives





# POINTS TO WATCH OUT FOR



## Risks

### Our « Frailties »

- Personalized collective, small in number, exposed to the risk of imbalance
- Limited number of really committed players (patients and relatives as well as professionals)

### Other points of vigilance

- New actors in the institution
  - Ex: **Heterogeneous status of partner patients in France**
  - Legal and reglementary concerns
  - Economic concerns

# A SEDUCTIVE MODEL THAT EVOLVES THANKS TO REGULAR WORKING SESSIONS



**A great source of ideas and innovation** supported by a shared vision of care (providers, patients, families and directions)

- Identifying topics of interest
- Prioritizing actions and projects



**An insight of the patients' experience** in the Hospital policy and organizations, besides the users representatives

**A rather good acceptance** of a « cultural revolution »

- Acculturation of Professionals to the patient experience
- Consideration for relatives
- A common objective: learning from patients (and relatives) experience to elevate the Human experience in Healthcare and Research



Benefits



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Thank you for your attention



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Back up slides



# THEMES OF INTEREST IN DETAILS



## **Better live the Cancer's Strain**

- Treatment (during and after),
- Taking care of the pain,
- Manage emotions ( trials, shocks, emotional emergencies, depression, sleep disorders ...),
- Address the family & genetics dimension.

## **Personalization of the CITY-HOSPITAL Interface**

- Transversal actors network animation : *Pharmacists, psychologists, paramedics, social workers, sports rehabilitation...*

## **Improve cancer care pathways**

- Prevention, Drugs Side Effects, Toxicity

## **Holistic approach promotion**

- relaxation, sophrology, meditation, hypnosis, acupuncture, auriculotherapy, EMDR

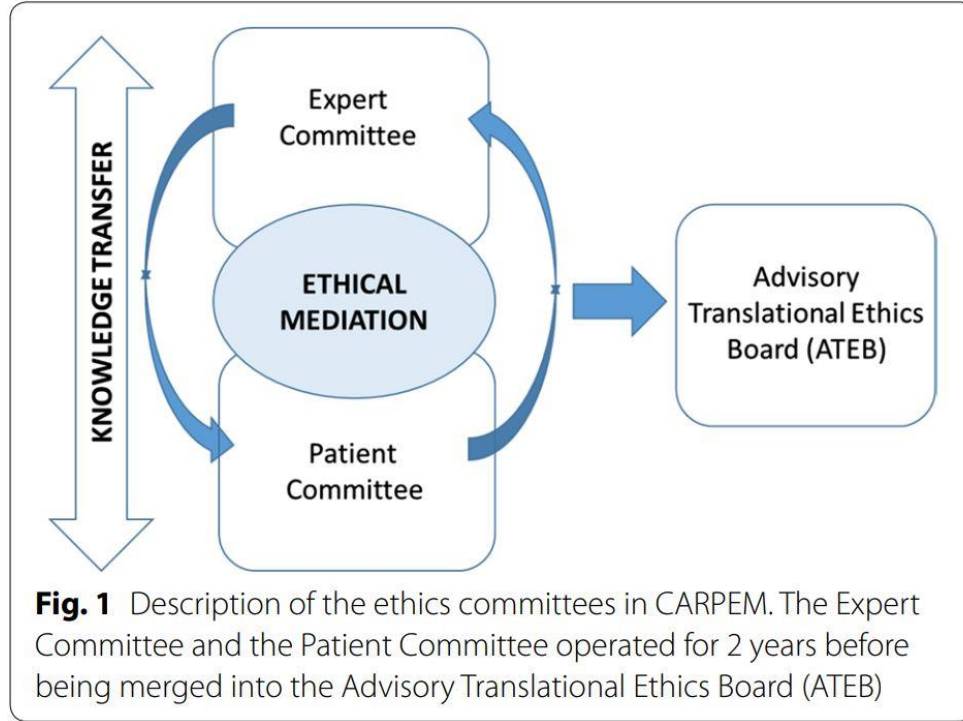
## **Resources Centre & info → Navigator**

- Informational Desk to navigate through Hospital Resources and all valuable support to the medical care : List of associations, Adaptive Sport & Training Programs.

## **Listening to and implementing best practices (in Europe and Worldwide) in the field of health democracy: PREMs, PROMs ...**



# L'expérience antérieure du CARPEM: un partenariat possible



**Fig. 1** Description of the ethics committees in CARPEM. The Expert Committee and the Patient Committee operated for 2 years before being merged into the Advisory Translational Ethics Board (ATEB)

Jacquier et al. *BMC Med Ethics* (2021) 22:21  
<https://doi.org/10.1186/s12910-021-00592-9>

BMC Medical Ethics

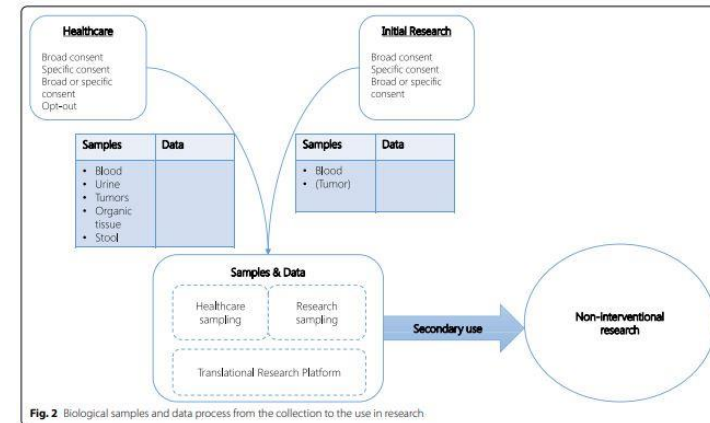
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RESEARCH ARTICLE

Open Access

## Facing new challenges to informed consent processes in the context of translational research: the case in CARPEM consortium

Elise Jacquier<sup>1\*</sup>, Pierre Laurent-Puig<sup>2,3</sup>, Cécile Badoual<sup>4</sup>, Anita Burgun<sup>5,6,7</sup> and Marie-France Mamzer<sup>1,8</sup>



**Fig. 2** Biological samples and data process from the collection to the use in research

Mamzer et al. *J Transl Med* (2017) 15:74  
 DOI 10.1186/s12967-017-1177-9

Journal of  
 Translational Medicine

RESEARCH

Open Access



## Partnering with patients in translational oncology research: ethical approach

Marie-France Mamzer<sup>1,2\*</sup>, Nathalie Duchange<sup>1</sup>, Sylviane Darquy<sup>1</sup>, Patrice Marvanne<sup>3</sup>, Claude Rambaud<sup>4</sup>, Giovanna Marsico<sup>5</sup>, Catherine Cerisey<sup>6</sup>, Florian Scotté<sup>1,7</sup>, Anita Burgun<sup>8,9,10</sup>, Cécile Badoual<sup>11</sup>, Pierre Laurent-Puig<sup>12,13</sup> and Christian Hervé<sup>1</sup>

## La piste du consentement dynamique

⇒ Enquête empirique (C. Despres)

⇒ Mise en œuvre 2022-2023