

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

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PARIS CARPEM CANCER INSTITUT - PERIMETER





- - 22 research teams addressing:
- CARPEM
- tumoral heterogeneity
- metabolism
- health democracy / ethics

- services that take care of adult cancer patients
 - hospitalization sectors
 - biological departments
- imaging departments







Who

are we?



A NEW COMPREHENSIVE CANCER CENTER



1) Defining the Quality Policy

Teams with self assessments based on 85 standards 2) Defining the scientific strategy with programs linking strongly research to care

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



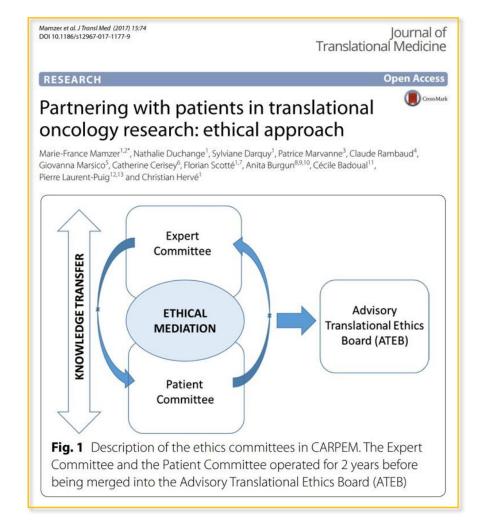


A LONG-STANDING CULTURE OF PARTNERSHIP WITH PATIENTS THANKS TO THE TRANSLATIONAL RESEARCH PROGAM CARPEM

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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.









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

EC

« Promoting innovation and quality for patients »

HAS

HAUTE AUTORITÉ DE SANTÉ

2022

OECI accreditation « standards for high qualitative

cancer care »



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

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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

- ✓ 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

Where do we come from?







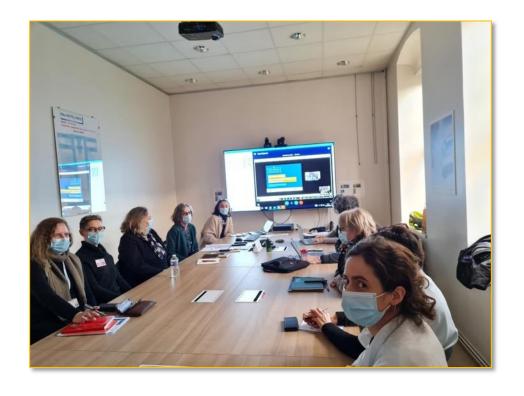
THE PATIENTS COMMITTEE IMPLEMENTATION

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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



=> 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

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✓ In association with care departments

The setting up

Through patients involved in associations

- ✓ Through Patient Care Satisfaction Committee:
 - o received claims/praises can help in recruiting people
- ✓ Through flyers advertising
 - Patients may send unsolicited applications









DEONTOLOGY CHARTER & FORMS

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



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

6 main rules

Vous pouvez excreer vos droits en contactant le responsable de la mise en œuvre du CHARTE DE DEONTOLOGIE trattement de données à l'adresse et dessous Comité des patients Institut du Cancer Paris CARPEM La présente charte de décatalogie du comité des potients engage tous ses membres. Elle est le Hipital Necker Enforce Melades fundement éthique de leur pratique et repose sur les valeurs portées par la Déclaration 140 rue de Sinves universelle des droits de l'housse. Son but est de gazantir les droits et les devoirs de ses 75743 Paris Celax 15 menches à traves un cadre les protégours. Teute partie gremante peut, à teut mement, mettre fix à sa participation su comité des patients. A cet effet, elle ne sem plus tenne per les En car de difficultés dans l'exercise de vos droits, voes prevez émettre une réclamation sugagements de la charte. auspoie de la Diliéguée à la Protection des Données de l'AP-RP à l'adresse protection données drabaphp fr, ou sur le site de la CNIL. CNIL de ARTICLE 1 - CONFIDENTIALITE Les informations transquises su Comité, sinsi que ses propres réflectors, sont confidentielles ARTICLE 6 - SORTIR DU COMITÉ DE PATIENTS Elles donnent lieu à un compte rendu à usage interne, dont la synthèse peut donner lieu à Tout micelere du comité de patients peut libocment mottre un torme à sa participation on uno diffusion plus élargie en plus cibble selon le thème abordé, avec l'accord du comité. informant la direction du projet. Tousefois, il est prédérable de s'engager pour une période Chacun des membres doit veiller à prendre teutes les précestions afin de ne communiques nigraficative de la vie du projet, afin de suivre la naise en astismo des travaces réalisés, et de angune information à un tiere pur une nectonne sant son accord express. Cette règle de kroziner le bos fixactionsement d'un groupe de travail. confidentialité est essentielle pour la mise en œuvre d'une relation de confiance sans laquelle le Cozzité des patients ne peut perfuzer. Les responsables du comité pourront également congédier un des membres en cas de désinvestissement notable laborare de participation son séances ; absence de répenses son ARTICLE 2 - RESPECT DE LA PERSONNE mails...) ou en cao de violation de la charte de décatelogie. Un mail lui sem alors adressé pour Le Comité des patients se tiendre dans le respect de chaque participant. L'absence de tout jugement de valeur est une condition essentielle au bon dérrulement des rencontres. Ce respect passe par l'acceptation de la différence des idées et des divergences de position. Il s'applique à tous les écharages quelque suit l'interlocuteur. ARTICLE 3 - INDEPENDANCE Les analyses et suggestions du Comité des patients sont libres et indépendantes. Les digrature membres du Comité maintiennent une porition d'indépendance leur garantissant de me par (Précédée de la miention « Lu et approaré ») être confronté à des situations dans lesquelles leur intécêt personnel entre en conflit avec celui des membres du comité. En ce sens, chaque membre doit se déterminer en trets conscience et en toute intégrité à l'égard du comité. En cas de non respect d'une des régles édictées, tout membre du comité des patients peut se prévaloir de cette charte. Chacun des membres peut s'en saisir dans toute communication estorne, rappelant qu'il est tenn au respect de ladite charte. ARTICLE 5 - DONNEES PERSONNELLES Les données personnelles collectées dans le formulaire ci-après sont enregistrées dans un fichier informatisé par la direction qualité du groupement hospitalier Centre Université de Paris. Les informations recueilles sercen communiquées aux seules personnes susceptibles d'être en lieu avec le comité des patients et soumites de ce fait au respect d'un devoir de KSSSEANCE (HÖPYTALIK PUBLIKSIAN DE PARIS confidentialité. Les données vous concernant seront conservées sur la durée de votre adhésion + 3 aux. Vous disposer d'un droit d'acole, de rectification, de suppression des données vous concernant ou de celles de vos proches, dans la limitation des nécessités de gestion du comité.

ORGANISATION ASSESSMENT AFTER 2 YEARS **Experience** feedbacks **Presentation** to and [Identification of exchanges with themes of The professionals interest. setting up prioritizations] **Sharing** with Co-Patients, family construction of Caregivers and new projects professionals

Committee started June 2021

15 meetings to date

- ✓ 13 permanent members :
- 7 patients and family caregivers
- 6 professionnals

✓ 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



- Active attendance to the OECI certification
- Promotion of the implementation of PROMS
- High support for opening the doors to a Patient – Partner (PP)





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







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







POINTS TO WATCH OUT FOR

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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

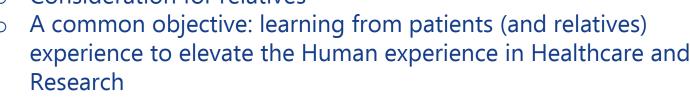




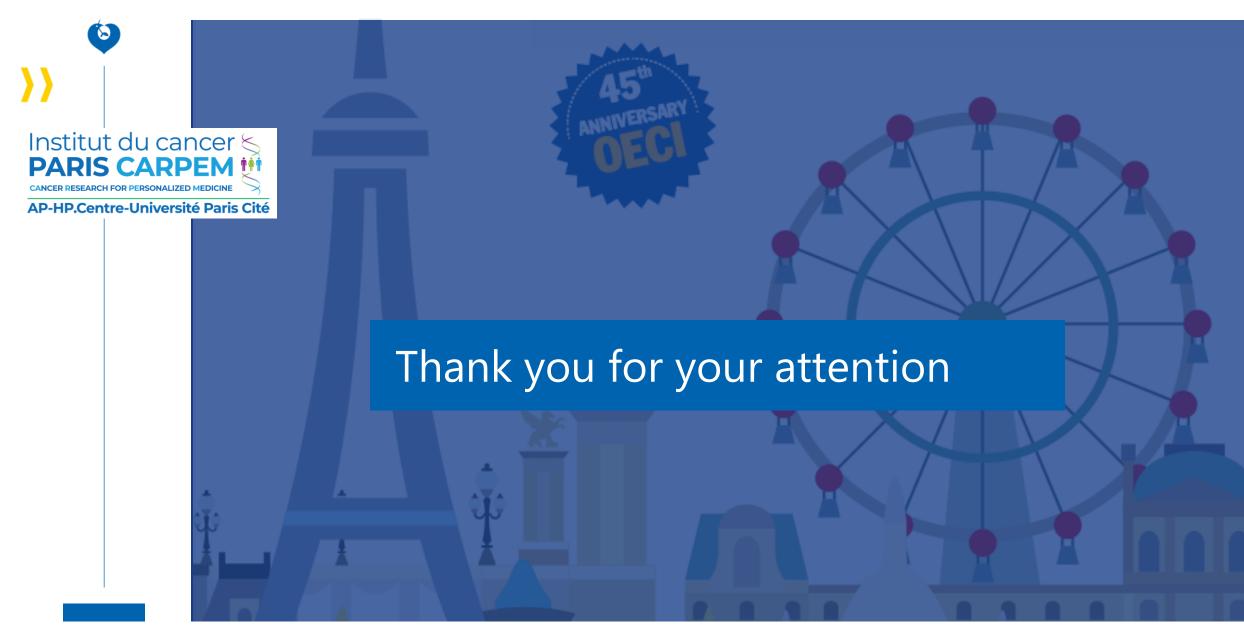
An insight of the patients' experience in the Hospital policy and organizations, besides the users representatives



- Acculturation of Professionals to the patient experience
- Consideration for relatives
- experience to elevate the Human experience in Healthcare and























THEMES OF INTEREST IN DETAILS

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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, Adaptative 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

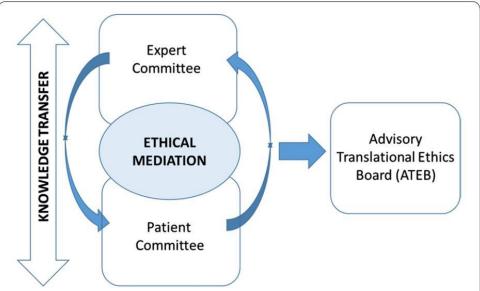


Fig. 1 Description of the ethics committees in CARPEM. The Expert Committee and the Patient Committee operated for 2 years before being merged into the Advisory Translational Ethics Board (ATEB)

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

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

BMC Medical Ethics

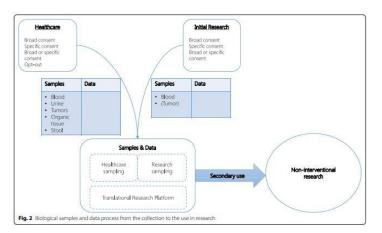


RESEARCH ARTICLE

Open Access

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

Elise Jacquier^{1*}, Pierre Laurent-Puig^{2,3}, Cécile Badoual⁴, Anita Burgun^{5,6,7} and Marie-France Mamzer^{1,8}



La piste du consentement dynamique

- ⇒ Enquête empirique (C. Despres)
- ⇒ Mise en œuvre 2022-2023

