



**Chaire de recherche
en évaluation des technologies
et des pratiques de pointe**

Engagement des citoyens et des patients
dans la transformation des organisations
et du système de santé



**Chair of Evaluation of
State-of-the-Art
Technology and Methods**

Citizen and Patient Engagement
in the Transformation of
Organizations and Health Systems



Canadian Experience of Patient Partnership in Quality Improvement

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OECI2022 ONCOLOGY

Valence, June 15, 2022



I have no conflict of interest regarding this presentation, other than being a passionate proponent of patient partnership.

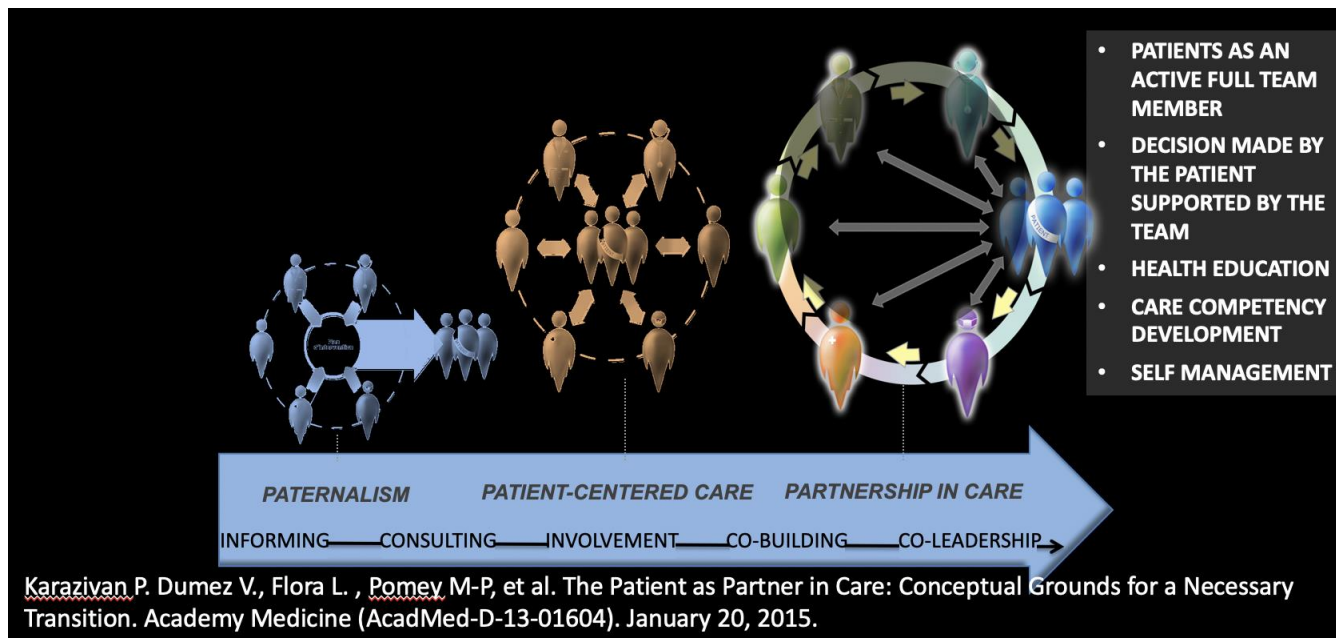
Who I am

- ✓ Professor at the School of Public Health of the Université de Montréal
- ✓ Researcher at the Centre Hospitalier de l'Université de Montréal
- ✓ Chair of Evaluation of State-of-the-Art Technologies and Methods
- ✓ Co-Director of the Centre of Excellence on Patient and Public Partnership
- ✓ Public Health Physician
Institut national d'excellence en santé et service sociaux (HTA agency)

Objectives

- To share current, action-based research to improve the quality of professional care and the patient experience in oncology.
- To demonstrate how the patient partnership can be implemented in the patient's journey.

Patient partnership



Centre of Excellence on Partnership
with Patients and the Public

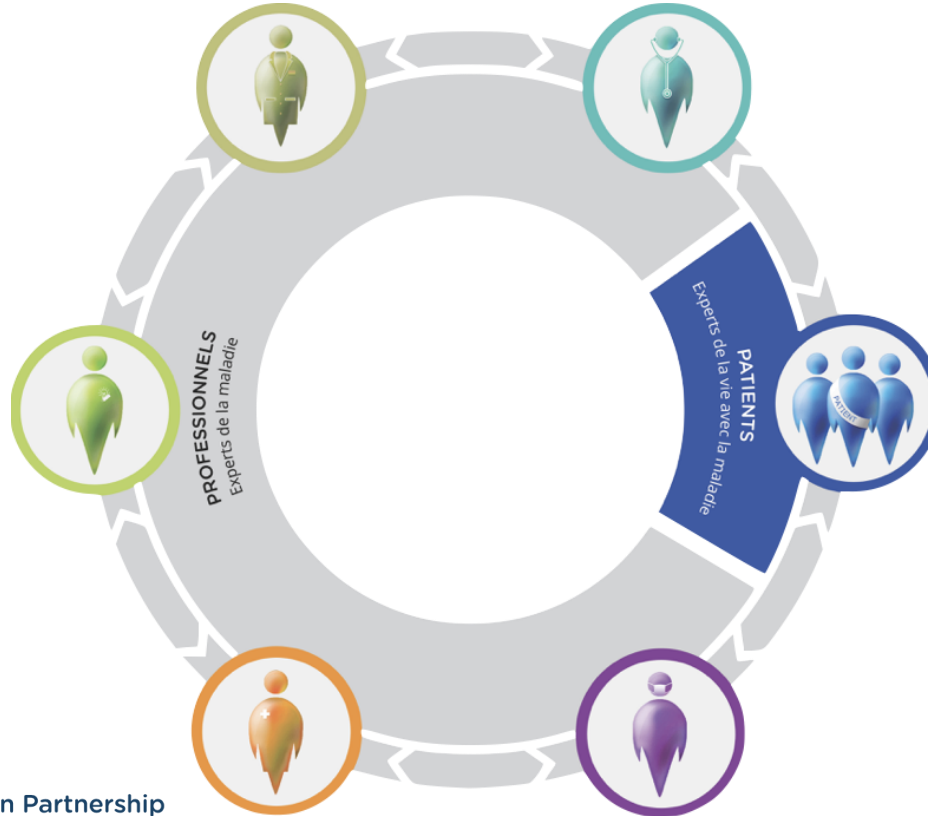
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Patient partnership (continued)

Health professionals:
Disease experts



Patients:
Experts in living
with an illness and
in using the
healthcare system



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2020 Canadian cancer statistics*



225,800

Canadians will
receive a cancer
diagnosis

In 2020
Based on the
estimates:

IN QUEBEC

56,800 NEW CANCER CASES

83,300

Canadians
will die of a cancer



The situation...



Emotional support was the most lacking of the six patient experience domains assessed across network member organizations and across Canada (Rossy, 2017)

Rossy cancer network. P2-Outpatient rating of treatment experience according to 6 care domains

<http://www.mcgill.ca/rcr-rcn/scorecard/quality-dimension/patient-experience/p2-outpatient-rating-treatment-experience>





PAROLE-Onco

Patient AdvisoR, Organizational resource as Lever
for improved patient (and Professionnals)
Experience in Oncology



- 4 institutions: CHU de Québec - Université Laval; CIUSSS Mauricie-Centre-du-Québec; CIUSSS est de l'Île-de-Montréal; CHUM
- The 4 institutions decided to implement PAROLE-Onco on the breast cancer journey
- Funded by CIHR and MSSS (2017-2021) in a Health Services Improvement Program



IRSC CIHR

Instituts de recherche en santé du Canada Canadian Institutes of Health Research

Santé
et Services sociaux

Québec





Principal Investigators



Marie-Pascale Pomey

Principal Investigator, Regular
Researcher at the CRCHUM, CHUM
Chair in Technology Assessment
and Advanced Modalities



Mado Desforges

Patient Co-researcher,
Coordinator of the integrative
oncology organization CROIRE



Dr. Michèle de Guise

President and CEO of the
Institut National
d'Excellence en Santé et
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Co-researchers



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Medical oncologist



Jean-François Pelletier
Researcher in socio-politics and mental health



Zeev Roseberger
Researcher in psychology
oncology



Nicolas Fernandez
Researcher in medical education



Lynda Bélanger
Researcher in oncology
psychology



Sacha Ghadiri
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Antoine Boivin
Physician researcher
in care partnership



Michel Dorval
Researcher in psychology
oncology



Isabelle Ganache
Ethicist



Michel-Alain Danino
Plastic surgeon



Innovation



Introduction of a new player in the cancer care journey and team: the accompanying patients (APs)



Characteristics of the accompanying patients (APs)



Has experienced an episode of care and has used the services of a facility



Is willing to share this experience with other patients going through a similar episode to help them in being partners in their care



Complements the care team's service offering as an integral member of the team

Key times when the accompanying patient can intervene

- A patient may encounter several APs depending on their trajectory
- An AP coordinator acts as a link between the clinical team and the patients



Proposal to meet with an AP



CONSULTATION

with a physician or nurse navigator at the time of diagnosis and treatment plan decision



FOLLOW-UP CONSULTATION

Follow-up consultation (professionals etc.)



END OF TREATMENTS

The "bridge to home" and back to everyday life

Step 1

Step 2

Step 3

Step 4

Step 5

Step 6

Detection of symptoms

FIRST APPOINTMENT

- predisposition to cancer (genetic)
- for the assessment of suspected cancer

TREATMENT 1

Performance of treatment 1 (example: surgery, chemotherapy, radiotherapy, etc.)

NEW TREATMENTS

End-of-life care

Objectives of PAROLE-Onco



01

Coconstruction

Co-constructing support with APs at the clinical level, in collaboration with the teams

02

Assessment

Evaluate how knowledge is transmitted between APs, patients and professionals

03

Explore the effects

Explore the dimensions that are sensitive to the effects of AP intervention

04

Identify factors

Identify factors that promote or hinder the implementation of APs

05

Ethical and legal issues

Identify the ethical issues involved in the introduction of APs into health care settings



Co-construction of the stages



PHASE 1

PREPARATION OF THE INSTITUTION

- Passing by the Ethics Committee
- Choice of the program where to implement the APs
- Membership of the General Management

PHASE 2

PREPARATION OF THE TEAM AND TESTING OF THE INTERVENTION

- Identification de patients interested in participating in the project and in co-constructing the intervention
- Presentation of the project to the interested program and formation of a clinical level working group including interested patients, a project manager, representatives of physicians, nurses, psychologists and others whose mandate is to implement the APs at the clinical level in the mode of a continuous quality improvement working group
- Co-construction of a project management charter (existing models) including the schedule
- Co-construction of the intervention: intervention modalities (where, when, how and by whom)
- Regular feedback on the progress of the working group to management, either to an ad hoc committee or to the institution's management committee
- Identification of APs (1-3) to test the intervention and evaluation: Mini-pilot

PHASE 3

INTERVENTION DEPLOYMENT

- AP training recruitment (6-7)
- Formalizing the relationship between APs and patients
- Carrying out the intervention over 2 years
- Evaluation with qualitative and quantitative data
- Monitoring of unintended, positive and negative effects

PHASE 4

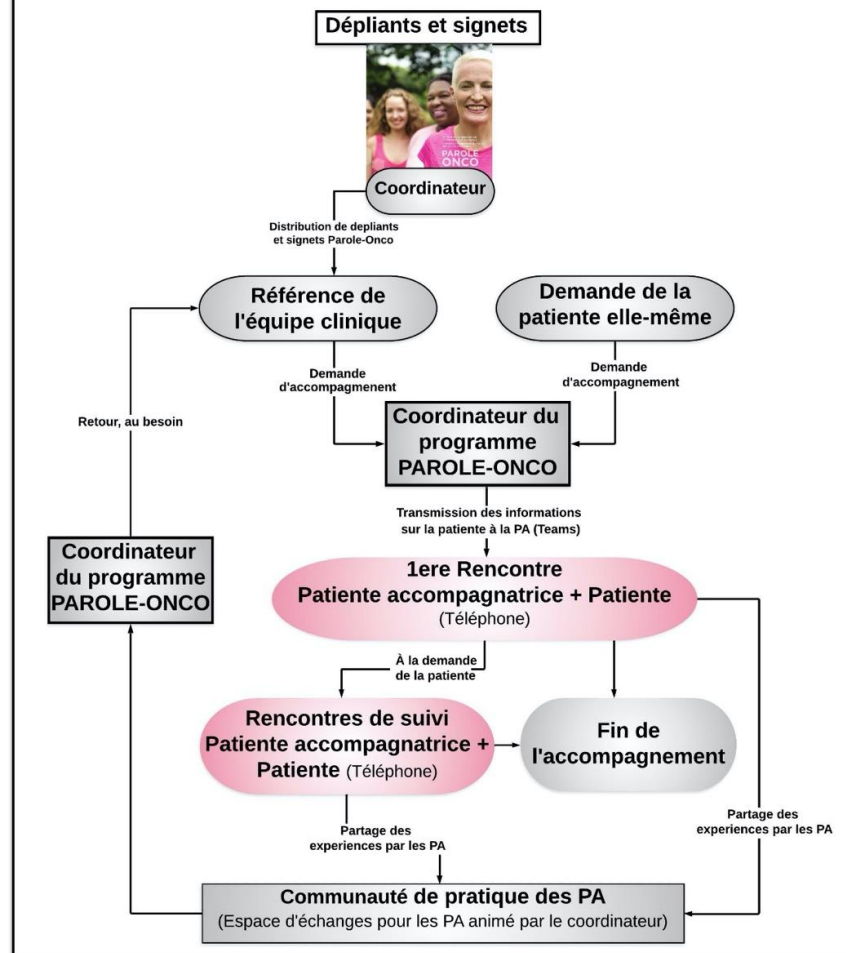
SUSTAINABILITY OF THE INTERVENTION

- Formalization of the service offer by the establishment in a permanent manner
- Regular recruitment of APs, training and coaching
- Formalizing the mechanism for connecting APs with patients
- Evaluation with qualitative and quantitative data
- Monitoring of unintended, positive and negative effects



Accompagnement process

Trajectoire PAROLE-ONCO pour une patiente qui accepte l'accompagnement



Introducing the APs



Marie-Andrée



Mado



Ginette



France



Diane



Zahra



Linda



Isabelle



Dounia



Carmen



Liette



Support provided (as part of the accompanying relationship) between December 2019 and December 2022



Total of **589 patients supported** by 25 accompanying patients in 4 institutions (1 of which is being restarted).

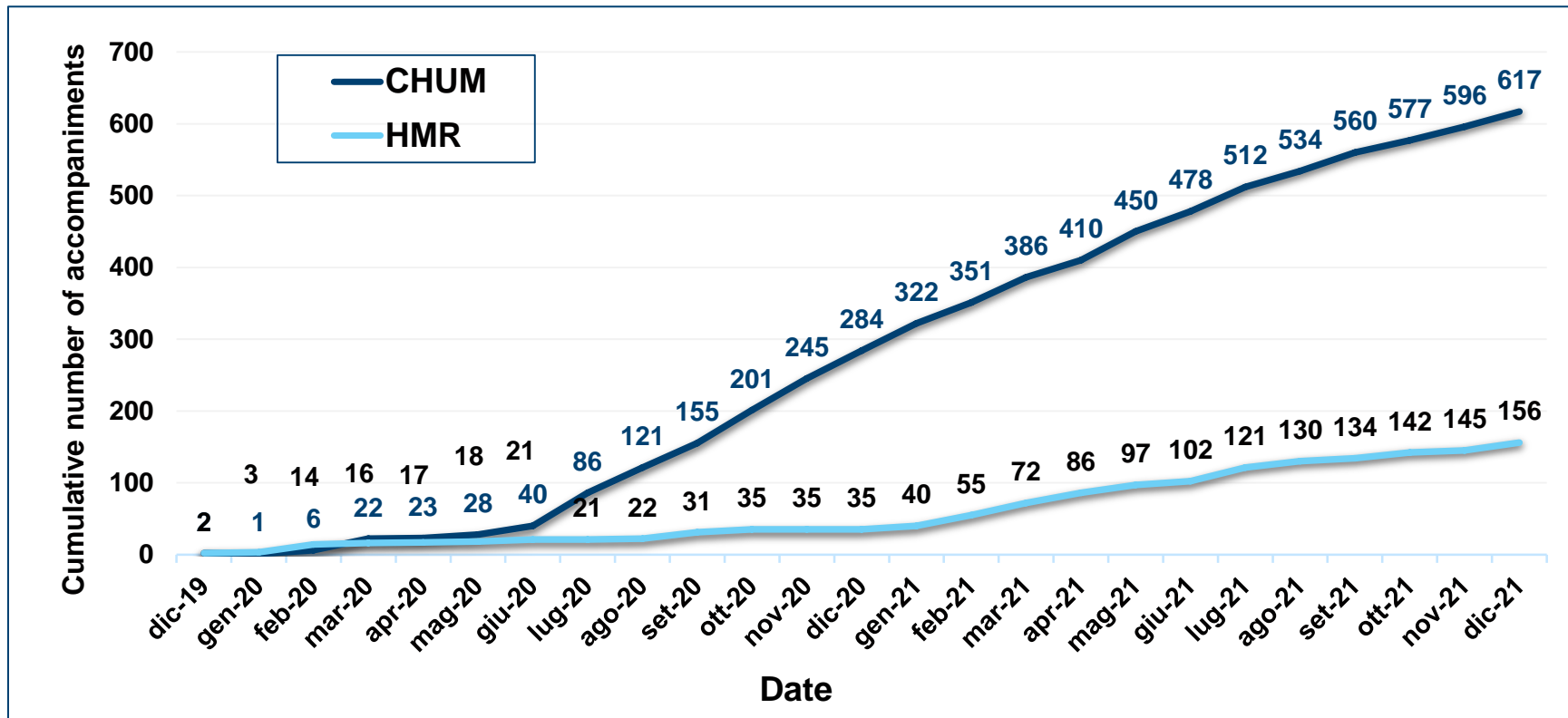


Approximately **665 hours of calls** between accompanying patients and accompanied patients.





Evolution of the number of accompaniments





Data collection process



1

Start of the project

- Interviews with management representatives
- Interviews with AP
- Discussion group with working committee
- Questionnaire for clinical professionals
- Questionnaires for AP

2

Mid-project

- Interviews with AP
- Discussion group with working committee

3

End of the project

- Interviews with management representatives
- Interviews with AP
- Discussion group with working committee
- Interviews with accompanied patients
- Questionnaire for clinical professionals
- Questionnaires for AP

*** Ongoing: after each accompaniment by an AP: logbook completed by the AP and questionnaire completed by the patient after the 1st contact with the AP and again 1 month later.**



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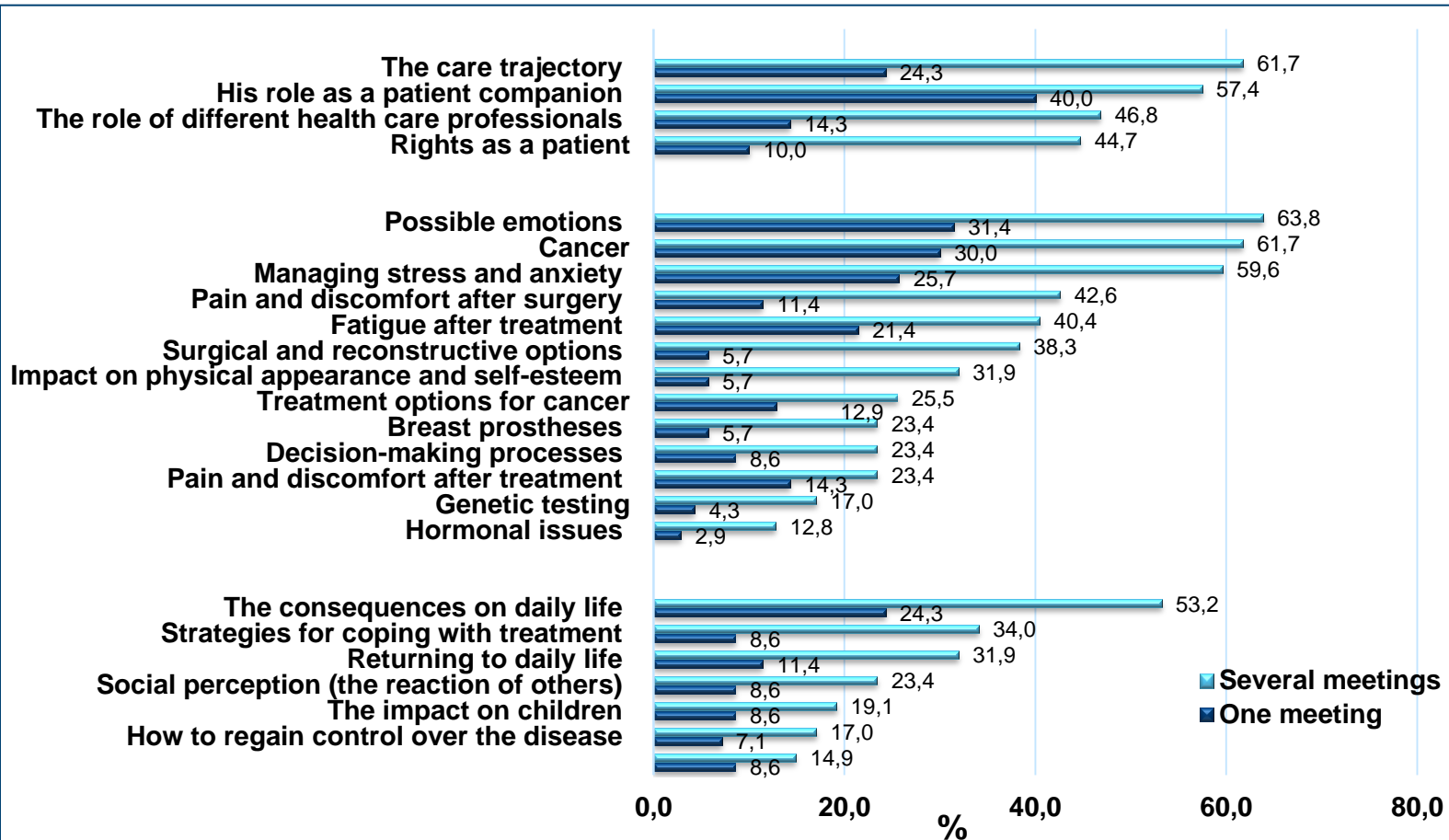
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Results on the patients

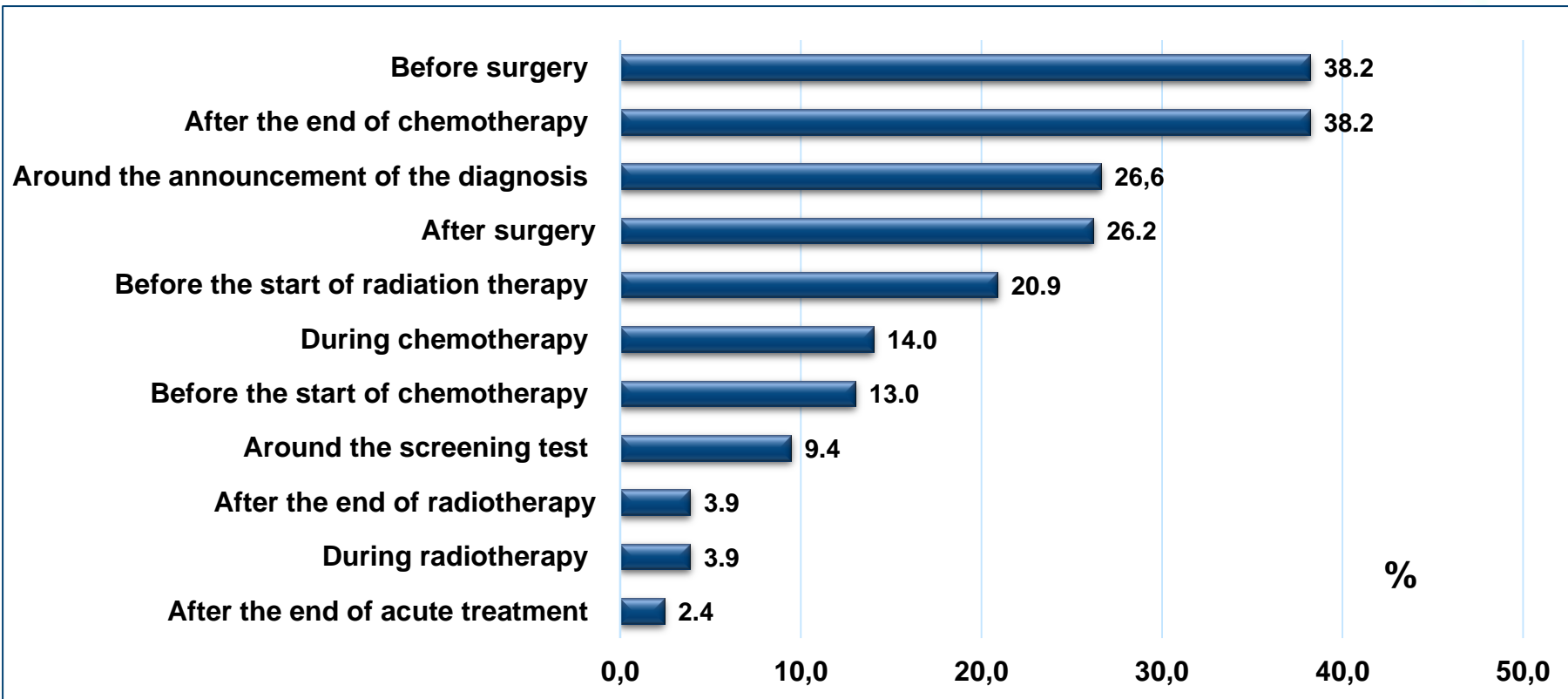


Themes addressed



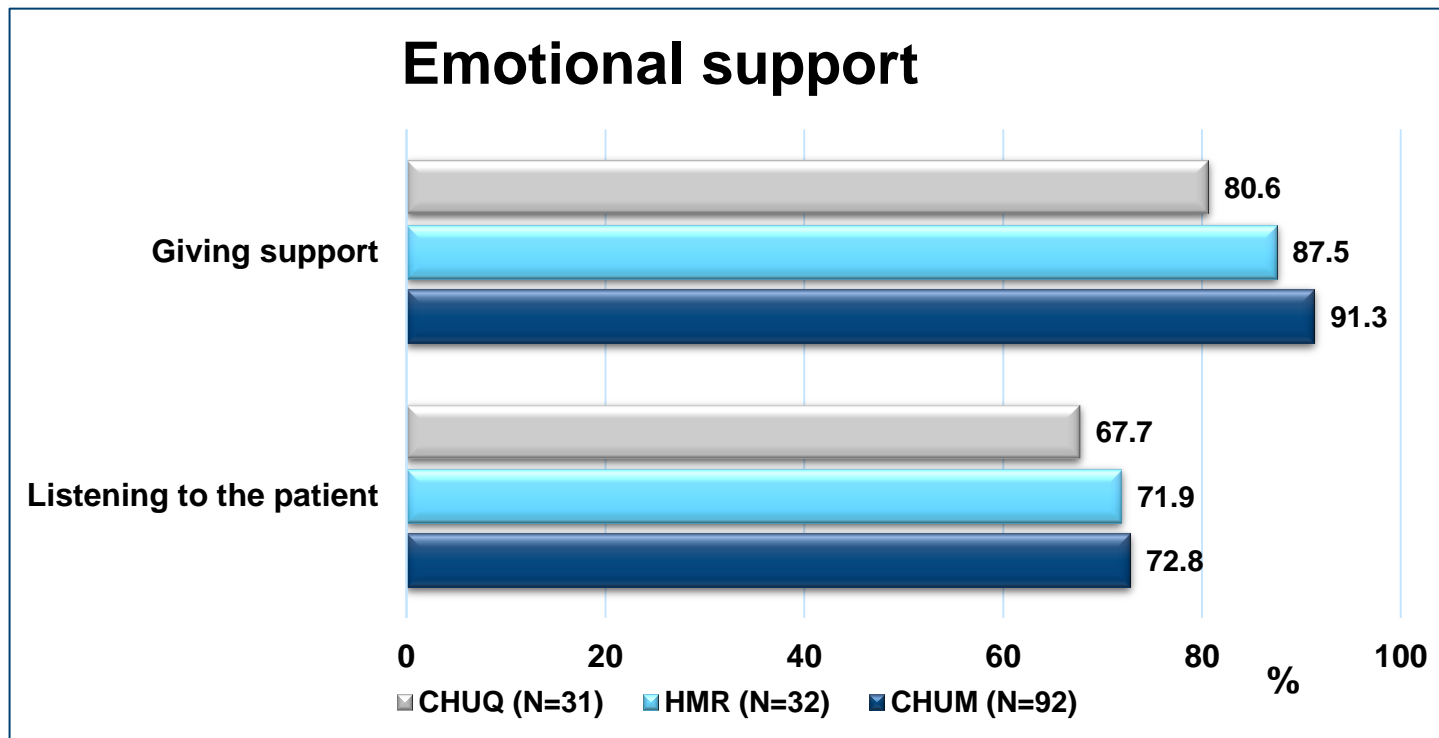


Different points in the trajectory (n=699)





Examples of impact measurement



Impact of anxiety

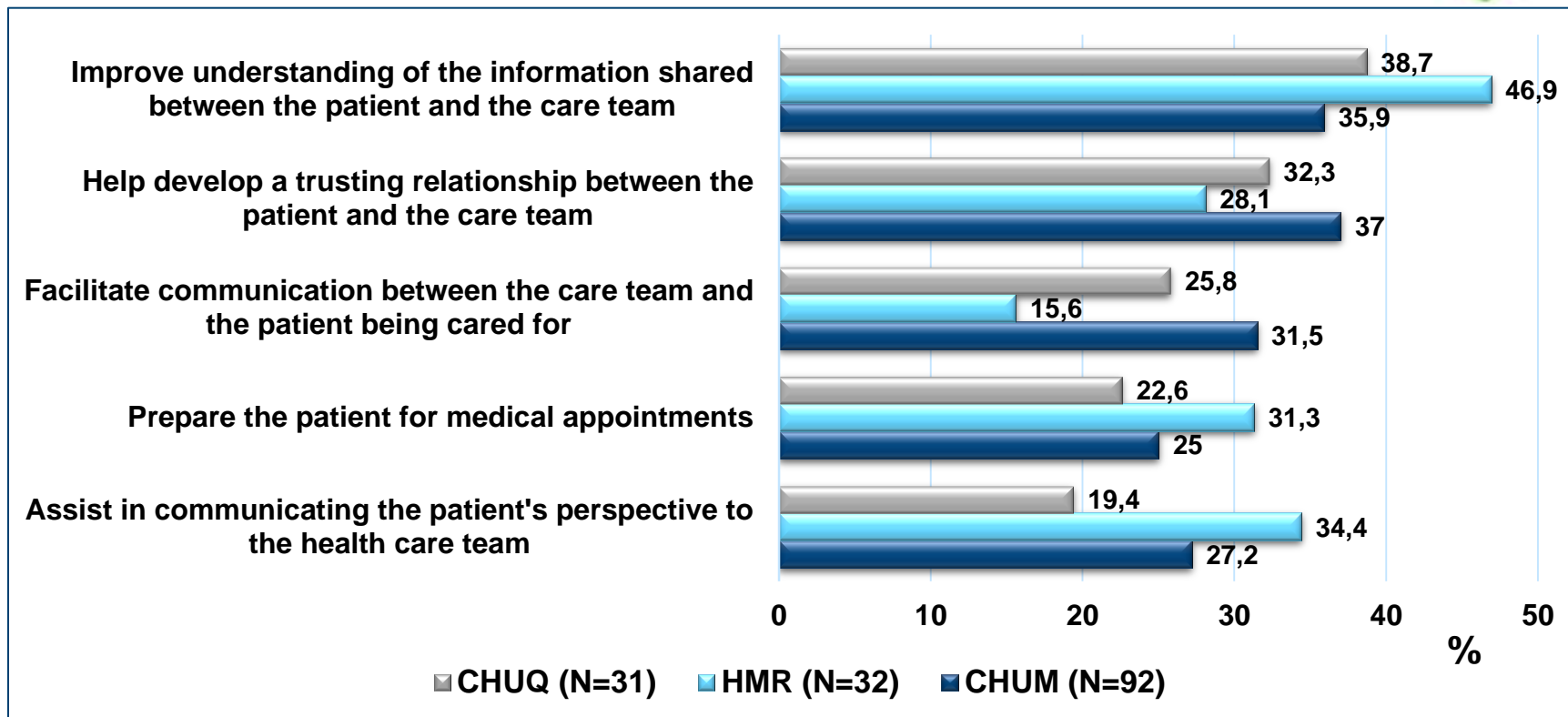


**75% during a
consultation
with a AP**



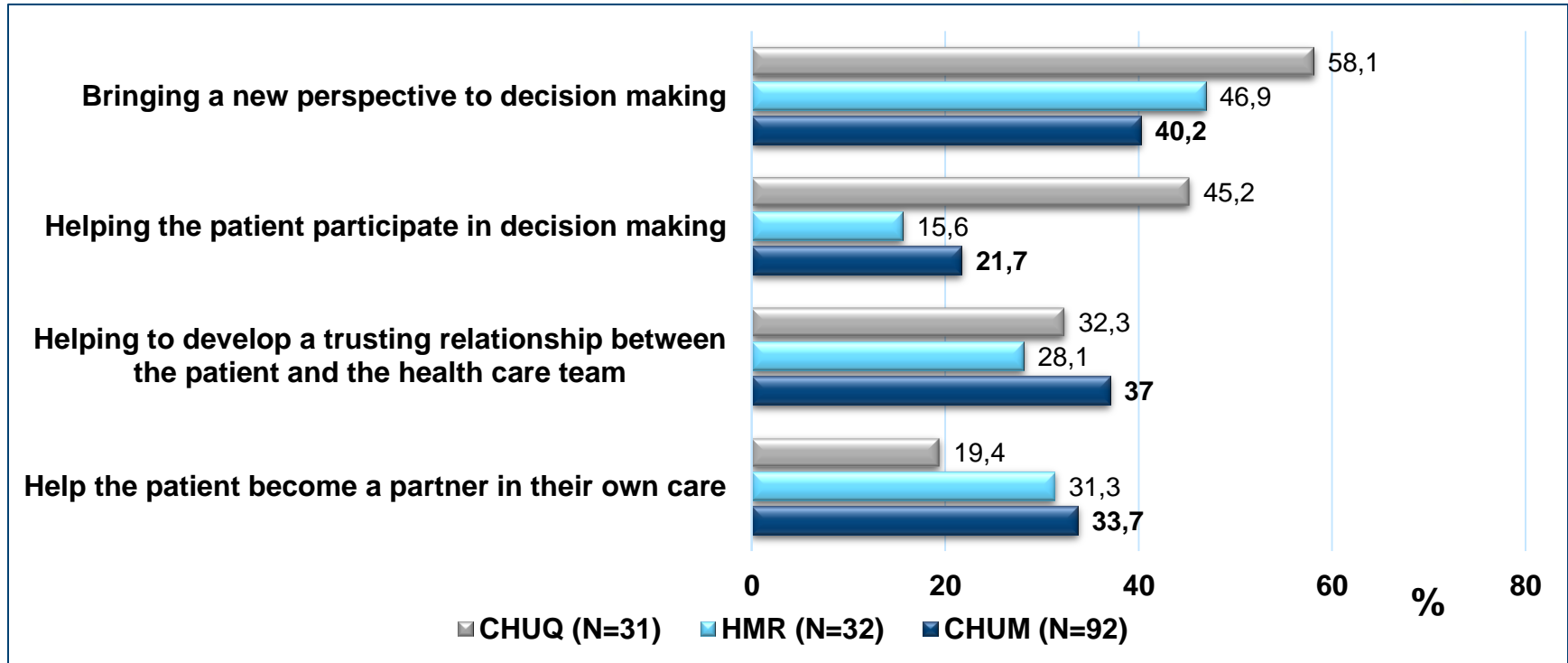


Navigation








Partner in her care





Roles of APs towards patients


 Give a concrete idea of the care pathway (navigation)


 "We know the health professionals well and also the different stages and pathways. The patients appreciate that we know the people and that we can project ourselves in the different stages of life." 

 Inform patients about available resources (information)

 "But you have to be aware of the role of other people on the team," "Patients don't know they have access to health care professionals and they always think they have to pay too."

 Detect the patient's emotions and refer them as needed (provide emotional support)

 "To be attentive to her distresses, her stresses, her anxieties perhaps also [...] to be able to respond if we can and then if not to be able to refer the patient as needed"

 Sharing experiential knowledge (therapeutic education)
"We are familiar with the range of treatments and services. We are also familiar with the entire chain of operations, having experienced them, so we are able to talk about them and we know the impact they have [...] in our lives, in our relationships, the impact they have on our children, on our loved ones. So we are able to talk to someone who may have questions."

Partner in her care (empowerment)

"During the meetings, I help the patients be involved and responsible in their treatment. I help them regain control over their lives and their journey. They are therefore better equipped to be in partnership with the health care team."



Perceptions of APs (collected through interviews)





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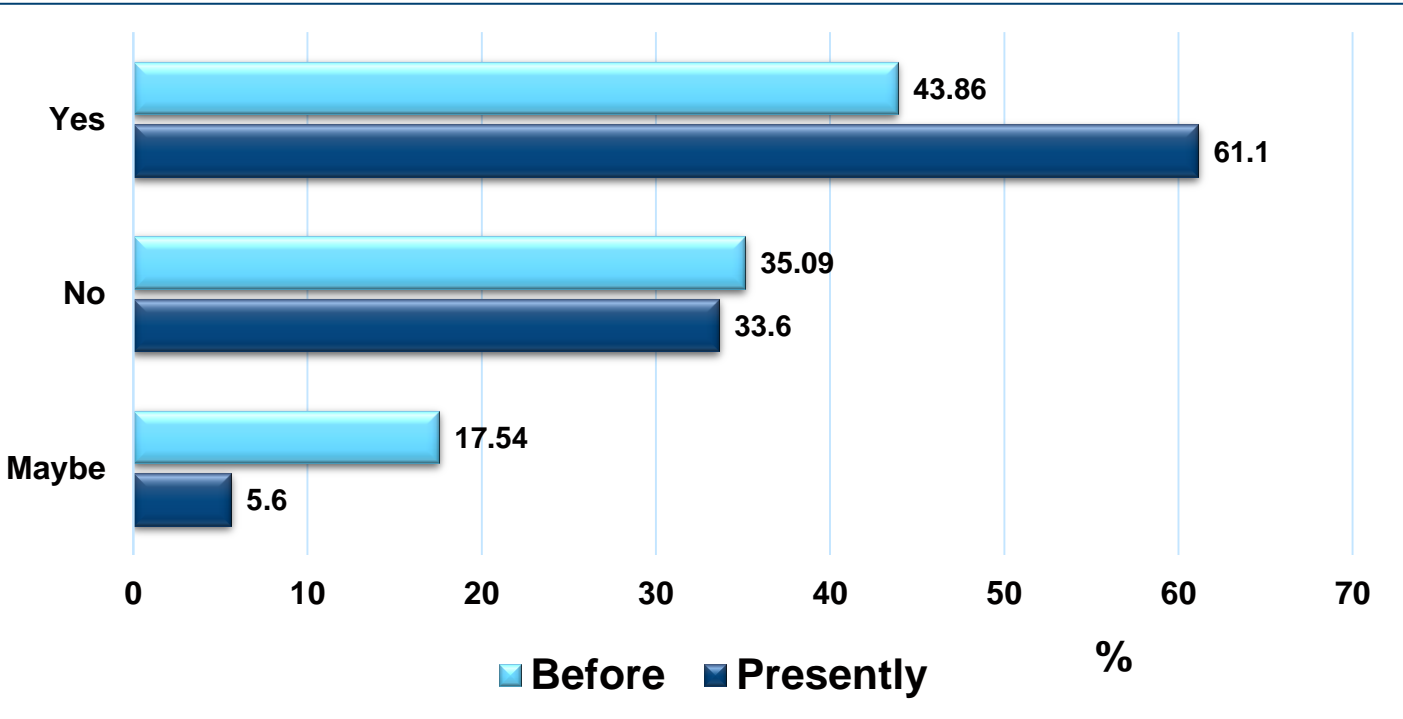
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Results on the care teams



Before and after results of professional's perception on APs



Before: Do you think these resource patients could be integrated into your clinic? (n = 61)
Currently: Are accompanying patients integrated into your team? (n = 18)



APs: A safety net



During the COVID-19 pandemic, physicians became aware of sub-optimal processes in place



The presence of the APs allowed for real-time feedback on dysfunctions, for example:

- More information on what to bring to surgery: APs provided the information
- Absence of relatives during consultations: request to be able to use the telephone to contact relatives

"It was very difficult during the COVID-19; we had to cut corners at times and we were aware that this had a significant impact on the patients. Fortunately, the APs were there to avoid catastrophes." - Physician



APs: a translator/broker



APs know the vocabulary of health care professionals and are able to explain it to patients



APs understand patients' emotions and questions and are able to explain them to professionals



They are bilingual!

" I see myself as a spokeswoman between the health care team and the patients. I feel like I am bilingual! I can speak the language of the patients and I understand the language of the professionals. I act as a bridge". - AP

APs: a continuous improvement agent



APs are invited to participate with staff to discuss patient experiences

APs are invited to participate in the program's continuous improvement committee

APs are asked to engage in discussions with managers



- APs reported that some physician behaviours were inappropriate and unsympathetic: behaviour changed within days
- APs reported that the informed decision was not being implemented: a committee was set up with PAs to review how treatment alternatives were presented
- APs reported that the trajectory of care was unclear: there was a complete redesign of the trajectory of care
- APs reported that patients need more time to discuss the illness and the treatment : education classes will be created, co-facilitated by APs and professionals



APs: a continuous improvement agent



"I want the APs to play an instrumental role in improving care. It is important that they share the aggregated stories of patient experiences with us physicians and soon the oncology program coordinating committee so that actions for improvement can be implemented." - Physician



APs: a caregiver



APs make a note in the patient's file



APs are in contact with nurse navigators



APs can contact the coordinator at any time to raise important information for health care professionals

- Difficulty sharing the news of the diagnosis with loved ones: psychological support provided
- Refusal of treatment: taking additional time to properly explain treatments

" Patients alert us to situations of which we are totally unaware and that can have a very significant impact on the patient's life. " - Physician

" I see every day how my work and that of the APs complement each other. They allow me to support patients even better." - Nurse navigator



APs: an instructor



Physicians in continuing education are required to complete practice self-assessment activities

They seek out APs to help them evaluate their practice

APs are also involved in the training of medical students and oncology residents

" In the context of our continuing education it is difficult to obtain credits for self-evaluation, the federation of medical specialists has recognized PAs as evaluators of our practices. This allows us to look for several experiences and not those of some of our patients. It also limits the risks for our patients of trying to please us!" - Physician



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Conclusion

Input from patient researchers



- Two patient co-researchers
- One principal patient co-researcher
- Included from the beginning of the application and to contribute to the drafting of the protocol
- Included in all stages of the project (development of the intervention, choice of measurement instruments, data collection, interpretation of the data, drafting of the guide, design and implementation of the training, dissemination of the data)
- Involvement in the follow-up of the project



Contributions of APs to quality of care



Are repositories of information that no one else has



Are able to report information in real time



Are able to have access to decision-makers and clinicians to challenge them on situations



Are able to have an impact on professionals emotionally to lead them to make changes quickly



Are able to create continuous improvement loops for the patient experience and process improvement (technical and relational) **FAST!**

APs are able to foster the 5Cs: **C**ompassion, deep **C**omprehension, **C**ritical mind, professional **C**onsciousness and **C**onfidence/Trust



Follow up for PAROLE-Onco



Scaling-up PAROLE-Onco+: 4 facilities sustain the project and implement it in another trajectory & 5 new facilities will deploy the program (Funded under the Oncopole pôle cancer call for projects of the Fonds de recherche du Québec - Santé (FRQS)).

In France

- the Assistance-Public Hôpitaux de Paris is interested to implement the program
- UNICANCER is also looking to implement it



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Thank you!

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