

WHY IS **PATIENT INVOLVEMENT** CENTRAL IN THE EUROPEAN CANCER MISSION ?

1st Meeting of OECI European Cancer Mission Working Party
October 3rd, 2018 - Brussels

Dr Dominique de Valeriola & Patrick Miqueu

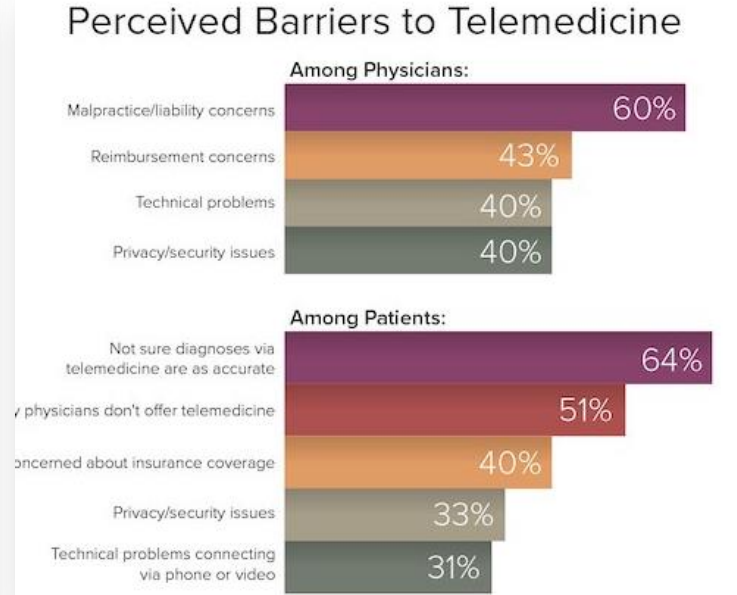
Chair of the **OECI Collaboration for Good Practices with Patients** Working Group (CGPP)

General Medical Director, **Institut Jules Bordet, Brussels**



Why is PI central in the Mission ?

1. Because we acknowledge and value that patients and professionals may have different perspectives



<https://www.medscape.com/features/slideshow/public/technology-in-medicine>



Why is PI central in the Mission ?

3. Because our patients are our best supporters



What is a Patient Research Ambassador?

<https://www.nihr.ac.uk/patients-and-public/how-to-join-in/patient-research-ambassadors/>



Why is PI central in the Mission ?

4. Because, nowadays, involving patients is mandatory to access funding



WHY ARE PATIENTS IMPORTANT TO IMI?

IMI recognises that patients can make a vital contribution to shaping research, make it more effective and more oriented to patient needs.

Therefore, IMI champions a patient-centric approach, encouraging all the projects that it funds to work in partnership with patients wherever possible.

IMI2 funding
2014-2020

€ 3.276 bn
TOTAL IMI2 BUDGET

see in detail



KCE
Belgian Health Care Knowledge Centre

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Patient and Public Involvement

The KCE Trials programme strongly recommends to have patients and public actively involved in the design of the study. This can include, for example, involvement in the choice of the research topic, choice of outcomes, assisting in the design, advising on the feasibility of the research etc.



The OECI CGPP WG

Our motto:

*Expanding **Patient Involvement** helps cancer centres increase the **quality** of Care, Research and Education*

Our Activities :

- We collect, share and value **experiences** of PI
- We support **projects** between OECI centres and patient org.
- We define **indicators** of success and update **standards**.

Our Concept:

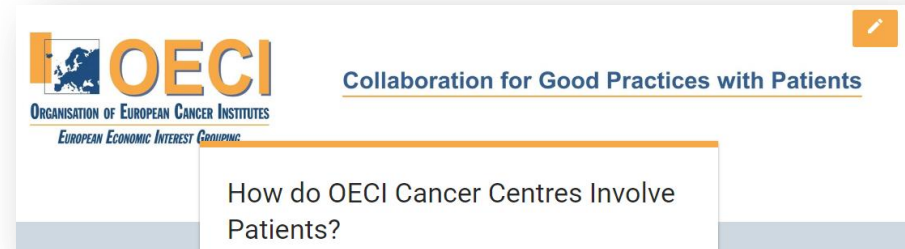
- Developed in partnership with ECPC



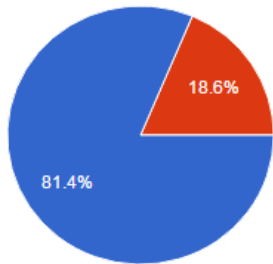
OECI centres truly involve Patients!

Survey : Mapping best practices in terms of PI and collaborations with Patient Organisations in OECI centres

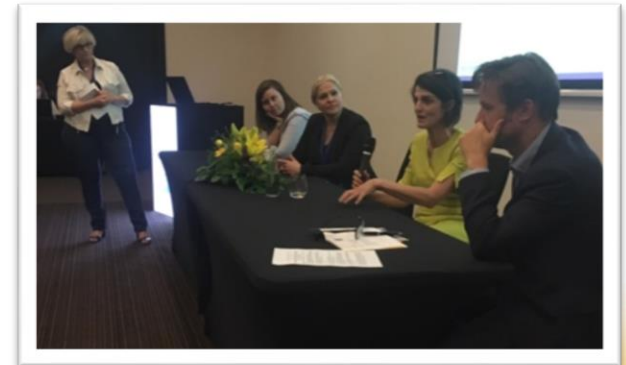
81% of OECI cancer centres involve patients in the design of services or the improvement of research.



- **May 2018**
- **Response rate (full members): 87%**
(all members): 78%



Projects
 Indicators Topics
 Collaboration ECPC
Patient Involvement
 Organizations
 Structuring
 Standards
 Sharing



Our Proposal for the Mission

1. Ask patients !

- Priorities in cancer research and healthcare should clearly stem from patients' reflections and needs
- The mission proposal should be written with patients!

2. Patient involvement is not a pillar but the cement between the stones

- Each pillar is driven by the patients' needs and calls for specific PI developments and initiatives.



WHY IS **PATIENT INVOLVEMENT** CENTRAL IN THE EUROPEAN CANCER MISSION ?

BECAUSE **COMPREHENSIVENESS** INTEGRATES:

Care

Research
Education

&

Patients' perspectives



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Thank you!

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