


INSTITUT JULES BORDET
 INSTITUUT

BAU2018
 18th ANNUAL CONGRESS
 BELGIAN ASSOCIATION OF UROLOGY
Orléans - La Hulpe/Orléans - 4 & 7 DECEMBER 2018


Patient Involvement: Opportunities and Challenges in Cancer Care and Research

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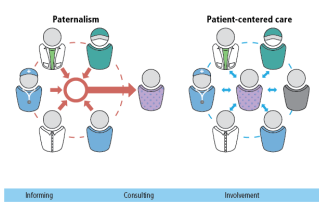


Outline

- Patient Involvement
- Opportunities
- A Model for Patient Involvement in Cancer Centres
- Patient Involvement in Research
 - 2 examples
- Challenges



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Patient Involvement



Not this one...

(Adapted from Comité sur les pratiques collaboratives et la formation interprofessionnelle 2013 - Québec)



Patient Involvement

...but, this one !



EUPATI Belgian Patient Forum (European Patients' Academy) October 27th 2018, Brussels



Patient-Centered Outcomes Research Initiative (PCORI) Conference 2015

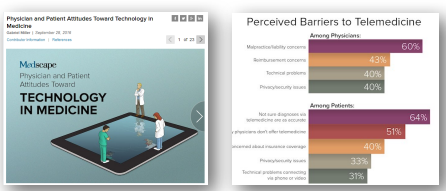



Comprehensive Cancer Center Patient Family Advisory Board (University of Michigan)


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Why Patient Involvement ? = Opportunities

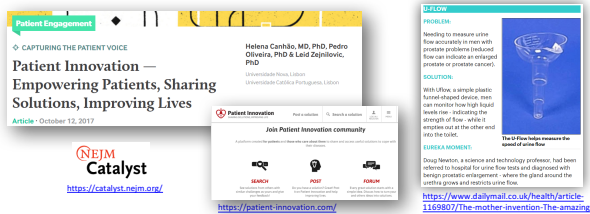
1. Because we **acknowledge** and **value** that patients and professionals have different perspectives






Opportunities

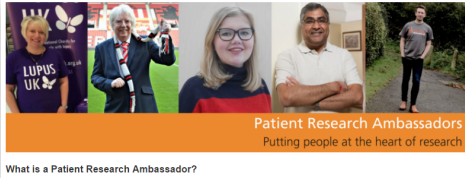
2. Because we need to promote **patient-driven innovations**




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Opportunities

3. Because our patients are our best supporters



What is a Patient Research Ambassador?
<https://www.nhr.ac.uk/patients-and-public/how-to-join-in/patient-research-ambassadors/>



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Opportunities

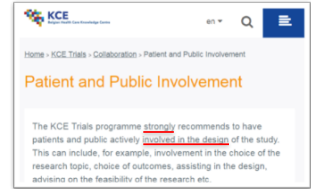
4. Because, nowadays, involving patients is mandatory to pretend to any funding



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.

€3.276 bn



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A Patient Involvement Model



OECI
 Organisation of European Cancer Institutes
 European Cancer Patient Coalition

Non-governmental organisation
 87 cancer centres across Europe

EUROPEAN CANCER PATIENT COALITION

400 members
 Europe's largest umbrella cancer patients' association
 400 members - 28 EU

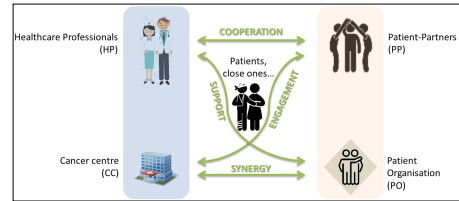
- Accreditation and Designation Program
- Improving quality of cancer care and research
- Quality standard for patient empowerment



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OECI-ECPC model



Principles of Collaboration to Achieve Patient-Centeredness in Cancer Care And Research. Miquèu P, Florindi F, De Lorenzo F, Makaroff L, de Valeriola D. (Submitted)



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OECI-ECPC model

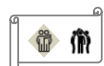
Partnerships around local projects



Organisational tools



Convention of partnership between Local Patient Org. and Cancer Centre



Membership application Patient-Partners joining Local Patient Org



Engagement Program run by the Cancer Centre for Patient-Partners

Models of Collaboration to Achieve Patient-Centeredness in Cancer Care And Research. Miquèu P, Florindi F, De Lorenzo F, Makaroff L, de Valeriola D. (in preparation)



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OECI-ECPC model

OECI centres truly involve Patients!

Survey: Mapping best practices in term of Patient Involvement and collaborations with Patient Organizations 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%



Organisation of European Cancer Institutes

OECI General Assembly - Proposal - June 22, 2018 - OECI40

Results

In which activities are Patient-Partners involved?

92%: Improving the support to patients and patients' relatives
 75%: Improving the organization of care or care itself
 56%: Improving administrative processes
 54%: Working on the centre's corporate image and values
 52%: Collaborating for the improvement of research
 28%: Staff training
 21%: Other

Reading any news to be communicated to patients + Planning and organizing patient education activities + Participation in Tumor Boards, Etc.




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Patient-Partner

The Patient-Partner is not the « *Empowered Patient* »





Empowerment: "a process through which people gain greater control over decisions and actions affecting their health" (WHO 1998)

Patient-Partners inspire and support the change in the Institution.

"Characteristics":

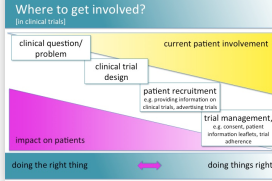
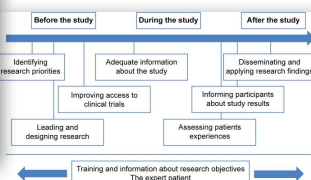
- Experience with the « life with the disease »
- Able to take some « distance » from their personal situation and history
- Motivated to improve the healthcare service/research
- Experience of being treated in the Institution
- Volunteer (having time, available for meetings...)
- Member of patient organization(s) (*optional*)



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Patient Involvement in Research

Where to get involved? (in clinical trials)

From the EUPATI toolkit <https://www.eupati.eu/>

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Patient Involvement in Research

- 2 examples:
 - **Involving Patients to develop a Decision Support Tool to Consent to Clinical Trials**
Institut Jules Bordet – Les Amis de l'Institut Bordet (Patient Org.)
 - **How to settle a Patient Advisory Group in Research ?**
Institut Jules Bordet (Brussels) – Institut Paoli Calmettes (Marseille) – Centre Oscar Lambret (Lille)

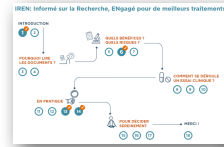




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Patient Involvement in Research

IREN: Decision Support Tool to Consent to Clinical Trials

- Interactive tool with 18 videos and animations (22')

Available in FR, NL and EN

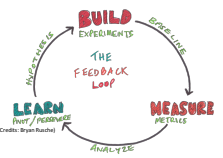



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Patient Involvement in Research

IREN: Decision Support Tool to Consent to Clinical Trials



- Patients recruited through the IJB « **Patient & Partner** » program and the support of Les Amis.



Working Group

- 3 oncologists (investigators)
- 4 clinical study coordinator
- 1 patient
- 1 patient relative
- 1 psychologist
- 1 ethicist
- 1 project leader


IREN: "Informed on Research, Engaged for better treatments"



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Patient Involvement in Research

Oncodistinct Patient Advisory Panel



- Advisory group of patients "trained" in clinical research and available to :
 1. Review and provide opinions on research protocols under development
 2. Proofread patient information documents and consent forms
- Mutualized resource shared by Oncodistinct members

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Patient Involvement in Research
Oncodistinct Patient Advisory Panel

<http://www.oncodistinct.net>

Local PI Officer : Martine Bouyssie (in progress)

Local group: Patrick Miqueu PISARO Group

Local group: Nicolas Penel (in progress)

Oncodistinct Patient Advisory Panel

Patients (in Patient Committees) interested and trained in Clinical Research

- Local or virtual meetings
- Support for "lay" presentation
- Meth. for collection of patient opinions

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Challenges
 SYSTEMATIC REVIEW

Patient and public involvement in the design of clinical trials: An overview of systematic reviews

Price et al. 2017 (J Eval Clin Pract)

*Challenges identified include lack of clarity within common language, roles, and research boundaries, while **logistical needs** include extra time, training, and funding. Researchers report struggling to report involvement and avoid tokenism.*

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Thank you!

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