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

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**

Patient Involvement

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Patient Involvement
Opportunities

3. Because our patients are our best supporters

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

A Patient Involvement Model

Non-governmental organisation of cancer centres across Europe

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

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

OECI-ECPC model

Partnerships around local projects

Organisational tools

Cancer centres
Local Patient Organisation
Healthcare Professionals (PH)
Patients, carers and Partners

OECI-ECPC model

OECI centres truly involve Patients!

In which endpoint are Patient Partners involved?

- Patient Partners involved in 100% of OECI centres
- 25% or more of the total sample
- 50% or more of the total sample
- 75% or more of the total sample

Results

OECI centres truly involve Patients!
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)

“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)

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

Patient Involvement in Research

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

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)

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

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

Working Group

- 3 oncologists (investigators)
- 1 patient
- 1 patient relative
- 1 psychologist
- 1 ethicist
- 1 project leader

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

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
Patient Involvement in Research
Oncodistinct Patient Advisory Panel

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

Challenges

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!