Towards a Joint Declaration

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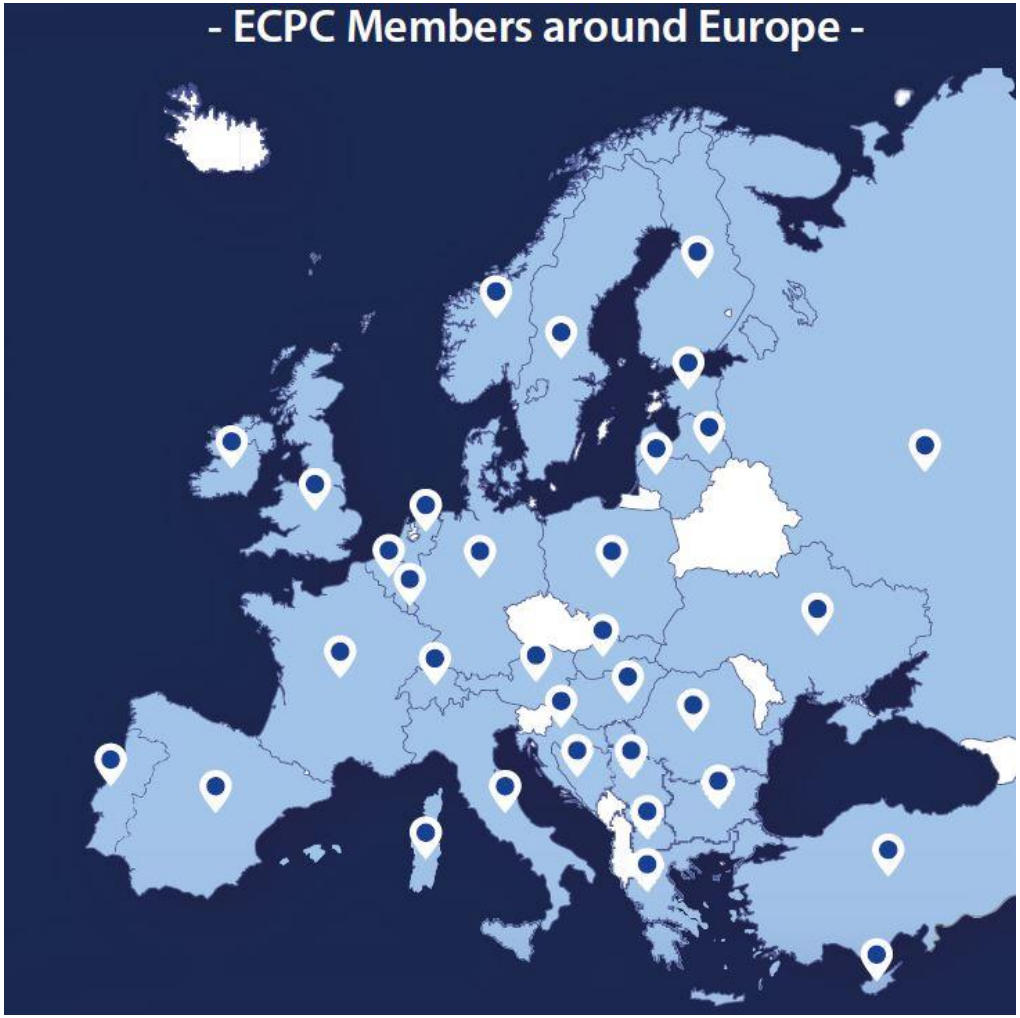
ECPC / OECI Annual Meetings
Brussels, June 4th and June 17th, 2016

What is the Organisation of European Cancer Institutes (OECI)?

- Non-governmental organisation
- 70 cancer centres across Europe
- Founded in Vienna in 1979
- ***Brings together the cancer research and care institutions throughout Europe***
- Accreditation and Designation Program
  - Improving quality of cancer care and research
  - Reducing inequality of care
  - Specific topic in Accreditation on quality standard for patient empowerment

OECI Network & ECPC Membership



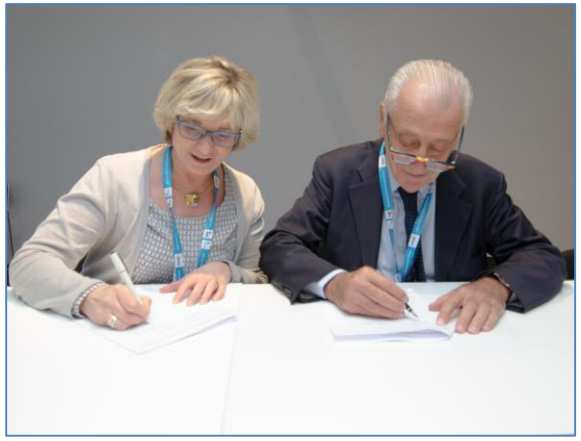
ECPC and OECI Affiliates

Countries where we both have members:

- Austria
- Belgium
- Croatia
- Czech Republic
- Denmark
- Estonia
- Finland
- France
- Germany
- Hungary
- Italy
- Lithuania
- Norway
- Poland
- Portugal
- Romania
- Russia
- Serbia
- Slovakia
- Slovenia
- Spain
- Sweden
- The Netherlands
- Turkey
- Ukraine
- United Kingdom

ECPC – OECI
Memorandum of Understanding (MoU)

- ECPC and OECI together represent those who work to cure cancer everyday.
- Main idea: consolidate collaboration between ECPC and OECI and their members
- Agreement signed in September 2015

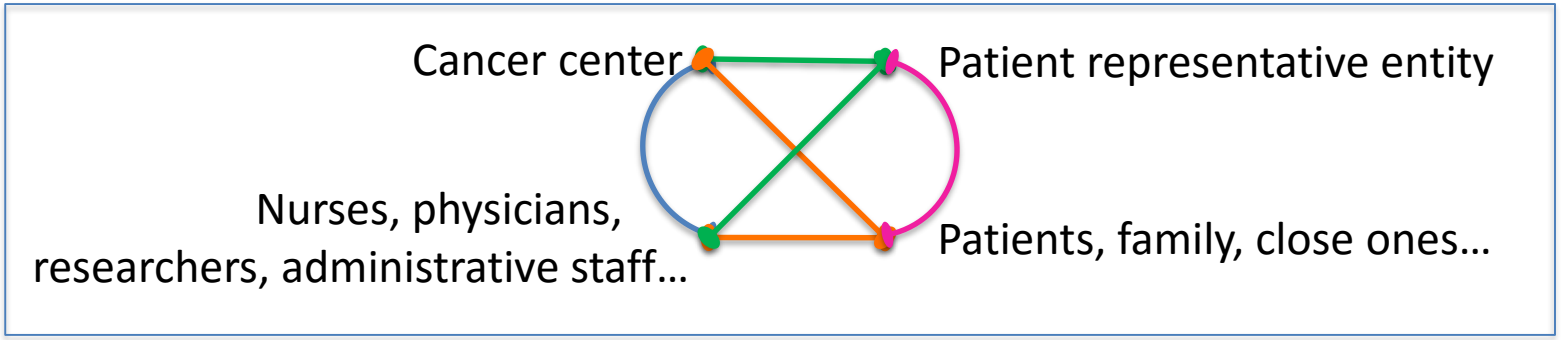


The Joint Declaration: 1st outcome of the MoU

ECPC and OECI **collaborate** to produce a **joint document**

Innovative, in its content and form

Shaping the **relationships** between stakeholders



Why a Joint Declaration?

Examples of existing documents

- **Charter**:
  A written instrument or contract executed in due form… a *document that gives rights and obligations…*

=> To protect, guarantee rights and empower individuals or organisations

- **Testimony**:
  A solemn declaration…

=> Individuals or organisations expressing commitments in order to communicate on their *principles* and *values*.

Why a Joint Declaration?

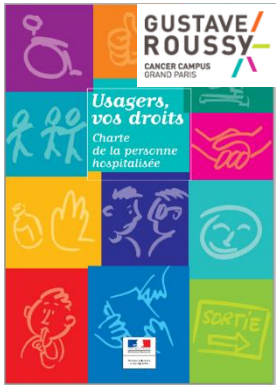
Examples of existing documents

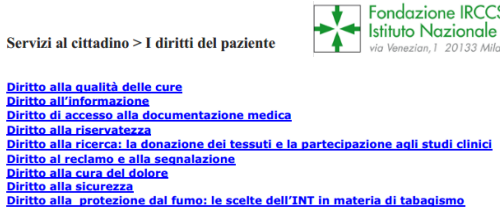
A Bill of Rights for patients with cancer in Europe

THE LANCET Oncology

Mark Lawler, Thierry Le Chevalier, Ian Banks, Pierfranco Conte, Francesco De Lorenzo, Françoise Meunier, H M Pinedo, Peter Selby, Martin J Murphy, Patrick G Johnston, on behalf of the European Cancer Concord (ECC)†

OECI centers' patient charters





Why a Joint Declaration?

A Joint Declaration that refers to ECPC and OECI Members:

1. *Supporting the common vision and shared values of ECPC and OECI*
2. *Increasing collaboration of OECI and ECPC Members*
3. *Taking into consideration the European context (Cross Border Healthcare Directive)*
4. *Avoiding redundancy with existing documents*
5. *Adapted to the national contexts: highly heterogeneous, multicultural…*

Why a Joint Declaration?

From Charters and Testimonies to a Joint Declaration

- Joint Declaration:
  - **General principles + practical examples to increase cooperation between ECPC and OECI Members**
  - On « **Good Relational Practices** » (like GLPs, GCPs)
  - On favorable «Attitudes »
  - On « Partnering »
  - …
- ⇒ Promoting:
  - ⇒ **Dialogue,**
  - ⇒ **Mutual Comprehension,**
  - ⇒ and **Actions!**

ECPC & OECI
Joint Declaration

Patients, nurses, family members, doctors,

1. *We* are convinced…
2. *We* are guided…
3. *We* acknowledge…

Building meaningful relationships that last!

Joint Declaration: Step-by-step

- First brainstorm: **February 2016**
  - With ECPC and OECI leadership
- **Spring 2016**: ECPC and OECI staff worked on the conceptual framework
- **June 2016**: framework presented to the ECPC and OECI Members
  - During our respective Annual Meetings, we will collect feedback from our members.
- **Autumn 2016**: publication of the Joint Declaration

Joint Declaration: Dissemination

- The Joint Declaration (framework)
  - "Visual document": Relationships' map
  - Orientation of the document: Main principles
- Examples and Best Practices
  - Collected from ECPC and OECI members' experience
  - On various topics
- Publication
  - Analysis and guideline of the process of creating the Joint Declaration

Joint Declaration: The Framework

Aim : **Developing « Good Relational Practices » in Cancer Care and Research**

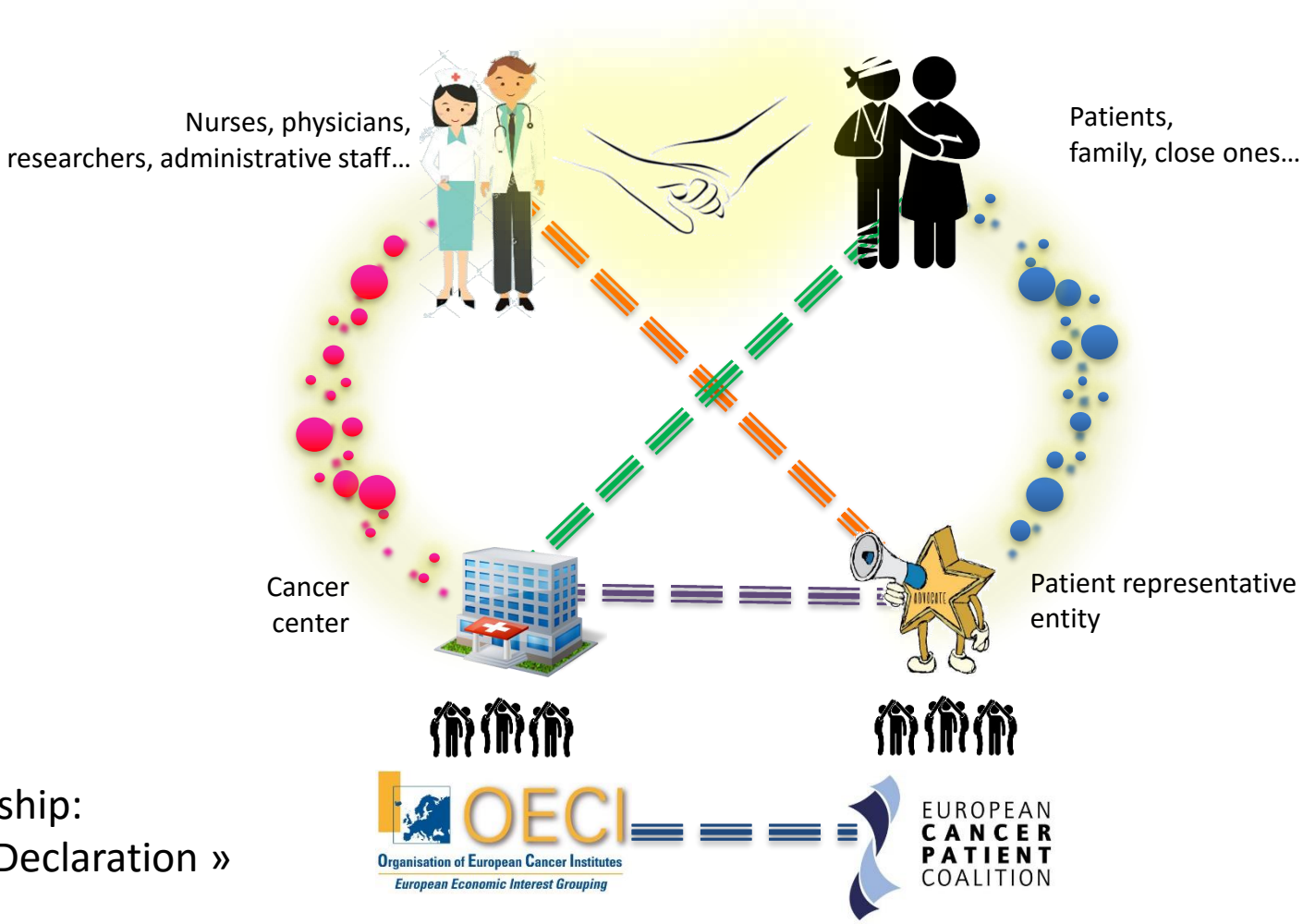
In order to :

Benefit the **patients' experience**

Strengthen the whole **web** of relationships

with practical solutions !

Joint Declaration: The Framework

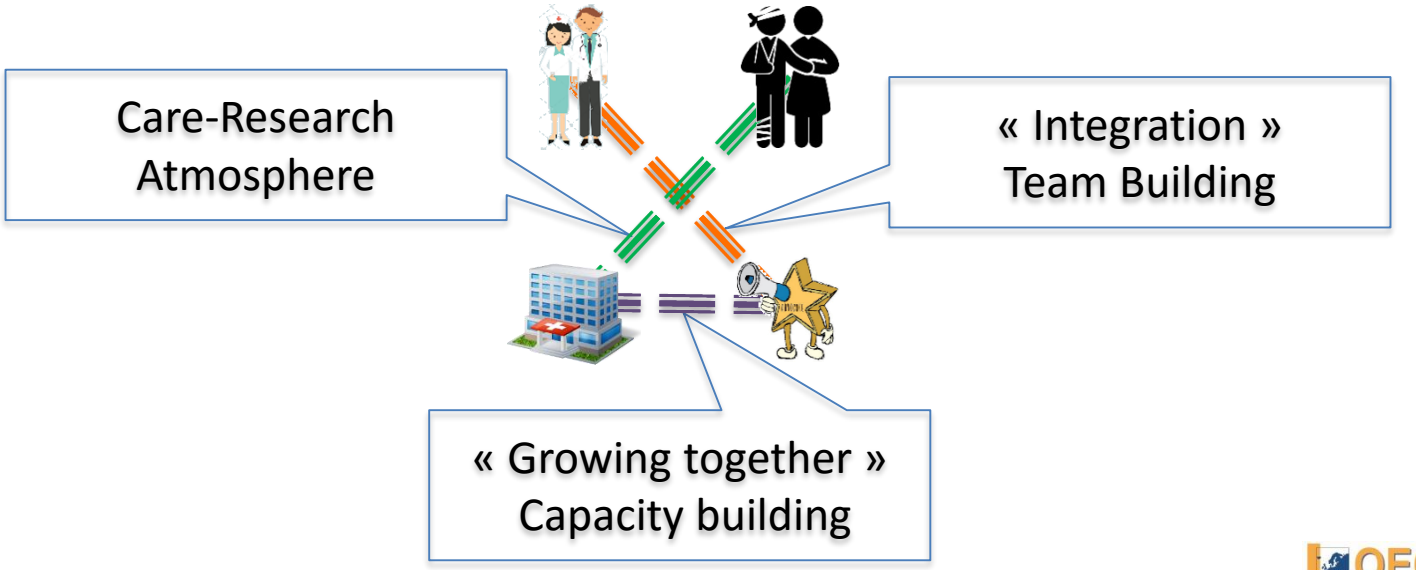


Partnership:
« Joint Declaration »

Joint Declaration: Building Relationships

- Focus on **3** relationships, and *inspire the change*!
  - Patient association – Cancer center
  - Patients and relatives – Cancer center
  - Patients associations – Healthcare professionals

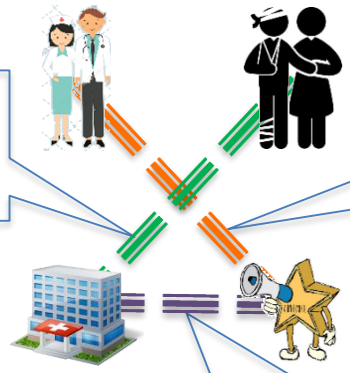
- **3** paths of improvement :



Joint Declaration: Building Relationships

Care/Research Atmosphere

« Integration » Team Building



« Growing togethter » Capacity building

An environment open to dialogue

Institutes proactively seeking the scrutnity of the patients and their needs

Promoting Extra-Care/Research activities by with patients and families

…

What does it mean for a Cancer center and for a Patient association « to grow »?

Reflecting about their roles in the Society…

Finding Synergies

…

Developing our roles in the Care and Research tasks…

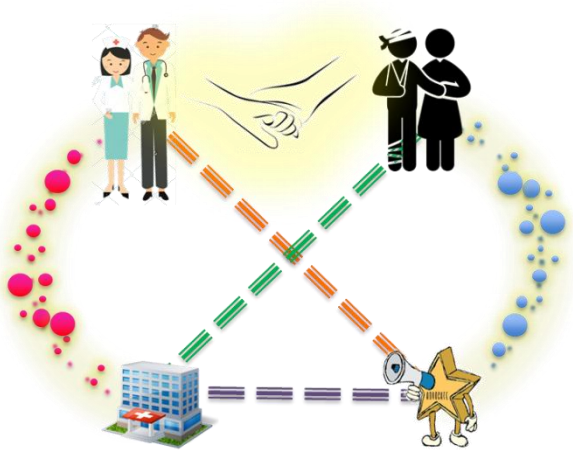
Feedbacks, sharing information, thoughts and emotions!

Say it differently!

…

Impact on the other Relationships

A new form of relationship, focused on the care, but expanded in other dimensions
…



Example:

Initiating a Corporate Social Responsibility program…

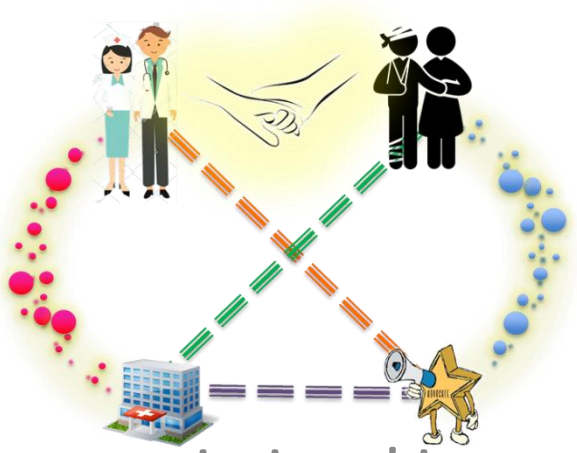
…

New tools to communicate, interact, educate and provide guidance and care….

Inspired “Best Practices”

- Examples of “Best Practices” will be an integrated part of the Joint Declaration!

- Some initial topics are foreseen:
  - Informed consent
  - Survivorship
  - Clinical trials
  - Training and integration of patients associations’ in cancer institute
  - Patients’ experience



Examples of Best Practices

- Informed consent
  - PROBLEM: Informed consent forms are too complicated and not enough informative
  - KEY QUESTIONS
    - Who produces the informed consent forms within the cancer institutes?
    - Are patients involved in the drafting?
    - How can cancer institute and patients organisation collaborate to write better informed consent?
    - Can patients play a role in explaining the informed consent to patients?

Examples of Best Practices

- Survivorship
  - PROBLEM: Cancer patients are poorly monitored after the acute treatment
  - KEY QUESTIONS
    - Is there a space in the cancer institute where cancer patients can seek specific support for their survivorship care?
    - Are there cancer survivorship care plans?
    - What is the role of patients' associations in counselling survivors? Are they integrated in the survivorship care?

Examples of Best Practices

- Clinical trials
  - PROBLEM: cancer patients do not know enough about clinical trials
  - KEY QUESTIONS
    - Can cancer patients discuss their concerns about CTs?
    - Who can explain how CTs work to cancer patients?

Examples of Best Practices

- Training of cancer patients advocates
  - PROBLEM: cancer patients' associations can help a lot, but their advocates and volunteers might not know enough
  - KEY QUESTIONS
    - What should be rights and duties of cancer patients advocates working in the cancer institute?
    - Who can train patients advocates to work better within the cancer institute?
    - Can we define some general requirements for cancer patients organisations' training (respecting national rules and cultural differences)?
    - What kind of agreement should be in place between the patients' association and the cancer institute?

Examples of Best Practices

- Patients' experience
  - PROBLEM: patients go to best hospital for care, but their wellbeing is often not taken in due consideration.
  - KEY QUESTIONS
    - Are the hospital's spaces comfortable (seats, lightning and colours of the rooms…)
    - Is the hospital easy to access? Are there architectural barriers? Is it easy to move around the hospital?
    - Can patients communicate easily with the outer world (phone, internet, wifi)?
    - Are waiting times acceptable?
    - Does the hospital participate to the life of the local society (organisation of public events, open days, concerts…)

We need your help!

- What is your experience working within a cancer institute?
- How do you collaborate with oncologists and nurses?
- Do you have best practices showing good collaboration between patients and cancer institutes?
- What do you expect from the cancer institute? What can be improved in the three relationships we identified?

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