

OEI2022 ONCOLOGY DAYS

16:30

18:30

Collaboration for Good Practices with Patients WG Session

**Moving from Patient Involvement to
Co-Creation with Patients**

Chairperson: Dominique de Valeriola, Institut Jules Bordet, Brussels



Collaboration for Good Practices with Patients WG Session

Moving from Patient Involvement to Co-Creation with Patients

June 15th

Hotel Primus

Room:
Opera

- 16.30 **Introduction**
Dominique de Valeriola
- 16.45 **Patient Involvement 2.0: the Karolinska experience**
Eva Jolly and Yvonne Wengstrom
- 17.05 **Canadian experience of patient partnership in quality improvement**
Marie-Pascale Pomey
- 17.25 **Co-creation approach at Institut Jules Bordet with patients-experts, artists and professionals**
Patrick Miqueu
- 17.45 **The point of view of co-creation from a patient organization**
Bettina Ryll
- 18.05 **Discussion**



OEI Collaboration for Good Practices with Patients (CGPP) Working Group

Our motto:

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

Our activities :

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

... in collaboration with patient organisations

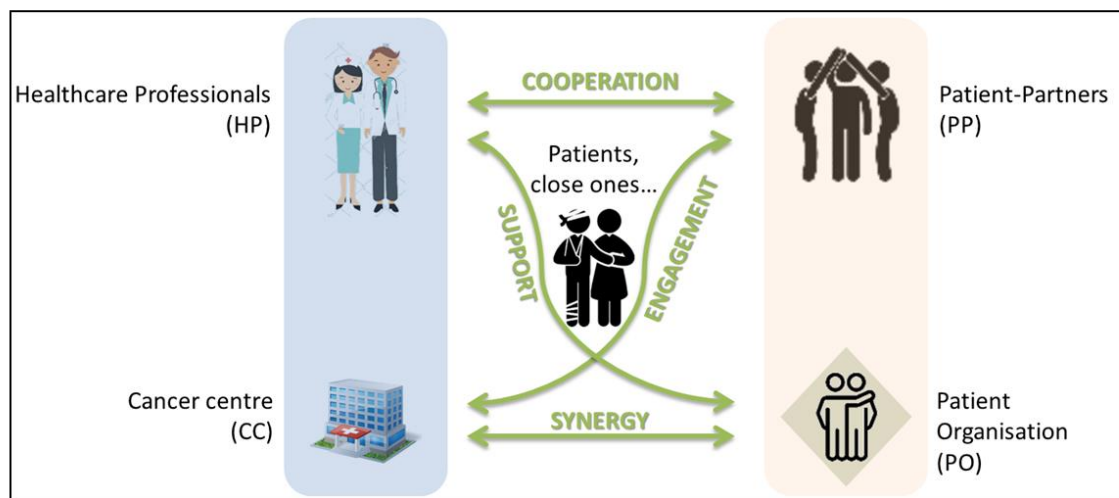
Milestones

- OECI-ECPC partnership Feb. 2016
- Framework for collaboration @ECCO17 Jan. 2017
- CGPP WG launch @OncoDays39 - Brno June 2017
- Survey on PI and Coll. with Patient Orgs. April 2018
- CGPP mini conference @OncoDays40 – Poznan June 2018
- First OECI #PatientDay in Bari June 2019
- Slowdown < 2020 (COVID-19 crisis)



OECI-ECPC Partnership 2017

Patient involvement in cancer centers



Principles and Model of Collaboration to Achieve Patient-Centeredness In Cancer Care And Research. Miqueu P, Florindi F, De Lorenzo F, Apostolidis K, de Valeriola D.

Partnerships around local projects



Organisational tools



Patient Involvement Survey 2018



The screenshot shows an email invitation from OEI. The header includes the OEI logo and the text 'Collaboration for Good Practices with Patients'. The main body of the email asks for patient involvement survey participation, explaining the purpose of the survey and providing contact information for the CGPP team. A required field for an email address is visible at the bottom.

OEI
ORGANISATION OF EUROPEAN CANCER INSTITUTES
EUROPEAN ECONOMIC INTEREST GROUPING

Collaboration for Good Practices with Patients

How do OEI Cancer Centres Involve Patients?

Dear colleague, dear friend,

The OEI CGPP working group aims at sharing and encouraging best practices in place in OEI cancer centres, in terms of patient involvement and collaboration with patient organizations.

May we kindly ask you to answer this survey?

The data collected will be treated according to strict confidentiality rules, and results will be presented during the OEI Oncology Days in Poznan, on June 21th 2018.

Thanks for your support,
The CGPP team

**Required*

Email address *

Your email address



OEI centres truly involve Patients!

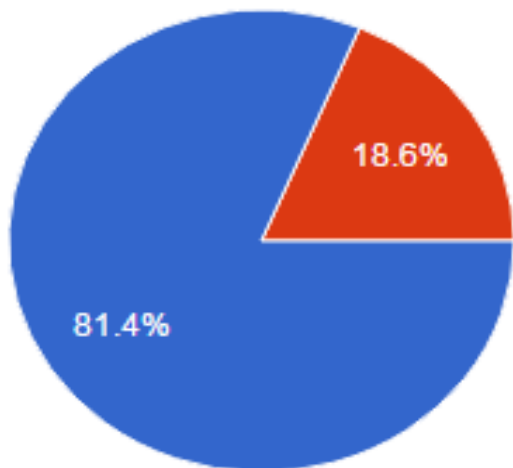
Survey : Mapping best practices in term of Patient Involvement and collaborations with Patient Organizations in OEI centres

- **May 2018 – 59 responders**
- **Response rate :**

All members	n = 76:	78%
Full members	n = 61:	87%
Associate members	n = 15:	40%



N=59



81% of OEI cancer centres involved patients in the design of services or the improvement of research

Only 2 CC had no plan to involve patients in the future



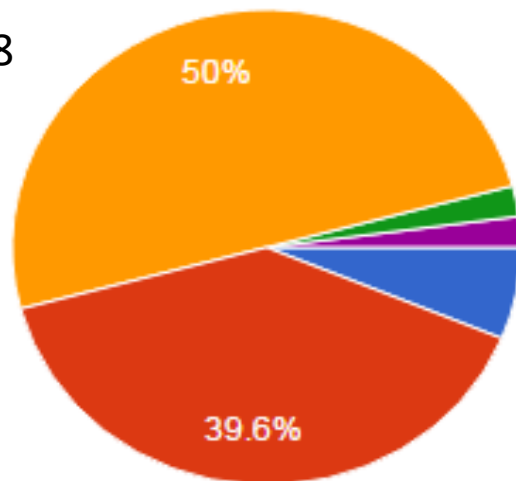
Results of Survey 2018



Institutional change

Did patient involvement produce a change in your institution?

N=48



- Not yet
- Yes, but only minor changes
- Yes, clear changes!
- Since we don't set up specific indicators of performance to assess the impact of patient involvement in projects, we can't yet measure the possible change.
- Very difficult to give precise figures

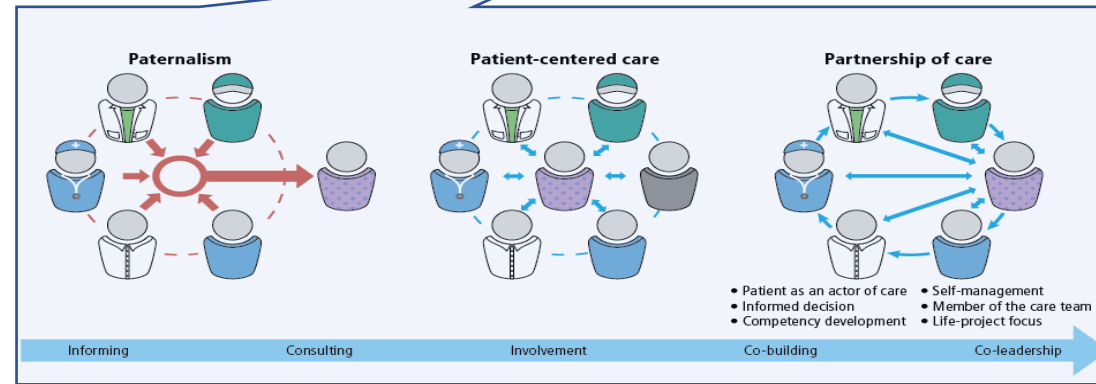


3 Priority Fields for PI

Research

Quality of Care

Survivorship



EUROPEAN CANCER PATIENT COALITION

ESMO-ECPC Cancer Survivorship Guide & Cancer Survivorship Plan
A unique care and cancer advocacy tool

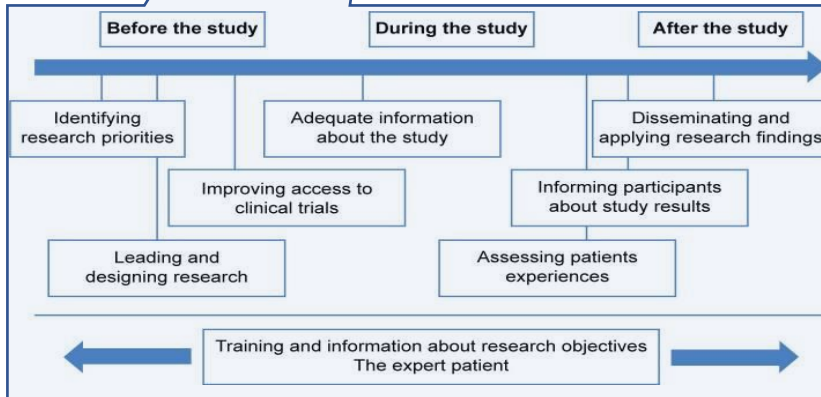
Kathi Apostolidis - ECPC Vice President
 Hellenic Cancer Federation - ELLOK President
 European Cancer Patient Coalition - Annual General Meeting, 7-9, 2018 - Brussels

ECCO2018 | 7-9 September 2018
 EUROPEAN CANCER SUMMIT

#ECCOSummit Session Highlights
Survivorship: The next frontier of cancer care improvement

Speakers include:
 Prof Françoise Meunier, EORTC
 Dr Marie Mianil, University of Rennes
 Sarunas Narbutas, Youth Cancer Europe
 Janette Rawlinson, Cancer Survivor & Patient Advocate

(EUPATI Toolbox
<https://www.eupati.eu/>)



(Source: Comité sur les pratiques collaboratives et la formation interprofessionnelle 2013 - Québec)



1st OECI #PatientDay in Bari - June 2019

Objectives

- Enhance Patient Involvement Visibility both internally & outside OECI
- Promotion of the OECI model of PI
- Sharing of experiences & building collaborations
- Show fruitful collaborations with patient organisations

Organisation of the #PatientDay

- Abstract submission process (19 abstracts received for presentation)
- Peer-reviews (5 reviewers)
- 11 abstracts selected and published in Tumori





122 registrations and around
100 attendees

CGPP WG Governance - Steering Committee

Country	Center name	First name	Last name	Function
Austria	Comprehensive Cancer Center Graz	Gerald	Sendlhofer	Leiter der Geschäftsstelle Comprehensive
Austria	Comprehensive Cancer Center Vienna	Natalija	Frank	Coordinating Manager for Patient & Care
Belgium	Kankercentrum Brussel	Mark	De Ridder	
Belgium	Institut Jules Bordet (IJB)	Patrick	Miqueu	Coordinator Patient Collaborations
Belgium	Institut Jules Bordet (IJB)	Dominique	de Valeriola	General Medical Director
Belgium	AZ Groeninge	Philip	Debruyne	Lead Clinician
Croatia	Klinika za tumore - Klinicki bolnicki centar Sestre milosrdni	Iva	Kirac	Surgical Oncology
Denmark	Kræftens Bekæmpelse - Center for Kræftforskning	Laila	Walther	head of Patient support
Denmark	Kræftens Bekæmpelse - Center for Kræftforskning	Bo	Andreassen Rix	
Denmark	Vejle Sygehus, Patienternes Kræftsygehus en del af Sygehu	Anne	Skov Villadsen	Senior Consultant
Estonia	North Estonia Medical Centre	Vahur	Valvere	Head of Oncology and Haematology Clin
Estonia	Sihtasutus Tartu Ülikooli Kliinikum	Mari-Leen	Varendi	Quality Manager
Finland	TYKS Syöpäkeskus	Mervi	Siekinen	PhD, Development manager
Finland	Tampereen Yliopistollinen sairaala	Anne	Kairenius	Projektiassiamies/Syöpäkeskus-hanke
France	Centre Léon Bérard	Irène	Philip	Contact
France	Centre Léon Bérard	Amine	Belhabri	président de la commission des usagers
France	Centre Léon Bérard	Nathalie	Blanc	Responsable Communication
France	Gustave Roussy	Anne	de Jesus	coordonnatrice des relations patients
France	Institut Curie	Sophie	Oger-Hodge	Quality Director and Risk Management
France	Institut Paoli-Calmettes	Martine	Bouyssie	Head of the Quality Department
France	Centre François Baclesse (Caen)	Laurence	Picard	Head of Quality & Risk Management Dep
France	Institut Universitaire de Cancérologie APHP	Joseph	Gligorov	
France	Institut Universitaire de Cancérologie APHP	Diariétou	Ndiaye Gueye	Medical Coordinator
Germany	Deutsches Krebsforschungszentrum (DKFZ)	Stefan	Frohling	
Germany	Charité Comprehensive Cancer Center	Cornelia	Grosse	Coordinator
Hungary	Országos Onkológiai Intézet	József	Lövey	Medical Director
Hungary	Országos Korányi TBC és Pulmonológiai Intézet	Krisztina	Bogos	Contact (osztályvezető főorvos)
Ireland	Trinity St. James's Cancer Institute	Maria	Kane	Quality Manager-Person Centred Care
Italy	Centro di Riferimento Oncologico Istituto Nazionale Tum	Ivana	TRUCCOLO	head, Scientific & Patients Library
Italy	Istituto Tumori Giovanni Paolo II, Istituto di Ricovero e C	Angelo	Paradiso	Director of Experimental Oncology
Italy	IRCCS Azienda Ospedaliera Universitaria San Martino - IS	Simona	Morganti	Company contact person Public Relation
Italy	Istituto Europeo di Oncologia	Pier Luigi	Deriu	Head Officer Quality and Accreditation (f
Italy	Istituto Nazionale Tumori -IRCCS "Fondazione G.Pascale"	Gianfranco	De Feo	Contact
Italy	Istituto Nazionale Tumori Regina Elena	Gaetana	Cognetti	Librarian
Italy	Istituto Nazionale Tumori Regina Elena	Stefano	Canitano	Medical Radiologist
Italy	Istituto Nazionale Tumori Regina Elena	Gennaro	Ciliberto	Scientific Director
Italy	Ospedale San Raffaele (OSR)	Rita	Piccolo	Ms
Italy	Istituto Oncologico Veneto IRCCS-IOV	Silva	Mitro	Contact
Italy	IRCCS, Centro di Riferimento Oncologico della Basilicata (I	Giovanni	Storto	Contact
Italy	Istituto Scientifico Romagnolo per lo Studio e la Cura dei	Marna	Bernabini	Quality Manager
Italy	Azienda Unità Sanitaria Locale di Reggio Emilia - IRCCS Ist	Elena	Cervi	Medical Library and Patient Library-Resp
Italy	Azienda Unità Sanitaria Locale di Reggio Emilia - IRCCS Ist	Maria Chiara	Bassi	Director of Medical Library and Patient L
Italy	IRCCS Istituto Clinico Humanitas	Pamela	Ferrari	Patient Experience Servizi Clienti
Italy	IRCCS Istituto Clinico Humanitas	Alexia	Bertuzzi	Oncologist Head of Sarcoma section
Italy	Istituto di Candiolo FPO-IRCCS	Piero	Fenu	Medical Director

CGPP Steering committee :

- Chairperson: Dominique de Valeriola
- Coordinator: Patrick Miqueu
- Member: Martine Bouyssie (IPC Marseille, France)
- Member: Chiara Ariotti (Humanitas Milano, Italy)
- Member: Ambi Williams (Kings' Health Partner London, UK)

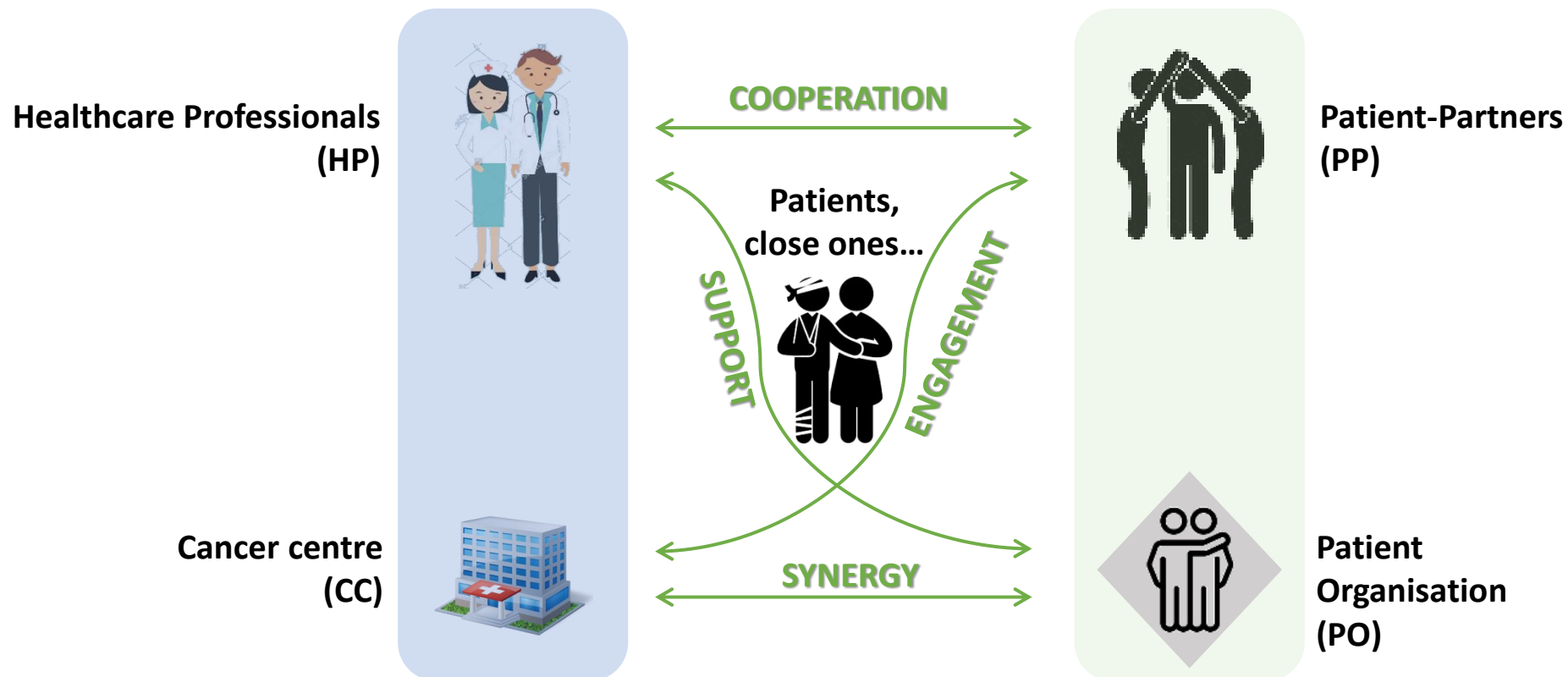
CGPP contact list (as of 2019)

62 OEI members

167 contacts



OEI Model of Patient Involvement 2017

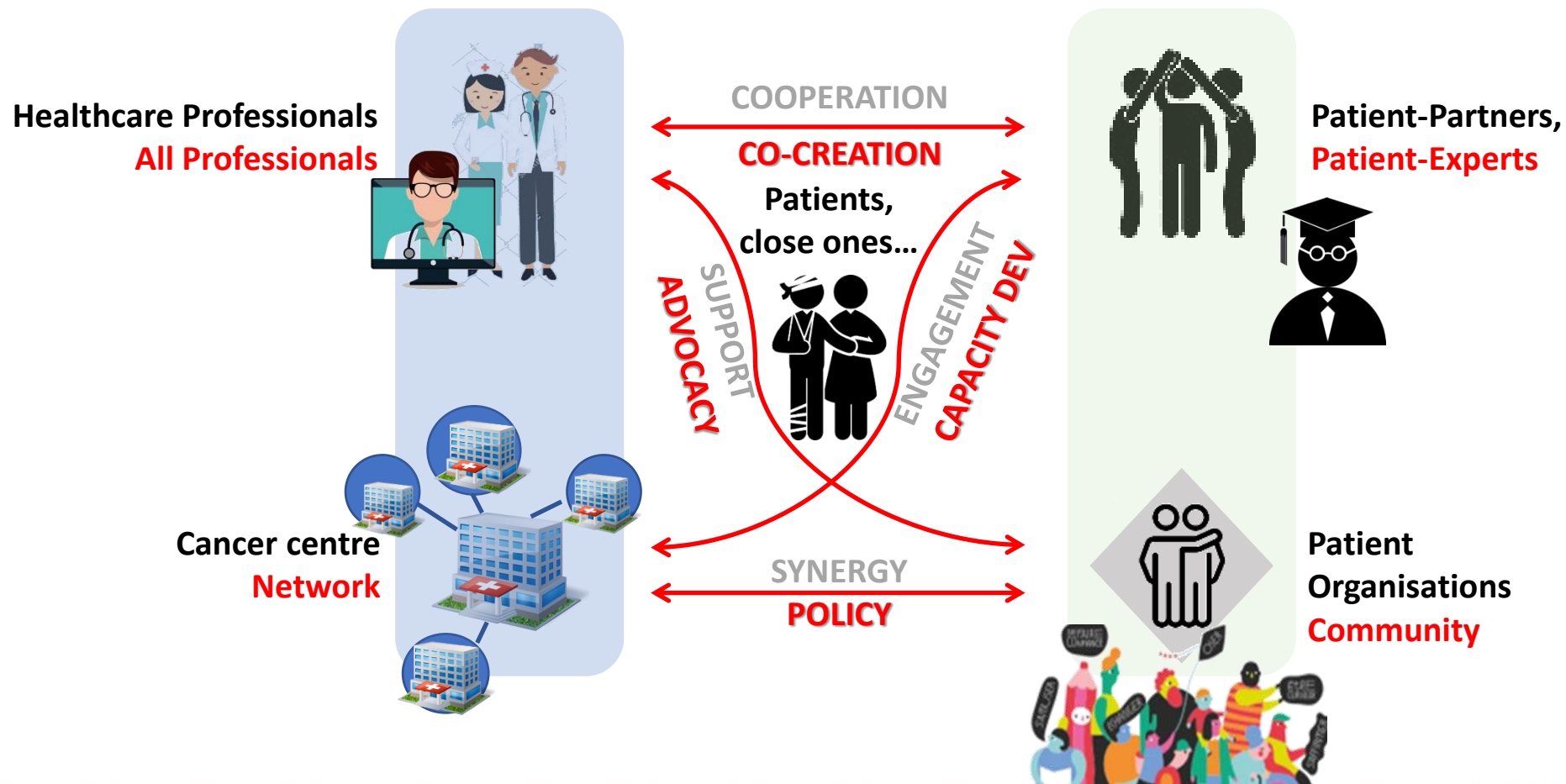


Conceptual framework for successful collaborations between individuals and organisations in CC

Organisation of European Cancer Institutes - EEIG



OEI Model of Patient Involvement 2021



Virtual Milan OncologyDays 2021 – CGPP session

Based on the Call of abstracts organised for the 2nd edition of OECI PATIENT DAY (planned in Helsinki but cancelled)

Just a session of 1 hour, not a one-day conference

Contributions from professionals and patient advocates concerning the promotion of the patients' perspective into professionals' activities and projects

30 abstracts received, reviewed and scored by 9 experts
9 abstracts selected

10.00 **Rebuilding on the successful experiences of patient** 11.00 **involvement**

For OECI centres, patients are bringing a different and valuable perspective to the quality improvement process in hospitals by expressing their special needs and priorities. A true alliance of patient involvement and quality assessment in cancer centres and networks will be key to rebuild a more resilient and humanistic healthcare system.

10.00 **Patient Involvement: OECI Centres' Greatest Asset for Quality**
Dominique de Valeriola

10.05 **Patient Engagement in the Research Unit: a Current Future**
Chiara Barbieri

10.20 **A 360° Look at Oncology by Patients for the Patients**
Emmanuelle Arfe & Amanda Olivon

10.35 **Tools for a more Personalized Oncological Care: from Digital Narrative Diaries to a Community Sharing Digital Space**
Maria Cecilia Cercato

10.50 **Discussion** (separate meeting room option to be confirmed)

CGPP Collaboration with Patients Organisations, A & D program and Cancer Outcomes Research WG

- Proving a new complimentary insight to quality standards
- Integrating more deeply patients' needs and perspectives and their evolution over time
- Comparing what is more meaningful from the standpoint of patients/health professionals in the OEI standards
- Providing guidance for Patient Involvement in PREMs and PROMS

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