

Embedding the cancer patient voice now more than ever

[#OECI_GeneralAssembly](#)

May 26th 2021

Dominique de Valeriola, MD

Chair, **OECI** Collaboration for Good Practices with Patients (**CGPP**) **WG**

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

Patrick Miqueu, PhD, MA

Coordinator, **OECI CGPP WG**

Coordinator Research Promotion & Patient Collaborations, **Institut Jules Bordet**, Brussels



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Patient and public involvement in covid-19 policy making

Absent in the early stages of the pandemic, it must now move centre stage

Tessa Richards, Henry Scowcroft

Patient and civil society advocacy groups may have **lacked seats on expert committees** but took the lead in providing information, advice, and support for their communities.³ They have lobbied for a voice in policy making,⁴ for a **focus on inequalities**,⁵ and for policies to take account of the reality of people's lives.⁶ They have also **accumulated a wealth of information from the patient community** on the physical, mental, social, and economic effects of the pandemic,^{7 8} effects that highlight the urgency of restoring essential medical services⁹ and the need for a comprehensive public health response.¹⁰



CGPP WG and COVID-19

- COVID-19 dominated our professional lives and changed our priorities
- Public and patient involvement has been sidelined
- Difficulties for CGPP members to liaise
- But maintaining contact and communication

But opportunities...

- Evolution of the OECI Model of Patient Involvement
- PROMs-PREMs implication



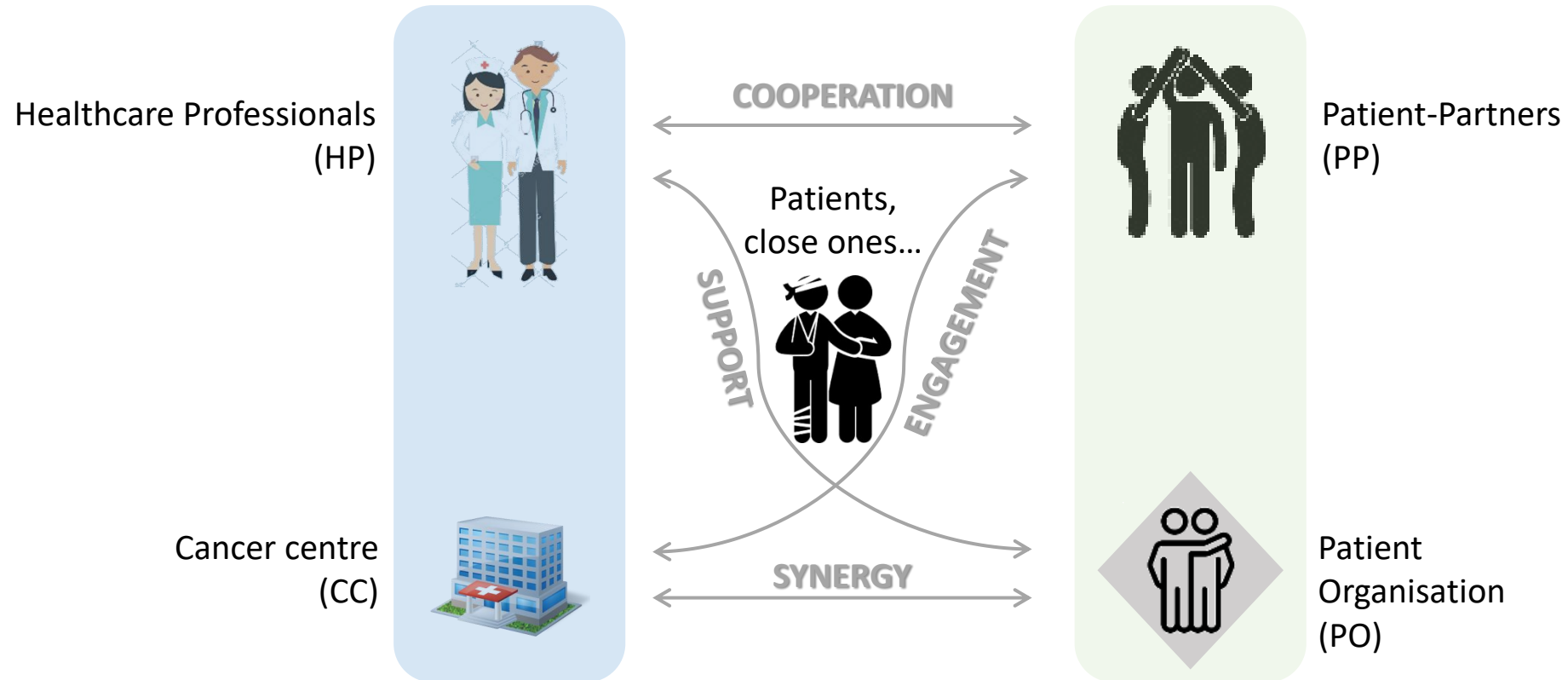
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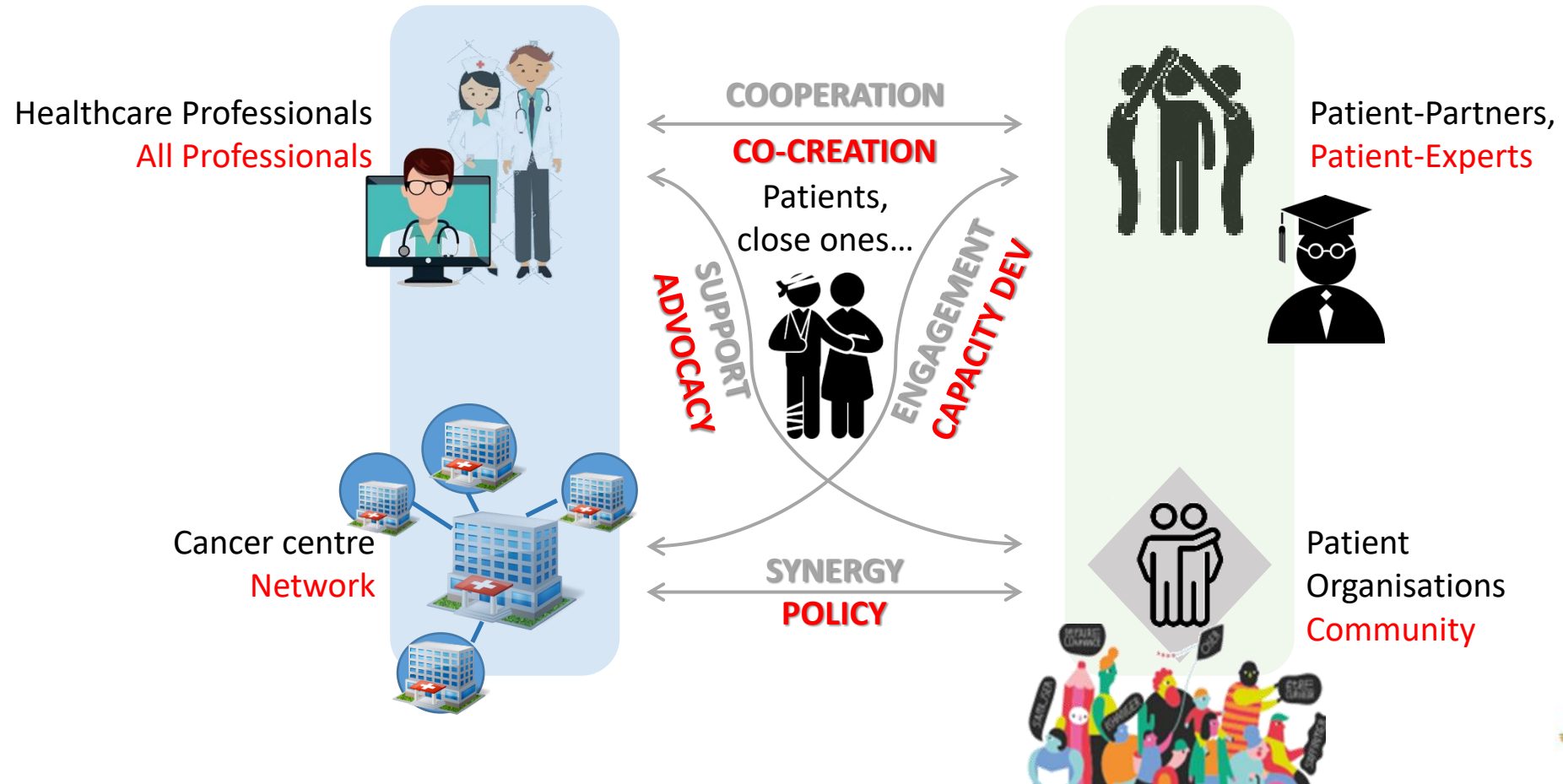
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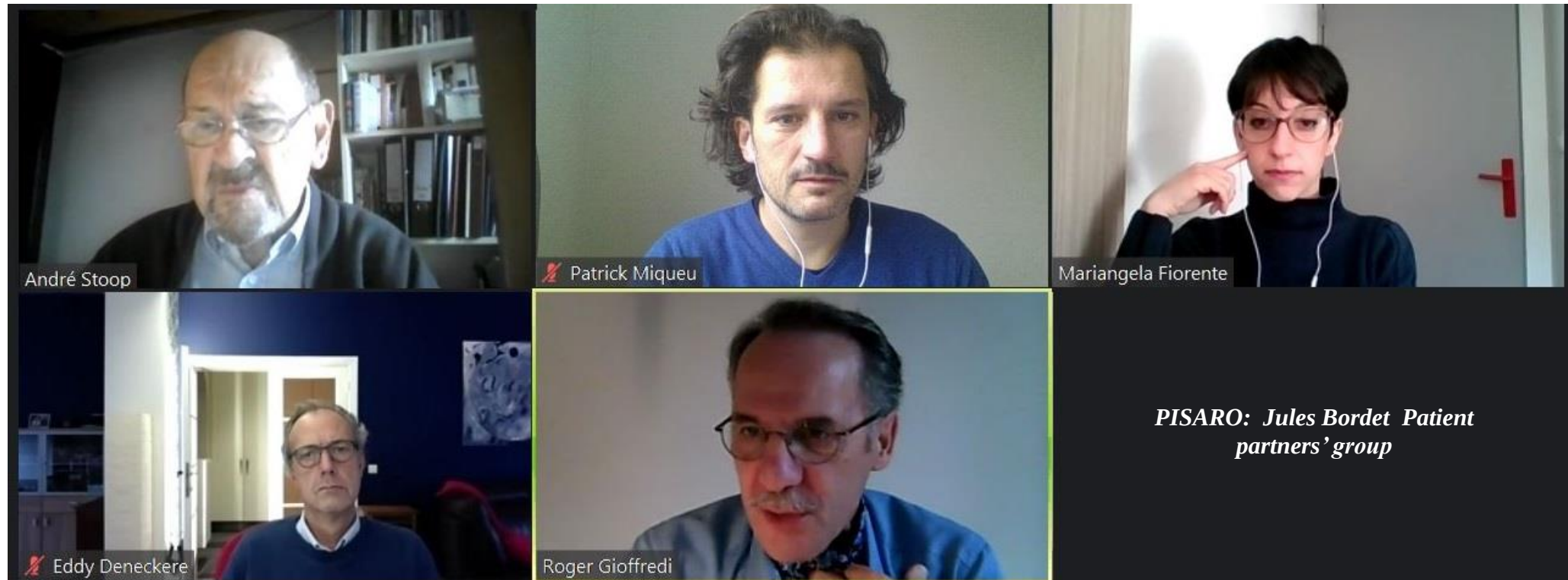
OECI Model of Patient Involvement



OECI Model of Patient Involvement 2021



Involving patients in a pandemic



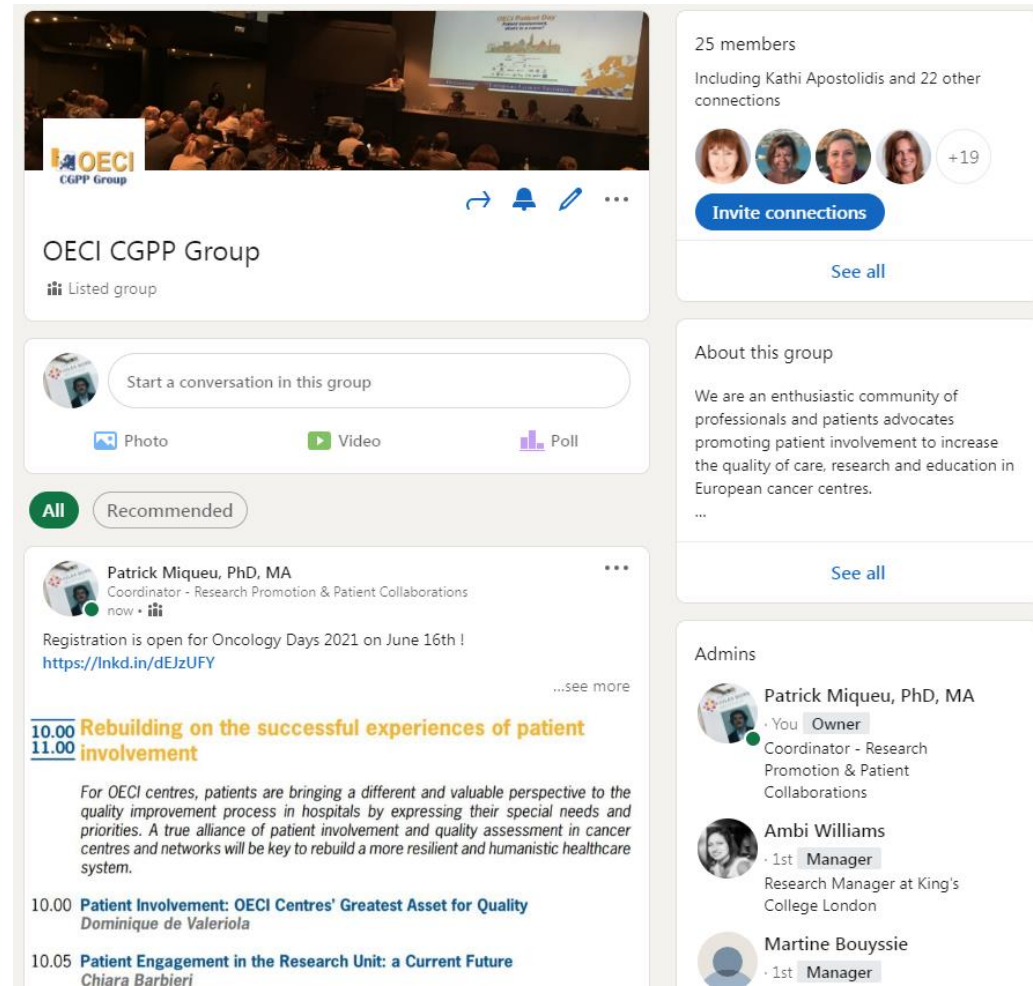
- From stopping patient meeting ...
- ... to managing virtual meetings
- And finally, increasing inclusivity and participation .



Digital environment creates opportunities

- **LinkedIn group** (April 2020)

<https://www.linkedin.com/groups/13843191/>



The screenshot shows the LinkedIn profile for the OEI CGPP Group. The header features a banner image of a conference and the group's name, 'OEI CGPP Group', with a 'Listed group' badge. Below the header is a section for starting a conversation, with options for Photo, Video, and Poll. A 'Recommended' tab is active, showing a post by Patrick Miqueu, PhD, MA, Coordinator - Research Promotion & Patient Collaborations. The post is titled 'Rebuilding on the successful experiences of patient involvement' and includes a detailed description of the group's mission. The right sidebar shows 25 members, including Kathi Apostolidis and 22 other connections, with an 'Invite connections' button. Below this is the 'About this group' section, which describes the group as an enthusiastic community of professionals and patients advocates promoting patient involvement to increase the quality of care, research and education in European cancer centres. The 'Admins' section lists Patrick Miqueu, PhD, MA as the Owner, and Ambi Williams and Martine Bouyssie as 1st Managers.



CGPP WG Governance & Membership

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	Gilgorov	
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 T	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 January 2019)

62 OECD members

167 contacts



#OncologyDays 2021 – CGPP session

Based on the Call of abstracts organised for 2nd edition of OECI PATIENT DAY : one-day conference on Patient involvement

Contributions from professionals and patient advocates where the perspective of the patients into professionals' activities and developments are promoted.

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.

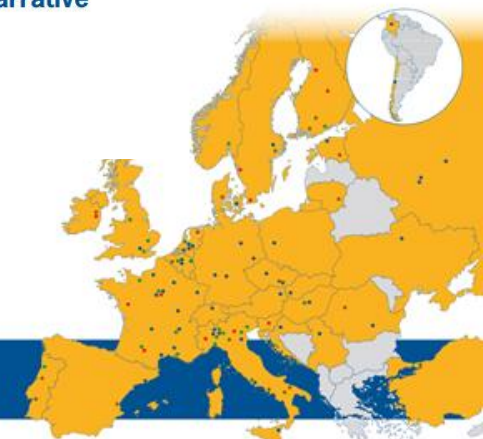
10.00 **Patient Involvement: OECI Centres' Greatest Asset for Quality**
Dominique de Valeriola

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)



Perspectives

Collaboration with the Accreditation & Designation Program

- Proving a new insight to quality standards
- Integrating patients' needs and perspectives

Collaboration with Cancer Outcomes Research WG

- Providing guidance for Patient Involvement in PREMs and PROMs



**OECI role in Cancer Mission of the EU Horizon Europe Framework
Program for Research and Innovation**



Patient Involvement in PREMs and PROMs context

*In collaboration with
Cancer Outcomes Research WG*

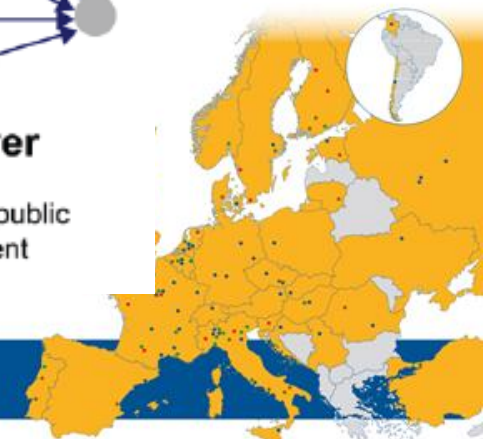
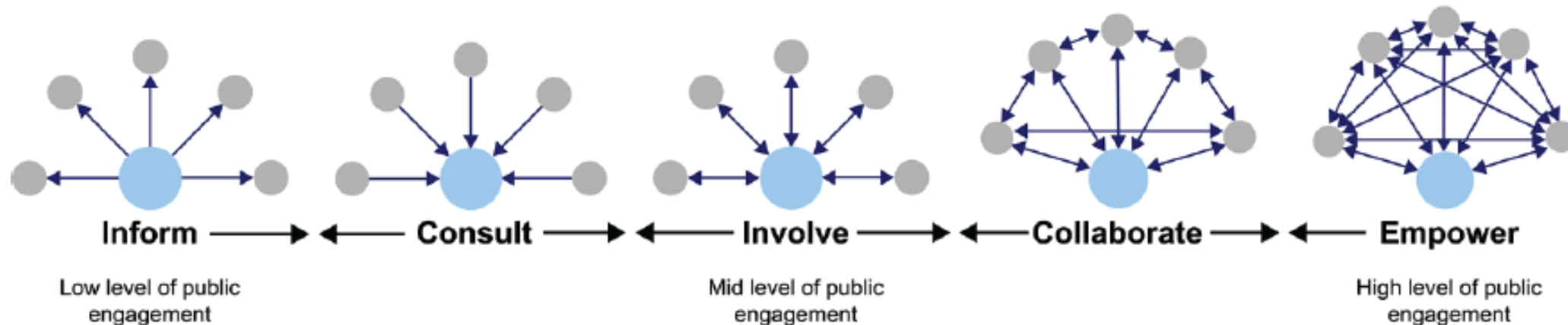
Valuing **experiential knowledge** of patients

Reassuring on the importance of patient involvement in research & care

Giving confidence that their own contribution can make a difference

Promoting integrative **Co-creation**

IAP2 Participation Spectrum



Collaboration for Good Practice with Patients Working Group

Reserve the date:
OECI Oncology Days 2021:
June 16th 2021
10:00 to 11:00 am

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11.00 **involvement**

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