Oncology Days

OECI46

Helsinki 2024

Alexandre Brutti Helsinki, June 2024
Stage IV Cancer Survivor

Collaboration for Good Practices with Patients WG Session

June 12th
14.00 - 16.00
Hotel Presidentti

14.00 **Enhancing patient involvement: OECI for patients, with patients**

Welcome
Giovanni Apolone (2')

Collaboration between cancer centres and cancer patients' organisations: the Patients WG Draft Proposal
Delia Nicoară (10')

Feedback on WG on Patients document
Francesco De Lorenzo (10')

Introduction and results of OECI Cancer Centres' Survey
Paulina Bravo and Francesco De Lorenzo (15')

Cancer survivors' perspective
Alexandre Brutti (10')

Discussion

Proposal of the WG Chairperson and conclusion
Claudio Lombardo

OECI#46 – Helsinki : Good Practices with Patients WG Session, Cancer Survivor's perspective

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Cancer Survivor's perspective

- My Story
- My contribution to the solid Comprehensive Cancer Centre (CCC) as a patient advocate
- My participation to the OECI EPIC-CARE Working Group (Enhancing Patient Involvement in Cancer CAre and REsearch)
- April-May 2024's OECI Survey results seen through a Patient Survivor's eye

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Cancer Survivor my Story, 1 of 2

My involvement in patient advocacy started in 2021 after being treated for a metastatic Lung Cancer Stage 4 (March 2020); I'm retired since March 2023 after a 38-year career in the Multimedia Industry (I'm 65 yo).

- Throughout my advocacy journey, I participate to various significant groups and projects :
  - Being Active Member & CTO of the FRENCH NPO named Patients En Réseaux (Mon Réseau Cancer du Poumon),
  - Being Treasurer @the European LuCE coalition OF 50 European Associations,
  - I wear various hats:
    - chairman of the Patient Advisory Board of the European Project PREVALUNG EU (together with IGR), "omics",
    - member of the Patient Advisory Board of the European Project GUID-MRD cTDNA,
    - member, since its creation in 2021, of the GHU APHP Paris Center Patients Committee and member of SIRIC CaRPEM (Cancer Research in Personalized Medicine) of the Paris Centre University GHU University Hospital Group,
  - OECI
    - I took part to the OECI GHU Paris Centre APHP accreditation (held in 2022) as I was interviewed in quality of "Patients Experts",
    - With OECI & GHU Paris Centre, we presented during the OECI #45 Oncology Days (in Paris June 2023) how we co-constructed the Hospital-Patient alliance in our CCC.
    - During the OECI #45 plenary session dedicated to Patients (Oncology Days in Paris), we all decided to create a joint Working Group in order to build & empower the role of the Patient in the Research

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Cancer Survivor, my Story - 2 of 2

- Cancer Survivor is a person who needs :
  - to find new foundations for his new life,
  - to build his own shelter and organize the future building projects anyway ,
  - to learn how to live a full life while managing the disease,

Terminology : A Cancer Survivor is a person who has his/her «cancer stabilized» and still living 5 years after the initial diagnostic. /!\ I will be an eligible survivor in March 2025…

- What to do, when you are in the «after cancer» or « post treatment» phase
  - Make everything you can do to heal, check your QOL and balance your life with your loved ones & friends,
  - Join a local/national NPO so to start showing the way to the next who are suffering (Give back what you received),
  - Help CC & CCC to improve together the way the patients are managed, educate the patients & learn from them,
  - Join international NPOs (coalitions and group of patients)
    - Pinpoint the inequalities,
    - Voice when policies are not at the standard they should be,
    - Co-construct and Codesign the new policies and best practices for a better Patient Pathway

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Who said conflict of Interest ??

- From a Patient’s perspective, here are some COI I can share with you 😊
  - Continue to be monitored by a solid Comprehensive Cancer Centre (CCC) so to make sure my metastatic Lung Cancer remains as stabilized as it is since 4 years,
  - Make sure there are leads with new therapies in case I have to face a rehearsal, and learn about these new therapies and assess the eligibility,
  - Work closely with my Comprehensive Cancer Centre regarding the Prevention, as, nowadays, many of the Cancers are still diagnosed too late (metastatic ,Stage IV) *

No prevention in place	🔴	For Lung Cancer, **~75** % of the people are diagnosed with Stage IV and the 5-year survival rate for this population is **~4%,**
Prevention in place but not enough followed	🟠	For Colorectal Cancer, **~55** % are diagnosed with Stage IV and the 5-year survival rate for this population is **13%,**
Great Prevention , but…	🟡	For Breast* Cancer, **~5 %** are diagnosed with Stage IV and the 5-year survival rate for this population is **31%.**

* 20% of the 95% (19%) diagnosed with local Breast Cancer will develop a Stage IV in the long run…

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As a patient, I was not born as Patient Advocate

European Organizations/Associations

ORGANISATION OF EUROPEAN CANCER INSTITUTES
EUROPEAN ECONOMIC INTEREST GROUPING

- Working Group EPIC-CARE WG Enhancing Patient Involvement in Cancer Care and Research

- EU projects / Patient Advisory Board Chair

EUPATI
European Patients' Academy on Therapeutic Innovation

EPF
European Patients Forum

LuCE Lung Cancer Europe

Local Organization/associations

- Patients Network
  - Lung Cancer
  - Breast
  - Colorectal
  - Gyn

PATIENTS EN RÉSEAU

- Patients Steering Co
- Discussions on ethics and best practices
- Advice and Consultation in Research Projects

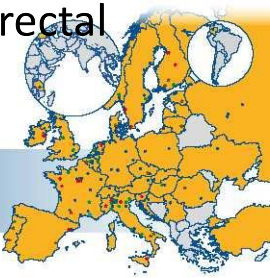
Institut du cancer PARIS CARPEM
AP-HP.Centre-Université Paris Cité

AP-HP. Centre Université Paris Cité

ASSISTANCE PUBLIQUE HÔPITAUX DE PARIS

Université Paris Cité

Université Sorbonne Paris Nord

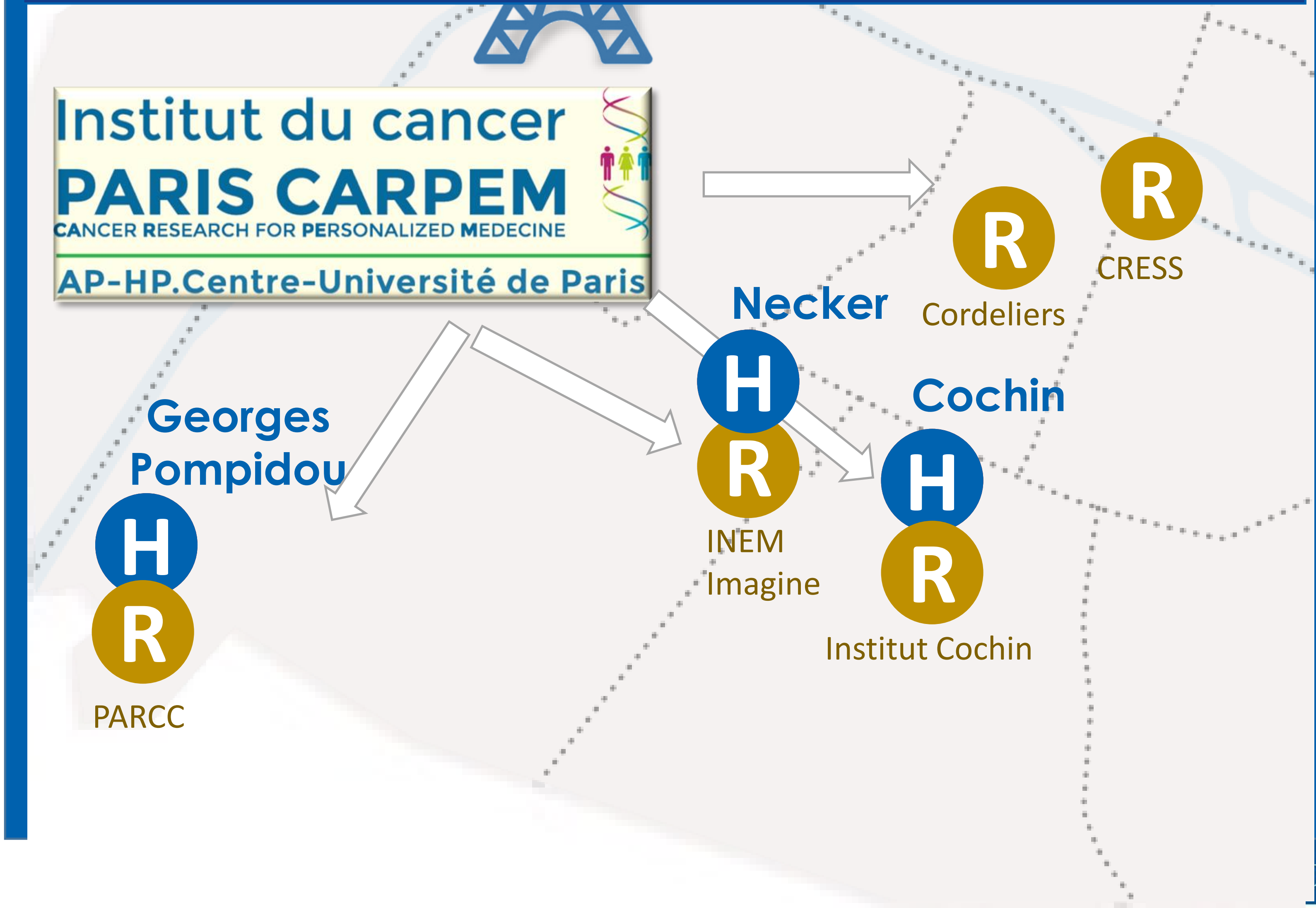


CCC Paris Centre - Paris CARPEM Cancer Institute

ECI

Translational Research

Institut du cancer
PARIS CARPEM
CANCER RESEARCH FOR PERSONALIZED MEDECINE
AP-HP.Centre-Université de Paris



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CARPEM
CANCER RESEARCH FOR PERSONALIZED MEDICINE

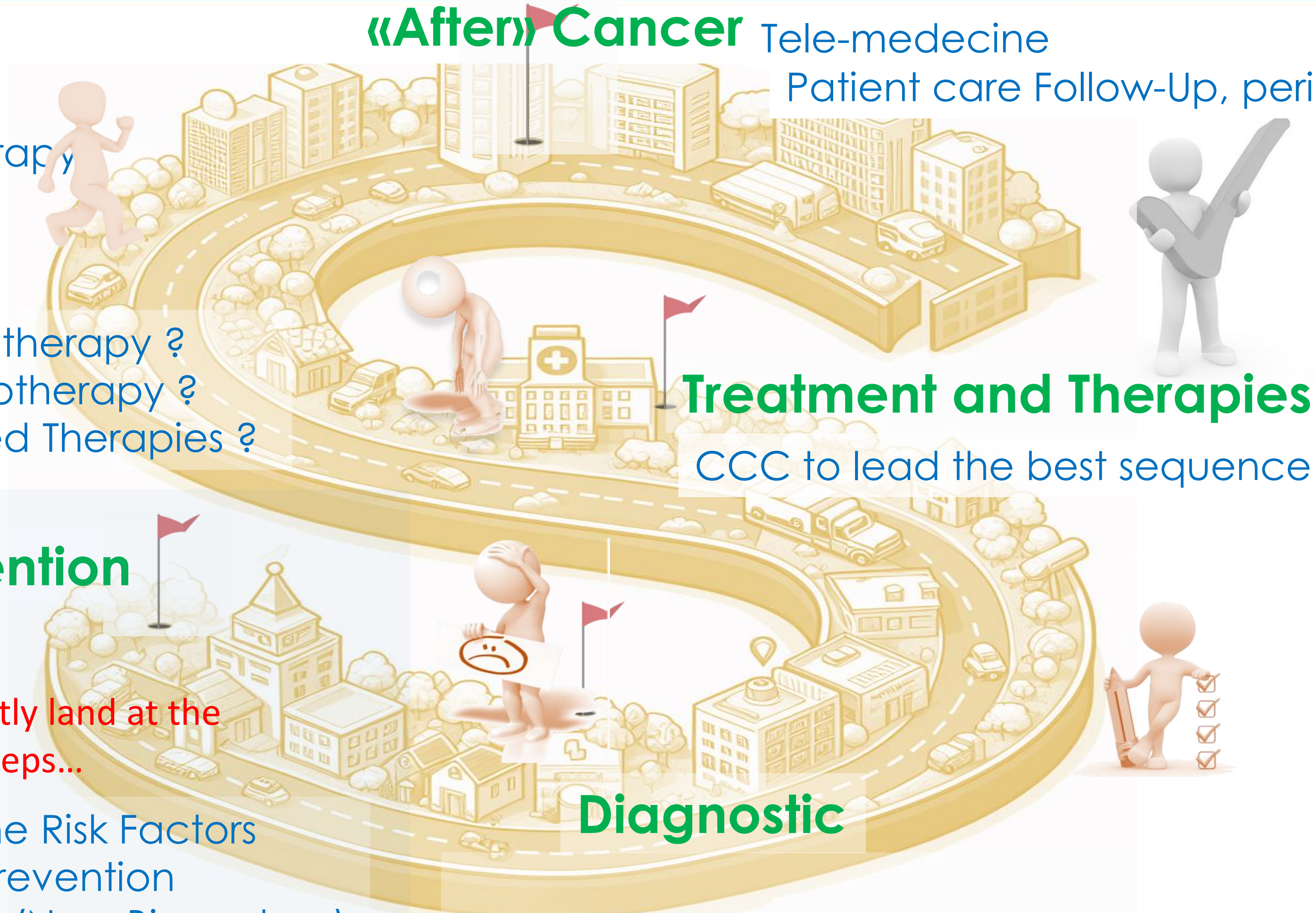
Research Teams
Addressing :

Tumoral Heterogeneity	Immunity
Metabolism	Genetic
Health Democracy	Ethics

6 Research Centres

Université de Paris

Patient Care Pathway



«After» Cancer

Tele-medecine

Patient care Follow-Up, periodic checkups

Radiation therapy

Surgery

Chemotherapy ?
Immunotherapy ?
Targeted Therapies ?

Treatment and Therapies

CCC to lead the best sequence of therapies

Prevention

Too often Patients directly land at the diagnostic/Treatment steps...

Assess and enrich the Risk Factors
Find new ways for Prevention
and early detection (New Biomarkers)

Diagnostic

cTDNA, «anapath», NGS, CTSCAN, MRI

The OECI EPIC-CARE Working Group

- During Oncology Days #45 (held in June 2023 in Paris), OECI asked to setup a Working Group so to build the future of the CCC-Patient cooperation **Collaboration for good practices with patients**
  - This led us to build the mission statement for the Epic-CARE Projet : **E**nhancing **P**atient **I**nvolvement in **C**ancer **CARE** and Research
    - A team of 12 persons worked together from July 2023 to June 2024; Clinicians, care givers and patients representatives from various part of Europe and from the world (even from Chile) worked on the Mission Statement
    - Need to build a Patient/Clinician/Care Givers alliance at a CC/CCC level (A tandem to bring the local highlights to the European Layer)

- Work with clinicians, care givers and patients representatives from various part of Europe
- Build a Patient/Clinician alliance (A tandem to bring the local light to the European Layer)

- Milestones
  - Working Group Team, started to work together in July 2023 → April 2024 Mission Statement finalized,
  - 1st Survey produced → Distributed on 10th April 2024 to all 53 OECI-accredited centers,
  - 1st Survey deadline for data collection → 15th of May 2024,
  - Analysis and Preliminary Results presentation → 12th of June 2024 during the OECI#46 session in Helsinki.

- What's next
  - Provide consolidated analysis
  - Decide who will take lead of the EPIC-CARE Working Group
  - Build togethers Goals and Roadmap

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April 2024's OECI Survey results seen through a Patient Survivor's eye

Preliminary results … Data set was completed early June 2024

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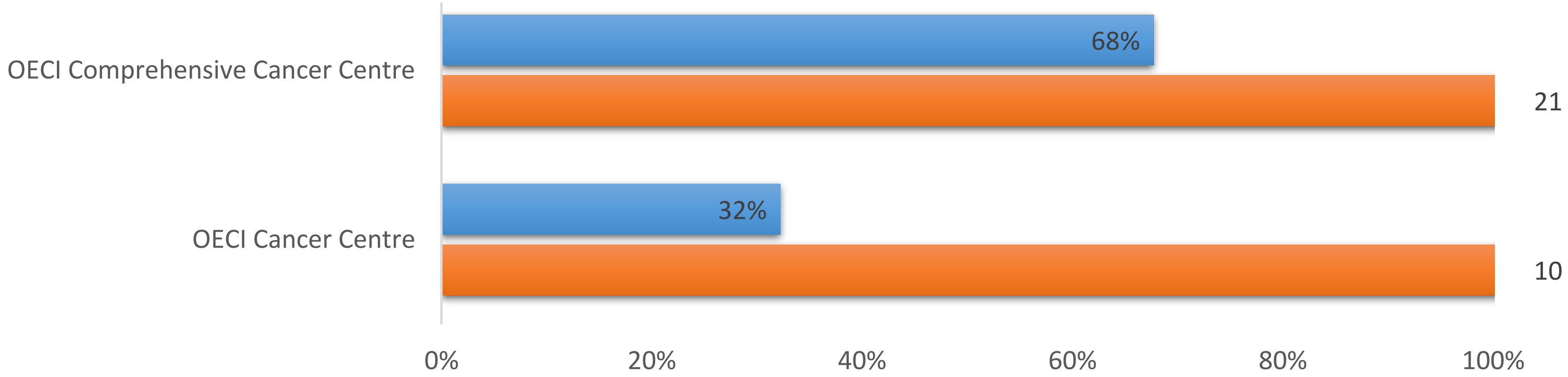
Q2: Centres Category

- Answered: 31   Skipped: 0



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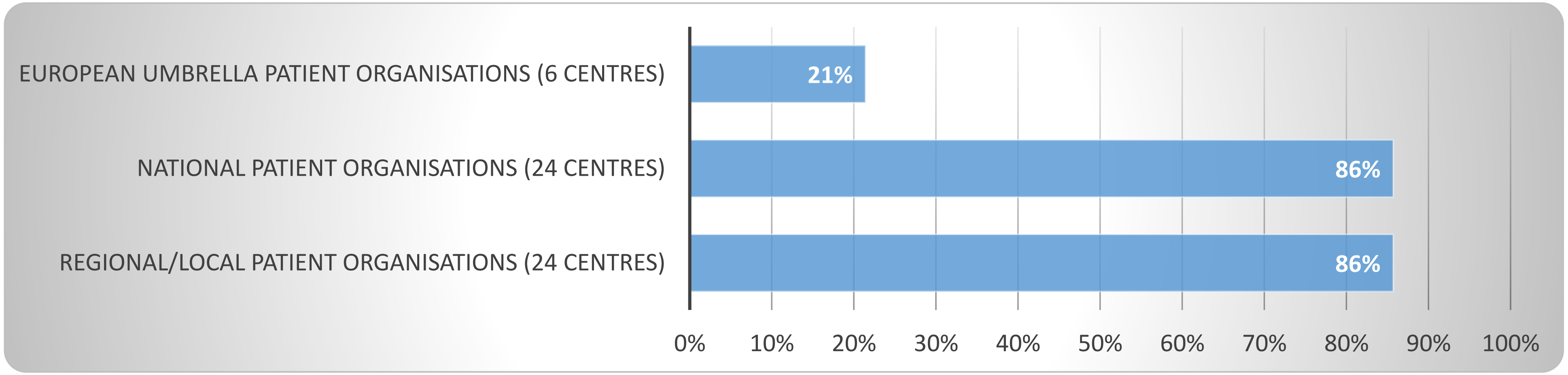
Q3: Has your centre taken steps towards formally and proactively involving cancer patients and/or patient organisations in its governing bodies/committees？

Answered: 28/ Skipped: 3

- **2 out 31 centres did not start the activity of empowering patients and/or patient organizations**



❑ CCCs involve Patient NGOs mainly @local and national levels…

Nevertheless CCC will gain attractiveness & competencies by :

- Choosing to go through the international route,
- Converging quicker to the National & European Health Accreditation Standards.

❑ Survivor Patients and Patients with rare diseases are naturally moving to European Umbrella Patients Organizations.

❑ **OECI is definitively at European/Worldwide Level.**

As for R&D, all CCCs should also swim in international seas in terms of Patient Engagement

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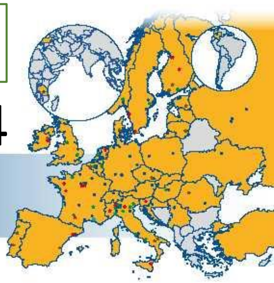

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Q6

May 24 2024 snapshot :

Total of 31 responders
Answered: 27 Skipped: 4

Q6: If your answer to Question 3 is YES, please indicate the three main areas in which patients and/or patient organisations are involved by clicking the relevant checkboxes:

/!\ Warning, the responders have not respected the rules… in average they gave 6 areas instead of 3
(~160 areas /27 responders)

This does not allow us to give the real 3 priorities areas we were targeting

ANSWER CHOICES	RESPONSES	
Patient Safety	48.15%	13
Cancer Supportive Care	44.44%	12
Patient Navigation	55.56%	15
Care Pathways	48.15%	13
Therapeutic Education	44.44%	12
Nutrition	14.81%	4
Cancer Policy	25.93%	7
Cancer Research	29.63%	8
Clinical Trials (in roles other than subjects of the trial or patient recruitment)	33.33%	9
Physical Excercise	25.93%	7
Patient Information	96.30%	26
Return to Work	11.11%	3
Rehabilitation	22.22%	6
Family Support (for caregivers)	40.74%	11
Patient rights and benefits	48.15%	13
TOTAL		159

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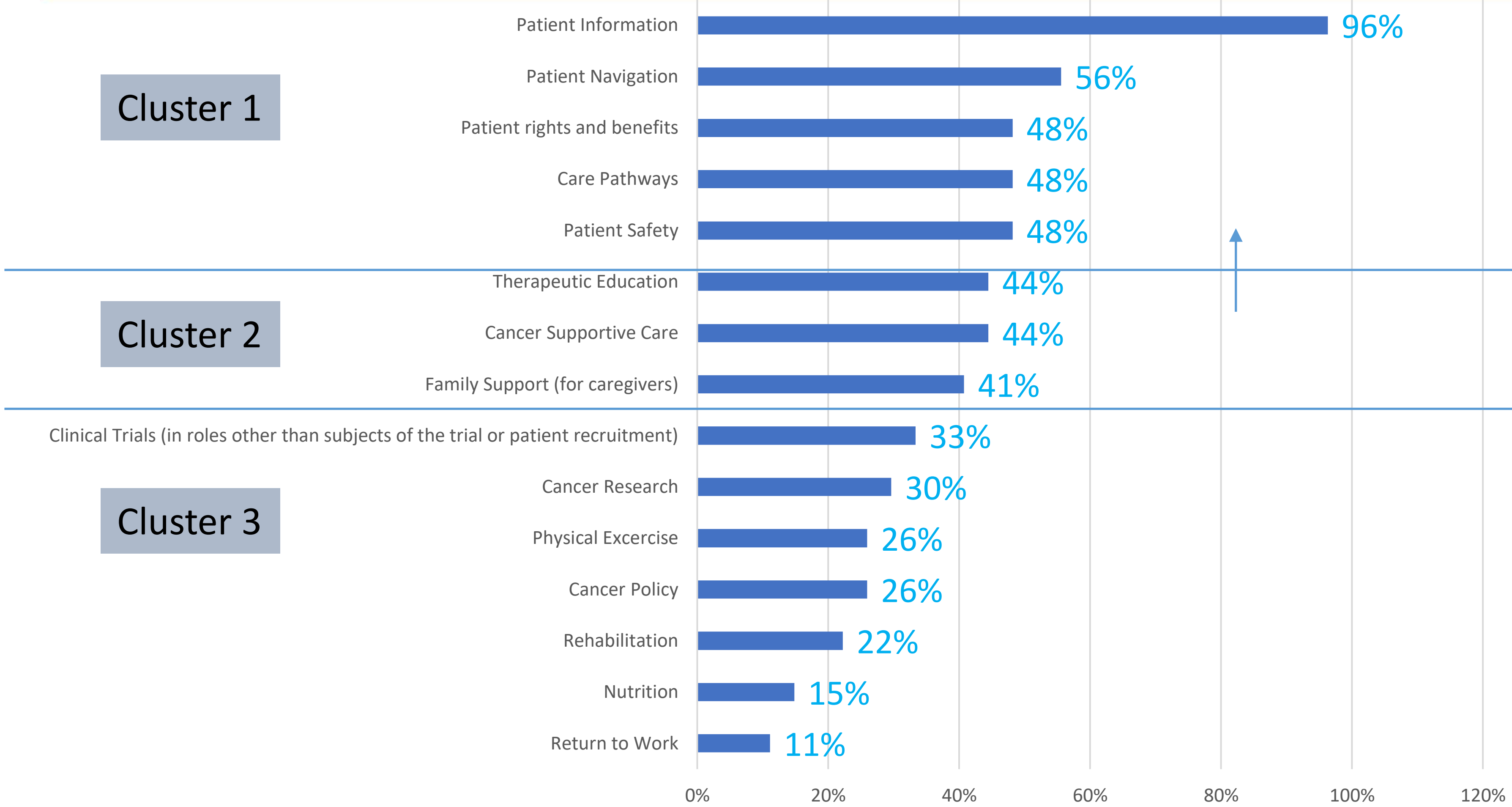
15 Patient Related Categories %

Cluster 1

Cluster 2

Cluster 3



End of May snapshot
/!\ Missing the CCC which answered in June

1st year ?

2nd year ?

Reality shall be different

- ☐ From patient standpoint, priorities should be set higher for {Nutrition, Physical Exercise & Rehabilitation, Return to Work}
- ☐ Cancer Research, Cancer Policy, Clinical Trial might come Year 2 (or earlier) for CCC (maybe later for a CC ?)

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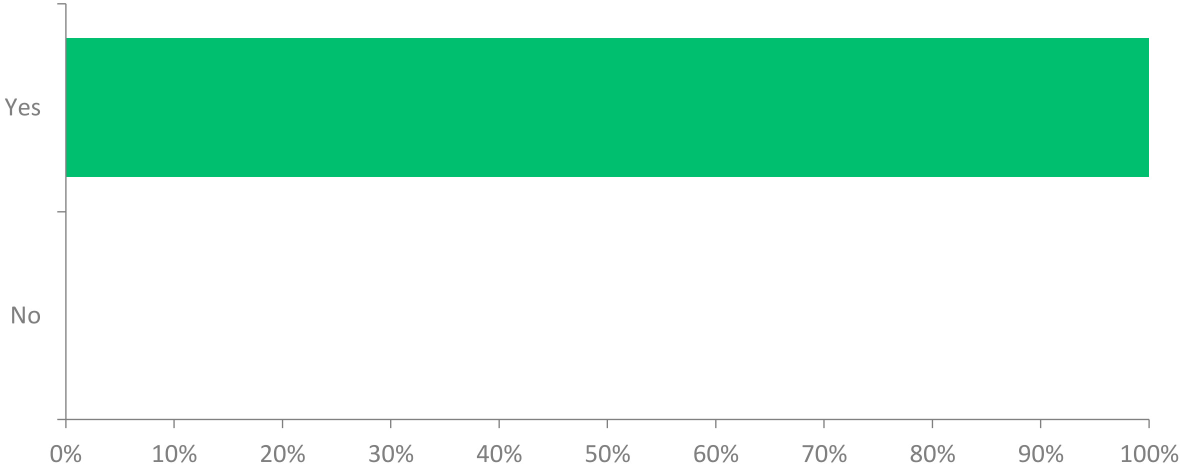
* Clinical Trials (in roles other than subjects of the trial or patient recruitment)

Q7: If your answer to Question 3 is NO, is your centre planning to introduce patients and/or patient organisations in your centre's decision-making bodies/committees over the next two years ?

- Answered: 7 Skipped: 24



ANSWER CHOICES	RESPONSES	
Yes	100%	7

100 % of the Centres which haven’t started to involved Patients yet showed interest in starting this activity within the 2 next years. This justifies the load that the team put in place by OECI .

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