



European Cancer
Patient Coalition

The European Cancer Patient Coalition: The Essential Link in the EU Health Policy

Francesco De Lorenzo
ECPC President

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OECI 2023 Oncology Days



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Who are we?

- Largest European cancer patients' umbrella organisation established in 2003 with more than 450 members.
- We advocate for patients to be acknowledged as equal partners & co-creators of their own health
- We work for a Europe of equality, where all Europeans with cancer have timely & affordable access to the best treatment and care available, throughout their life



New needs, new rights: CHALLENGES

Information and
Communication

Disparities

Rehabilitation
(phisc, nutritional,
sexual, cognitive
and social

Mother and father
after cancer

Patients and
caregivers rights

Right to be
forgotten

Pain therapy and
pallaitive care

Rare cancers

Neglected tumors

Follow up and
QoL for survivors

Life after cancer

Research



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Lack of integration of patients into the research and innovation agenda.

Europe strengthens patient involvement in cancer research

Patient-centred cancer research is to become the standard in Europe in the long term, becoming even more closely aligned to the needs of patients.

For this reason, the research ministers of Germany, Portugal and Slovenia have adopted the Principles of Successful Patient Involvement in Cancer Research. These new general principles were drawn up in a multi-stage process* by patient organisations, researchers, medical and care professionals, representatives from industry and funding organisations as well as other stakeholders from across Europe.

**"Principles of Successful Patient Involvement in Cancer Research" (September 2021)*

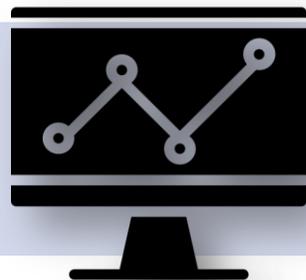
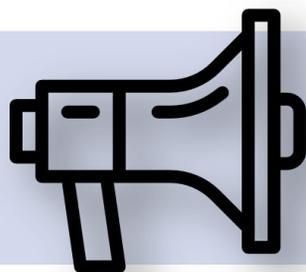
https://www.bmbf.de/SharedDocs/Downloads/en/210907-unite-against-cancer.pdf?__blob=publicationFile&v=2

Press release

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Advocacy Patients role in research: another added value

As research falls under the competence of the European Commission, but healthcare is a national competence, bio-medical research could serve as a catalyst between research and healthcare, thus, strengthening the social impact of translational research in cancer, integrating the patients' perspective.



Engaging European society at the forefront of cancer research and care

How discussions at the 5th Gago Conference on European Science policy led to the Heidelberg Manifesto

Michael Baumann^{1,2}, Julio Celis^{2,3}, Ulrik Ringborg^{2,4}, Manuel Heitor^{2,5}, Anton Berns^{2,6}, Tit Albrecht^{7,8}, Jeli azko Arabadjiev^{9,10}, Michael Boutros^{2,11,12}, Mario Brandenburg¹³, Helena Canhao¹⁴, Fatima Carneiro^{2,15,16,17}, Christine Chomienne¹⁸, Francesco De Lorenzo^{2,19}, Alexander M. M. Eggermont^{2,20,21,22}, Angel Font²³, Elena Garralda^{24,25}, Margarida Goulart²⁶, Rui Henrique^{27,28} , Mark Lawler^{2,29} , Lena Maier-Hein³⁰, Françoise Meunier^{2,31}, Simon Oberst³² , Pedro Oliveira³³, Maria Papatriantafyllou³⁴ , Joachim Schüz^{2,35} , Eric Solary^{2,36,37} , Alfonso Valencia^{38,39}, Rosalia Vargas⁴⁰, Elisabete Weiderpass^{2,35} , and Nils Wilking⁴¹

3. Patient-centred scope and public engagement with a focus on scientific culture

The partnership between researchers and patients, allows patients to contribute their experience towards effectively translating research into clinical practice.



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Advocacy Patients co-design RESEARCH PROJECTS: a reality in ECPC

European Policy Initiatives

- [4.UNCAN.eu](#) (1° Recommendation)***
- Can.Heal
- JANE
- CCI4EU



ECPC acts as the **essential link** between all stakeholders, always keeping in mind **patient centricity, ethics and sustainability**.

ECPC strongly advocates for a partnership model between researchers and patients.

ECPC from theory to action



European Cancer



...and many more



can.heal



prefer.
PATIENT PREFERENCES



MyPath 



26 ongoing projects related to:

- Big Data and Personalised Medicine
- Knowledge sharing networks
- Patients and Caregivers
- Palliative Care
- Treatments

All these projects are pieces of bigger puzzles:

«Conquering Cancer: Mission Possible»
and «Europe's Beating Cancer Plan»



Launch UNCAN.eu – a European Initiative to Understand Cancer

Mission Board proposes a **Europe-wide platform, UNCAN.eu**, that would provide breakthroughs in understanding how cancers initiate, develop and spread in the context of the host and thereby provide a basis for saving millions of European citizens' lives.

Work Package No	Work Package name	Lead Beneficiary
WP1	Coordination and Management of the CSA	1 - INSERM
WP2	Identification of cancer research challenges to address future EU priorities & research policies	2 - CIBER
WP3	Mapping of European Research Infrastructures and initiatives Roadmap for a European Federated Cancer Research Data Hub	3 - DKFZ
WP4	Patients and European Citizens in cancer research	6 - ECPC
WP5	Governance, organization, logistics, finances, and sustainability	14 - ACC
WP6	Inequalities in cancer research – improved science with improved outreach	5 - OOI



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4UN.Can - A survey of patients and general public

Within UN.Can, the European Cancer Patient Coalition (ECPC) and the Childhood Cancer International (CCI) conducted a survey to take account of the perspective of patients and also of the general public, with the aim to assess the level of scientific literacy among European citizens and to identify cancer research priorities and expectations from patients and the public.

Seven pillars were identified: **Cancer Prevention, Screening & Early Diagnosis, Sensitivity and Resistance to therapy, Pediatric Cancer, Cancer and Ageing, Survivorship & quality of life, Data Sharing**



1,700 participants



30 European countries



35 measures



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CCI4EU – Educational Platforms as guidance for Advocacy Patients



ADVOCACY PATIENTS SHOULD BE SYSTEMATICALLY INVOLVED AS ACTIVE PARTNERS OR CO-RESEARCHERS AT EYE-LEVEL, AND THEY SHOULD HOLD AN APPROPRIATE SHARE OF DECISION-MAKING POWER IN THE RESEARCH PROCESS.



ECPC WILL DEVELOP PLATFORMS THAT CAN PROVIDE GUIDANCE AND USEFUL FRAMEWORKS FOR ALL ADVOCACY PATIENTS THAT WANT TO PARTAKE IN PARTICIPATORY CANCER RESEARCH AND BEYOND.



ECPC WILL MAKE USE OF THE ESO LEARNING AND IARC REPOSITORY PLATFORMS TO DEVELOP EDUCATIONAL MATERIALS TO INFORM PATIENTS AT THE NATIONAL LEVEL ABOUT THE NEED AND STEPS FOR THEIR INVOLVEMENT IN CANCER RESEARCH.



ECPC, THROUGH THE MOU WITH OECI, AGREED TO DEVELOP AN EDUCATIONAL MODULE TO EXPLAIN TO PATIENTS HOW THEY CAN CONTRIBUTE TO AND WHAT THEIR ROLES ARE IN SETTING UP THE **COMPREHENSIVE CANCER INFRASTRUCTURE S (CCIS)**.



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CCI4EU - "Patient empowerment in Cancer Centres" Working group promoted by OECI

This WG will be an important tool of the CCI4EU to build a model for the best interaction between cancer patient organizations and Comprehensive Cancer Centers, along a **patient co-defined cancer pathway**.

It will investigate the new needs and new rights of cancer patients, facilitating the best interaction of advocacy patient' organizations and CCCs.

**Kick-off of
the WG on
June 15**



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Jane – Joint Action on Networks of Expertise

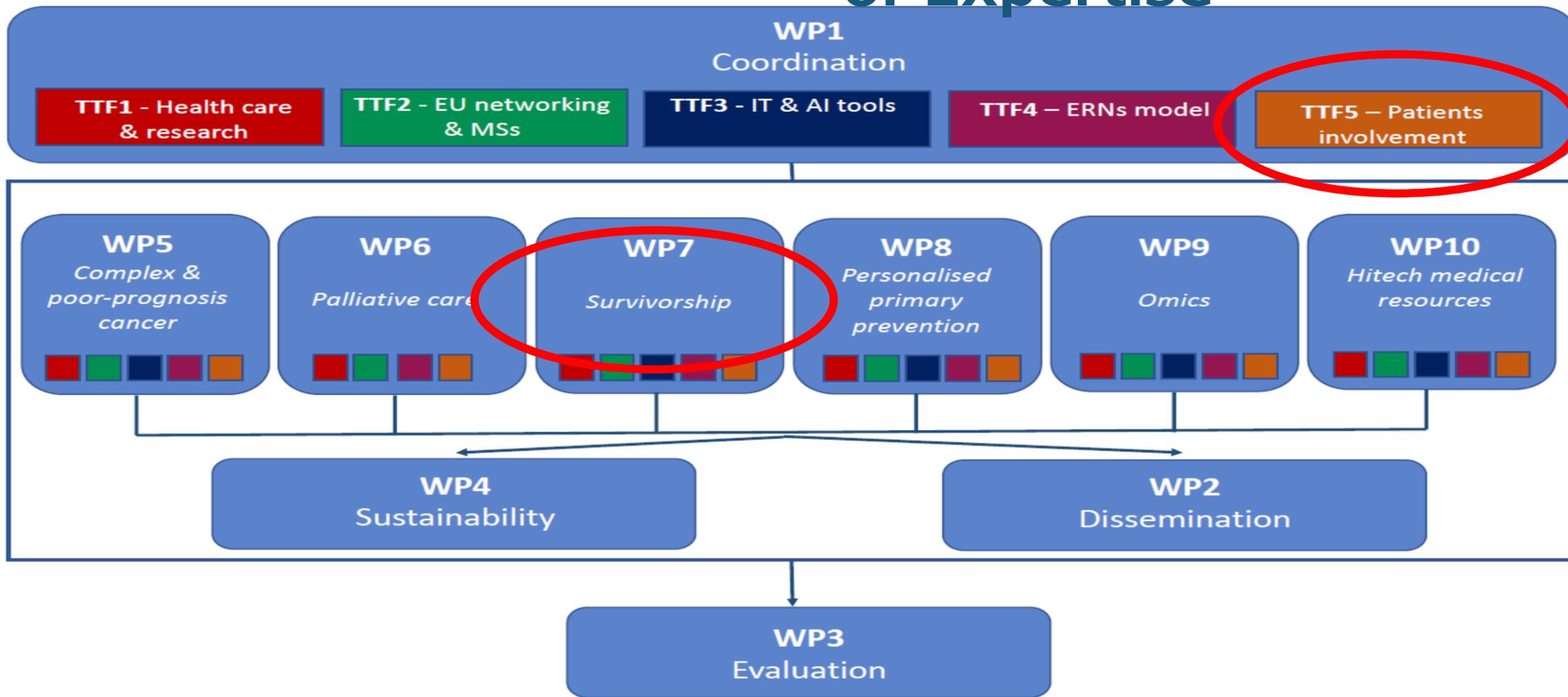
JANE will be a Joint Action to establish seven new Networks of Expertise in the cancer field in the following domains: **personalized primary prevention; survivorship; palliative care; omic technologies; hi-tech medical resources; complex & poor-prognosis cancer(s); adolescents and young adults with cancer**. It is envisaged to have 5 Transversal Task Forces that will operate transversally to all the Work Packages.

The ambition of this Joint Action is to bring about new Networks of Expertise able to function effectively, building on previous and ongoing EU networking experiences, and finding solutions rooted in the European oncology community.

ECPC is actively involved within Transversal Task Force 5 (TTF5) together with Sciansano and in the WP7 on Survivorship with Alliance Against Cancer and NIO and



Jane – Joint Action on Networks of Expertise

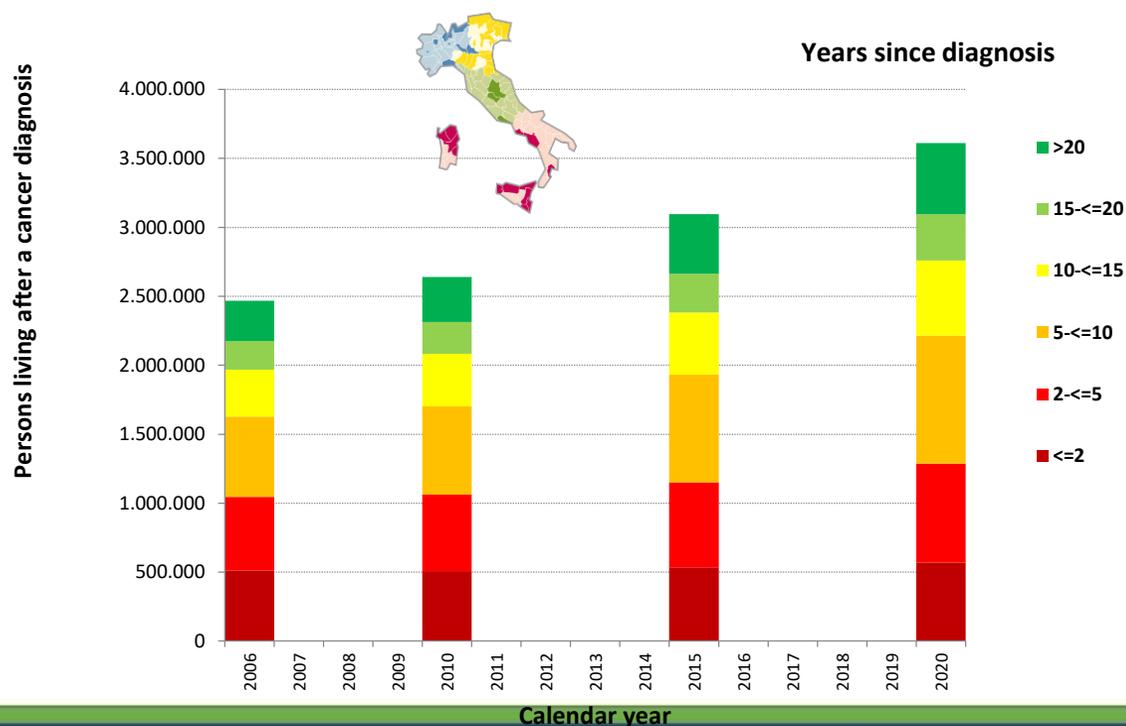




Why Survivorship Care is a specific Network of Expertise (WP7)?

We can estimate that 5% of individuals in several European countries are living after a cancer diagnosis (e.g., 3.6 million in Italy, 20-25 millions in Europe).

Italy: Guzzinati et al. BMC Cancer 2018

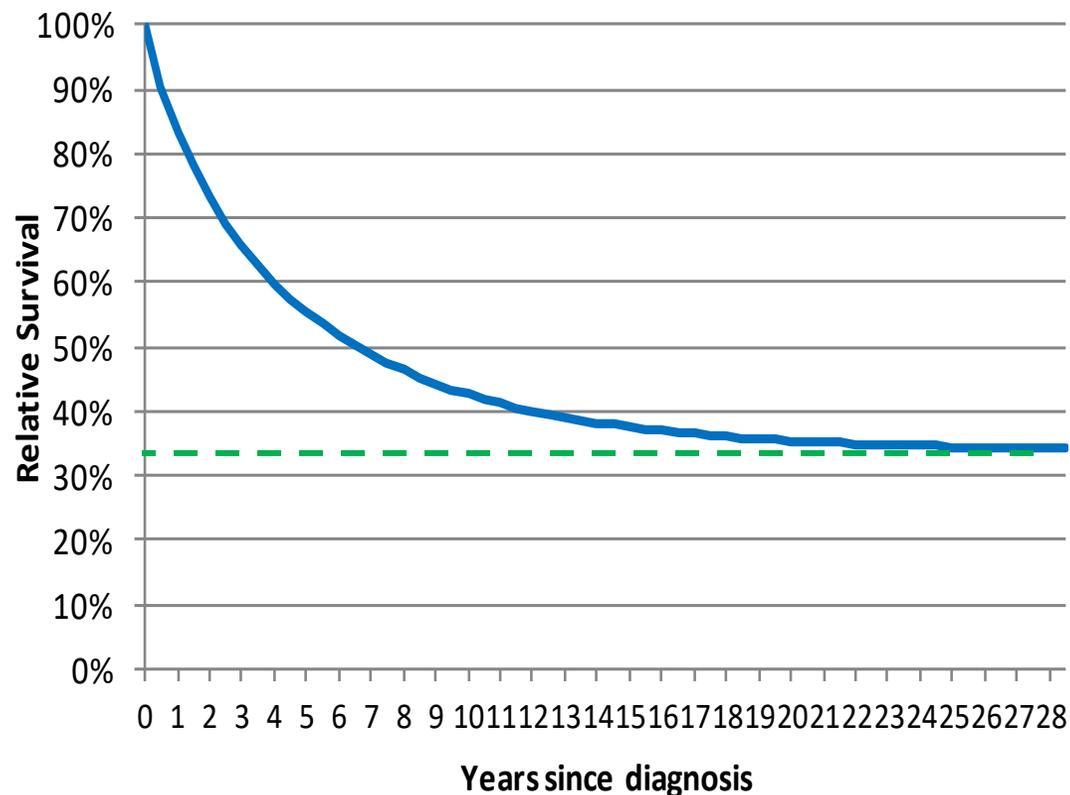


A large proportion of these people (e.g., 24% of cancer patients in Italy) are alive 15 or more years after diagnosis.

In green in the Figure



How many patients will be cured? - Cure F



Dal Maso et al. Int J Epid, 2020

Proportion of cancer cases who are expected to reach the same death rates of the general population.

It occurs when the relative survival curve becomes flat.

The dashed green line represents patients who will not die as a result of their cancer



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There is an absolute need to ensure that cancer research includes Health's related Quality of Life aspects.

Cancer survivorship research is a critical component of the overall cancer research activity in Europe.

- Long-term follow-up and survivorship including social consequences (Societal Acceptance, insurance, employment) and health economics aspects.
- Limited interdisciplinary research activity in the survivorship domain and a paucity of survivorship research tools.
- Paucity of specific research programmes for children, adolescents and young adult survivors.
- Lack of research on the legal aspects of reintegration of cancer survivors back into society (Right to be forgotten).
- Lack of knowledge of the stigma associated with cancer.
- Lack of specific research on survivorship support for patients and for patient empowerment.

Molecular
Oncology



Challenges and solutions to embed cancer survivorship research and innovation within the EU Cancer Mission

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POLICY ARTICLE

Towards a Cancer Mission in Horizon Europe





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Thank you!

Francesco De Lorenzo

ECPC President

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