

Bridging the Gap in Cancer Inequalities

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About the European Cancer Organisation

42 Member
Societies

21 Patient Advocacy
Groups

**Working together to build consensus
and achieve improvement
in cancer care**

*To reduce the burden of cancer, improve outcomes and
the quality of care for cancer patients, **through
multidisciplinarity and multiprofessionalism***



Our Members



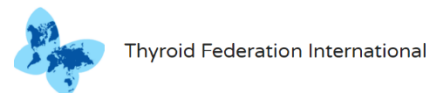
Our 42 Member Societies provide expertise in their discipline or profession in cancer

EAADV EUROPEAN ACADEMY OF DERMATOLOGY & VENEREOLGY
European Society of Endocrinology
CIRSE
EAPC VZW
ECL Association of European Cancer Leagues
EANM EUROPEAN ASSOCIATION OF NUCLEAR MEDICINE
EAU European Association of Urology
EFC European Federation for Colposcopy and Pathology of the Lower Genital Tract
eha
EUROPEAN HEREDITARY TUMOUR GROUP European Hereditary Tumour Group
ESM European Society for Sexual Medicine
EUROPEAN ONCOLOGY NURSING SOCIETY
EORTC European Organisation for Research and Treatment of Cancer
ERS EUROPEAN RESPIRATORY SOCIETY every breath counts
ESDO european society of digestive oncology
EASO European Association for the Study of Obesity
EFIC EUROPEAN PAIN FEDERATION
EHNS European Head & Neck Society
EUSOMA European Society of Breast Cancer Specialists
EUSOBI european society of breast imaging
ESCP European Society of COLOPROCTOLOGY
ESTRO
ESGO European Society of Gynaecological Oncology
ESOP EUROPEAN SOCIETY OF ONCOLOGIC IMAGING
UEG UNITED EUROPEAN GASTROENTEROLOGY
ESOP
European Society of Pathology
ESPEN The European Society for Clinical Nutrition and Metabolism
E-P-C European Pancreatic Club Founded 1965
EUROSKIN EUROPEAN SOCIETY OF SKIN CANCER PREVENTION
esso THE EUROPEAN SOCIETY OF SURGICAL ONCOLOGY
ean
IPOS INTERNATIONAL PSYCHO-ONCOLOGY SOCIETY
SIOG INTERNATIONAL SOCIETY OF GERIATRIC ONCOLOGY
MASCC Multinational Association of Supportive Care in Cancer www.mascc.org
EFOMP
IPVS International Papillomavirus Society
ECI
EASL™ The Home of Hepatology

Our Patient Advisory Committee



Patient Advocates are at the heart of the European Cancer Organisation, with 21 patient advocacy groups



The Patient Advisory Committee is involved in all policy-making and activities, including the Focused Topic Networks



Cancer Inequalities: ongoing



All cancer patients should have **equal rights** to quality cancer care as called for by the **European Code of Cancer Practice**;

The **Europe Beating Cancer Plan**, published in February 2021, included a chapter dedicated to inequalities but also the development of a monitoring tool, the **European Cancer Inequalities Registry**, proving the momentum on the topic.

Nevertheless, data and evidence on the topic shows that there is still a long way to go to beat cancer inequalities in Europe.



National and Social Inequalities



National Inequalities:

- Geographical inequalities exist in the EU across the cancer continuum. Disparities across countries in the European region are linked, among other reasons, to disparities in funding, technology, and national policies.

Data examples:

- Cervical Cancer Screening rate (women): 78.5% in Sweden vs 26% in Hungary (OECD, data for 2021)

Social Inequalities:

- Inequalities are pervasive among marginalised communities (e.g. people from racialised and LGBTQI+ community, people with disabilities etc..) across European countries. Inequalities for specific segments of societies are present different levels of cancer care.

Data examples:

- In Bulgaria, 42.8% of women with very low-income report to never have had X-Ray breast examination VS 13.30% of those in very high income (Eurostat, 2019)
- In Europe, 17% of LGBTQI+ people have felt discriminated in healthcare

Focused Topic Networks

Prevention,
Early Detection
& Screening Network



HPV and Hep B
Action Network



Health Systems and
Quality Cancer
Care Network



Research Policy
Network



Survivorship and
Quality of Life
Network



Digital Health
Network



Inequalities Network



Workforce Network



Emergencies and
Crises Network





The Inequalities Network

Aiming to achieve urgent actions to address inequalities, the Inequalities Network, is shining a spotlight on **policy mechanisms to bridge gaps and reach equity** in cancer across Europe.

Its work aligns with the **European Code of Cancer Practice's** aspiration to ensure equal treatment to every cancer patient.

The Network dedicates itself to **driving consensus, presenting policy recommendations and solutions, and sharing best practices** in relation to inequalities.





ECO's inequalities workstreams



- **LGBTIQ workstream:** launched in November 2022
Report on inequalities and recommendation for LGBTIQ disparities published June 2024
 - Ongoing development of survey on LGBTIQ cancer disparities for launch November 2024
- **Ethnicity workstream:** launched in November 2023, in collaboration with King's College and Exeter University
- **Rural-urban inequalities:** workstream focused on disparities between patients living in urban and rural contexts (in development)
- **Women and Cancer:** recently launched – publication of the paper taking place in November 2024



The European Cancer Pulse: From data to cancer action

- **Large inequalities exist** across the cancer continuum between countries and social groups in Europe
- **Timely data is crucial** for adequate public decision-making in health and cancer

Meanwhile...

- Data from the multiple stakeholder and international initiatives in quantifying cancer inequalities is **often not directly accessible** to policy-makers
- **Evidence gaps can drive implementation gaps** for health and cancer policy

The European Cancer Pulse: From data to cancer action

- The European Cancer Pulse is an **interactive data visualisation tool tracking inequalities in cancer** and their resolution across Europe
- Bringing together in one place multistakeholder data intelligence across:
 - All **EU and non-EU** European countries
 - All **areas of the cancer pathway and cancer policies**
 - All **determinants of inequalities** in cancer
 - All types of **available data** sources



The European Cancer Pulse: From data to cancer action

The European Cancer Pulse aims to:

- **Provide easy and public access** to, wide-ranging, currently fragmented data intelligence on cancer inequalities
- **Amplify data and initiatives** from across the cancer community on quantifying and tackling cancer inequalities
- **Foster political attention** to all determinants of cancer inequalities and their ambitious policy addressing

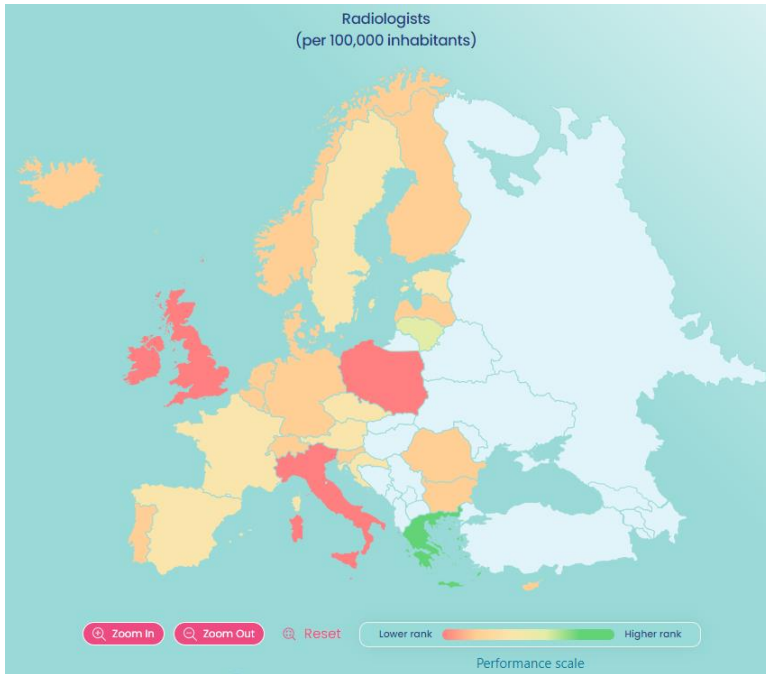
The European Cancer Pulse: Data

The **European Cancer Pulse dataset** includes:

- **250+ indicators** and **13,000+ data points** across **50 countries**
- Attention to **20+ inequality categories** covering differences:
 - **Between countries:** along the continuum of cancer epidemiology, prevention, care, research and policy
 - **Within countries:** according to socio-economic determinants and issues affecting historically marginalised communities
- **Best available comparable data** intelligence from international sources:
 - **Public institutions** (e.g. WHO, IARC, Eurostat, ECIS, EU agencies, OECD)
 - **Medical societies and stakeholder organisations** (e.g. EONS, EPF, WCRF)
 - **Academic expert groups and literature** (IHE, CONCORD, GBD)

The European Cancer Pulse: Cancer workforce issues

On cancer workforce, the **European Cancer Pulse** includes:



OECD/Eurostat **data on staffing across some major medical areas**

Lower rank Higher rank Performance scale

		Austria	Belgium	Bulgaria	Croatia	Cyprus	Czechia	Denmark
Cancer nursing patient and occupational safety index	Score	Green	Green	Orange	Red	Orange	Green	Yellow
Cancer nursing index	Score	Green	Green	Yellow	Orange	Yellow	Yellow	Green
Cancer nursing education and career development index	Score	Yellow	Yellow	Orange	Red	Green	Red	Green
Cancer nursing working conditions index	Score	Yellow	Green	Yellow	Yellow	Yellow	Orange	Orange
Cancer nursing recognition index	Score	Yellow	Yellow	Yellow	Yellow	Green	Yellow	Green

EONS Cancer Nursing Index on working conditions, safety, education and recognition

Overview Comparison

Compare

Countries: All Indicator: -

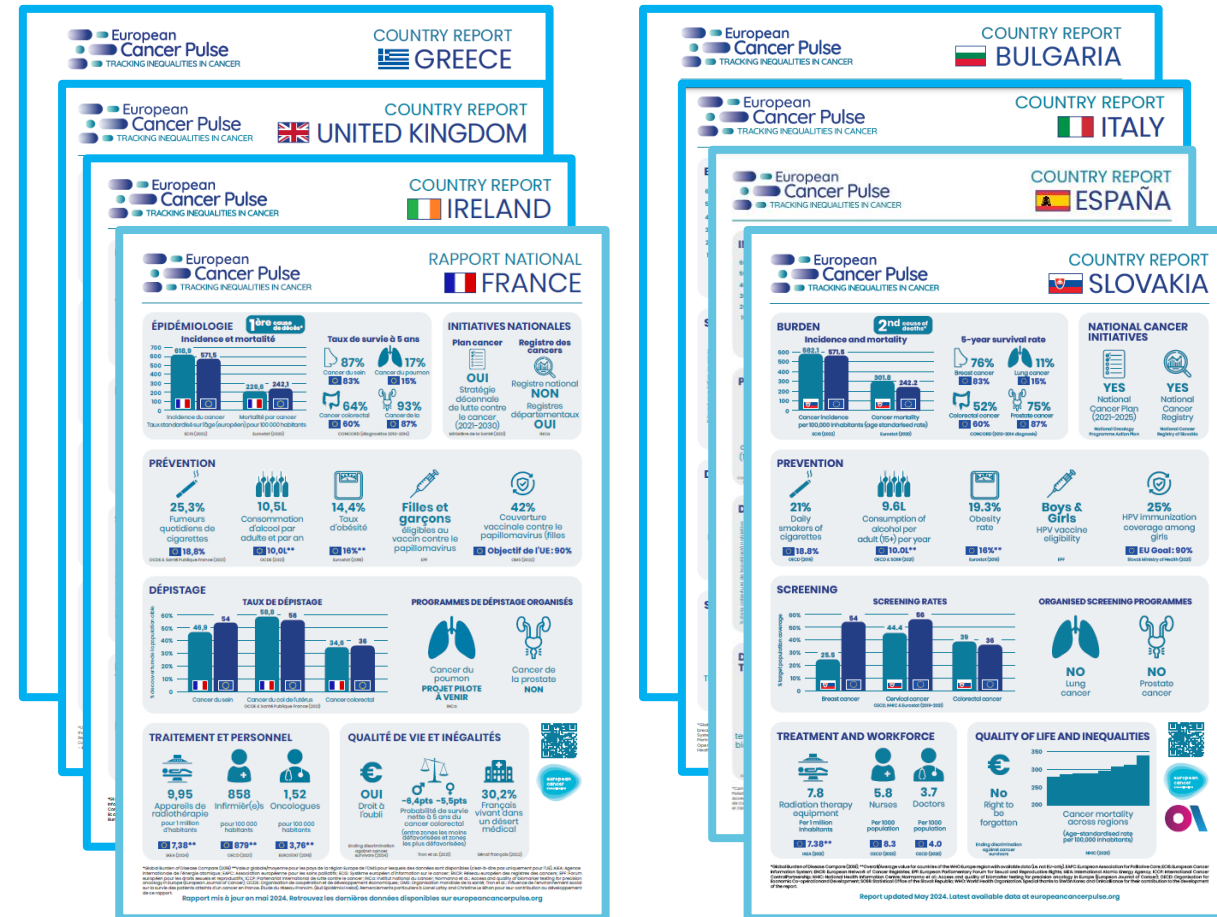
National cancer inequalities

- Cancer burden
- Cancer prevention
- Cancer screening and early detection
- Cancer diagnosis
- Cancer treatment and care
- Cancer survivorship and quality of life
- Cancer workforce
- Cancer workforce staffing
- Cancer workforce education, training and recognition
- Cancer professionals' working conditions and safety

The European Cancer Pulse: Action

The European Cancer Pulse informs cancer policy and advocacy:

- **Country reports** are produced as national factsheets including key data from the tool, in collaboration with local institutions and experts
- These reports form the basis of country visits of the **‘Time to Accelerate: Together Against Cancer’** pan-European campaign, driving **high media and policy impact** nationally

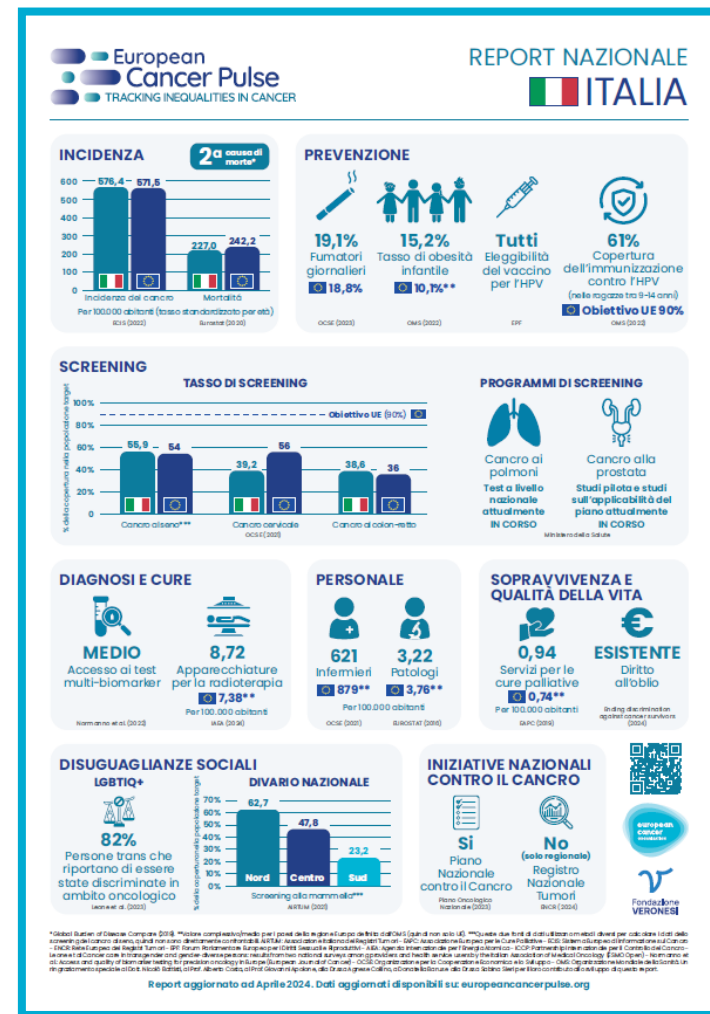




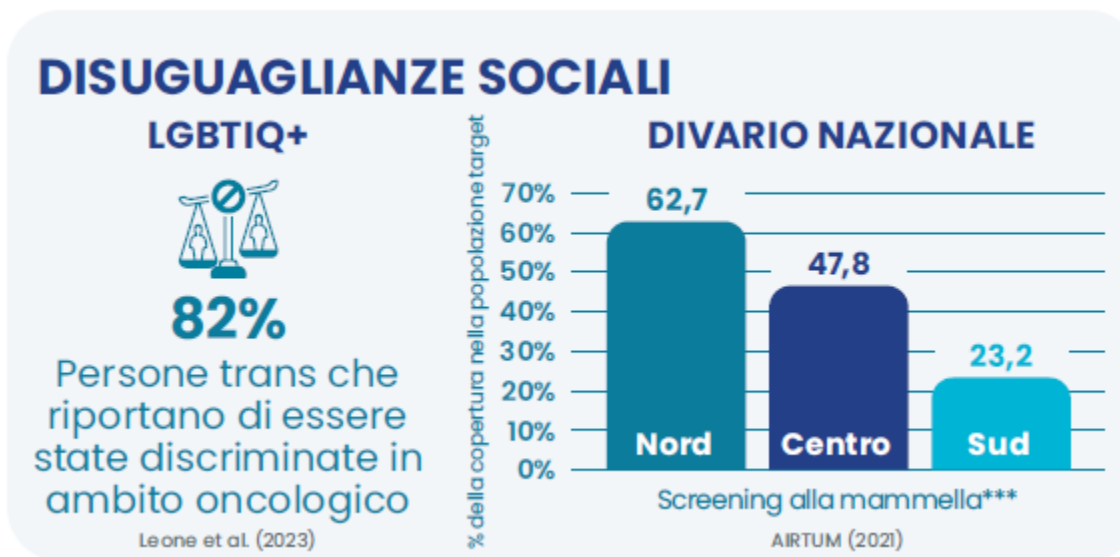
Report Nazionale per l'Italia



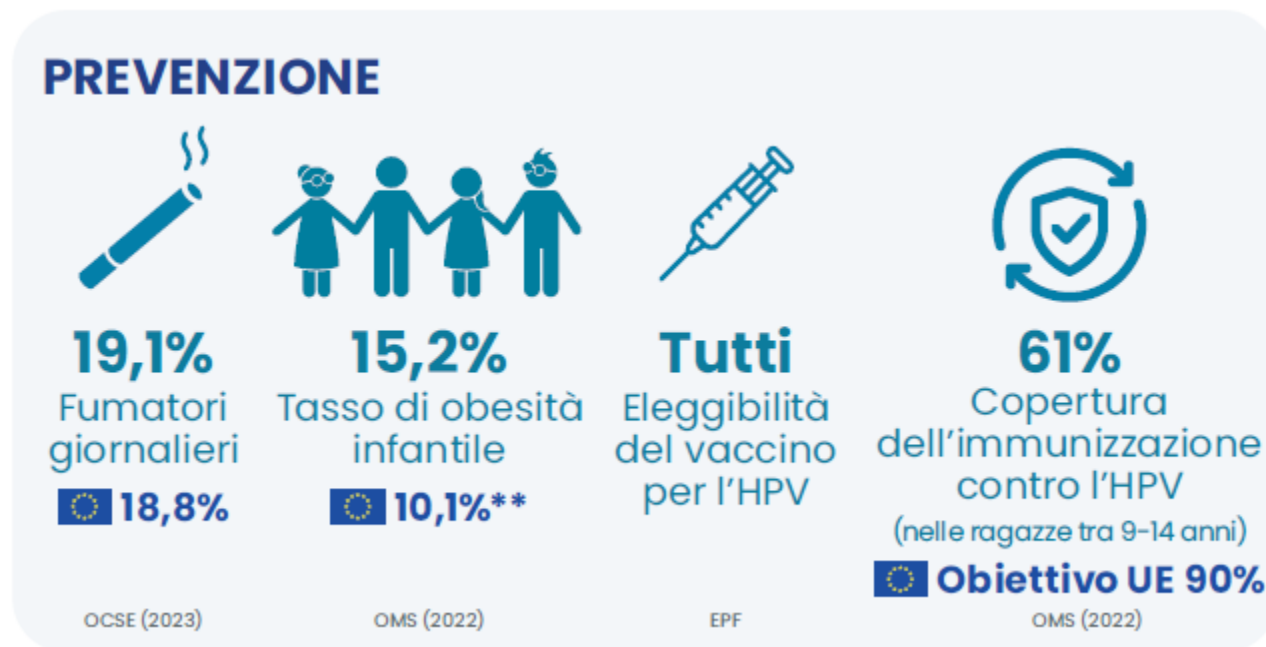
- Si tratta di una **scheda riassuntiva dei dati relativi all'oncologia in Italia**, con dati estratti dallo *European Cancer Pulse*
- Queste schede sono create per **informare la campagna *Time to Accelerate: Insieme contro il cancro***
- Report creato consultando **enti attivi sul territorio nazionale**



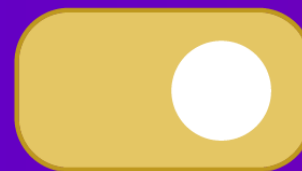
Disuguaglianze: pervasive regionalmente e a danno delle comunità marginalizzate



Prevenzione: Italia spesso peggiore della media europea in ambito di prevenzione contro il cancro



smartCARE



Empowering Cancer Survivors in Europe

Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Health and Digital Executive Agency (HADEA). Neither the European Union nor the granting authority can be held responsible for them.



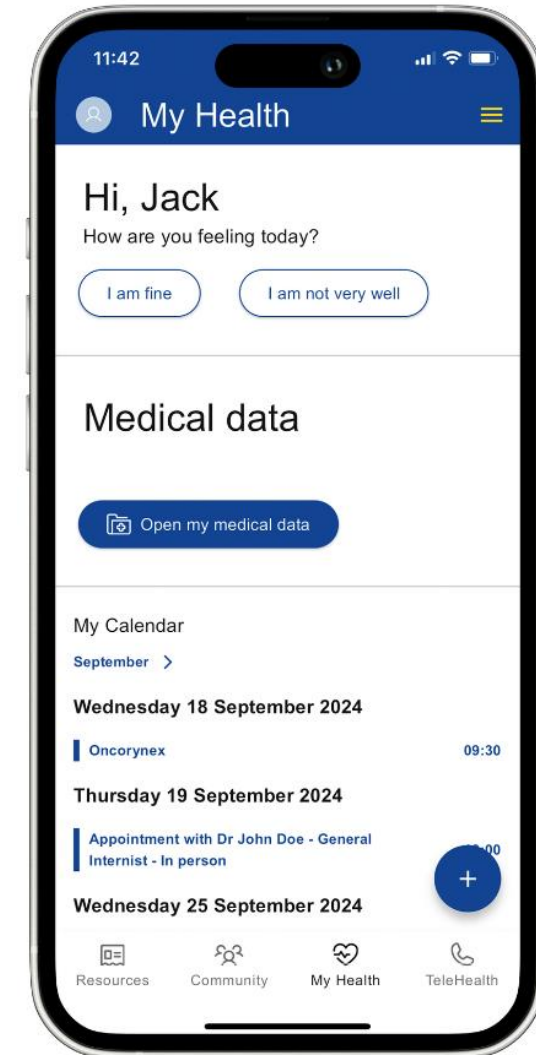
**Co-funded by
the European Union**

What is smartCARE?

smartCARE is a flagship initiative of the Europe's Beating Cancer Plan. It is an EU co-funded project that will look to develop a digital tool in the form of a mobile application that aims to improve the quality of life and health status for cancer survivors, patients and carers.

Main Aims and Objectives of the Project:

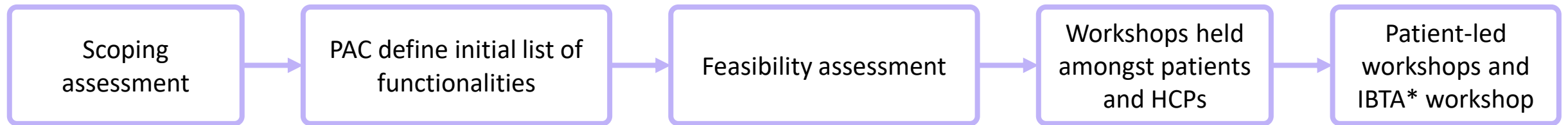
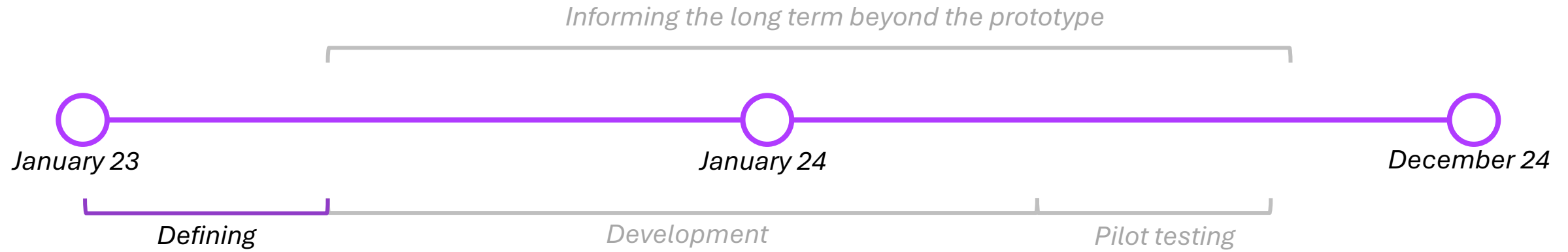
- Define the needs of cancer survivors for the App through an extensive user needs assessment and through consultation with the multistakeholder Consortium.
- The project will also support an App developer consortium to bring the vision to reality through the development and clinical testing of a prototype App.



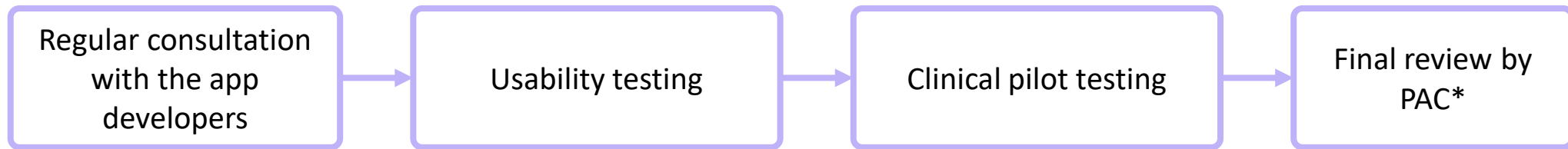
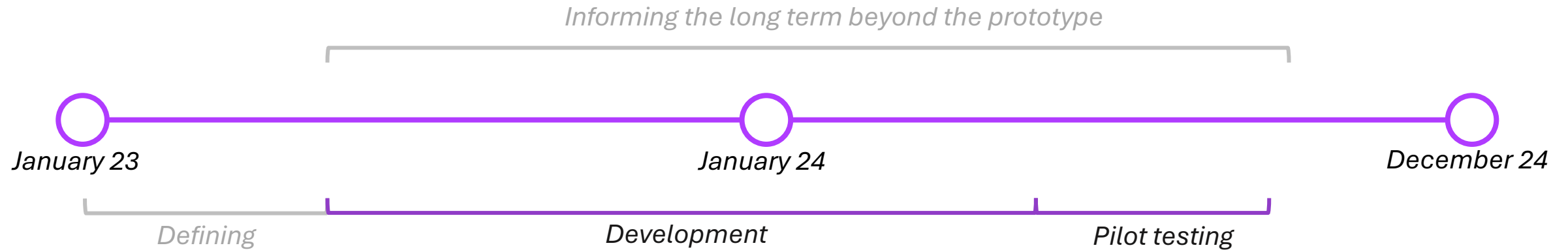
Who is behind the project?



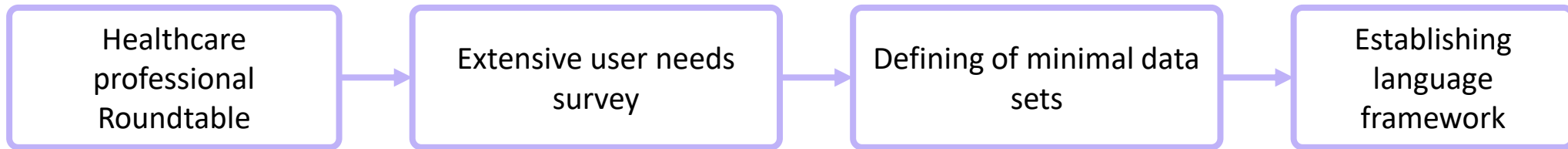
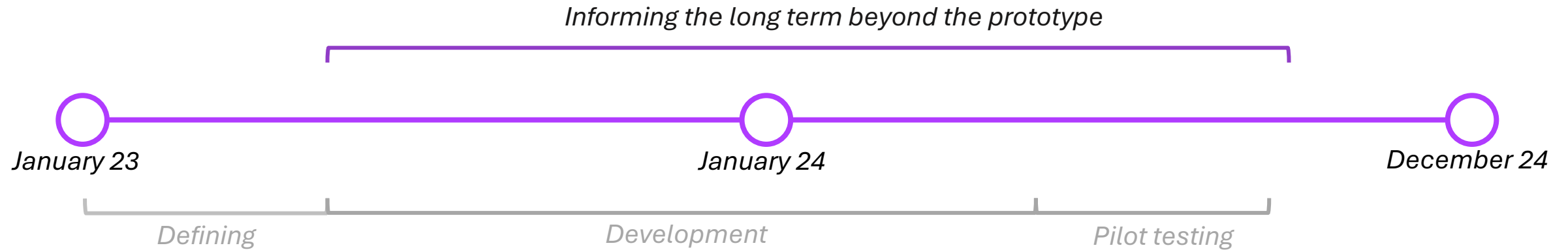
Key Timeline



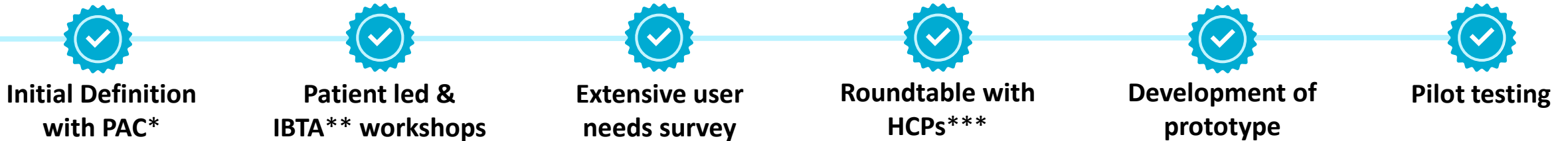
Key Timeline



Key Timeline



Summary of Key Achievements

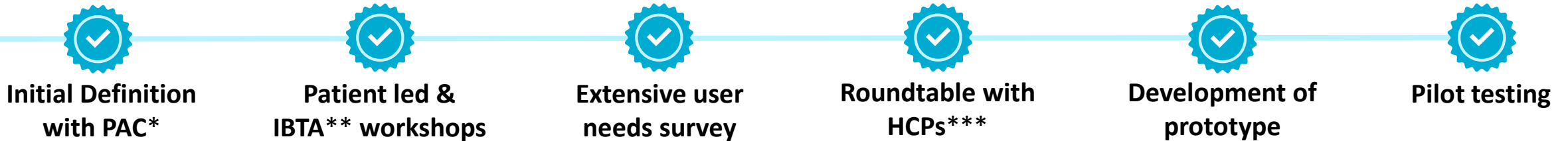


Initial definition with PAC: Initial definitions defined by the European Cancer Organisation’s Patient Advisory Committee.

Patient-led & IBTA workshops: 4 patient-led workshops and 1 additional workshop at the International Brain Tumour Alliance Work Summit held to understand the user needs from such an app.

Extensive user needs survey: An extensive survey amongst cancer survivors, patients and caregivers with over 1,000 responses to help define the future visions of the app. Survey translated into 18 languages and had tailored questions for different ages and co-morbidities.

Summary of Key Achievements



Roundtable with Healthcare Professionals: To understand how healthcare professionals see such App and whether the initial proposals make sense in the daily clinical practice.

Development of the prototype: Functional prototype developed in cooperation with an app developer consortium.

Pilot testing: Around 100 participants took part in a clinical test of the prototype in 5 hospitals across Europe, and an additional 50 in non-clinical structured interviews. Pilot testing concluded over the summer.

Key Findings from the User Needs Assessment

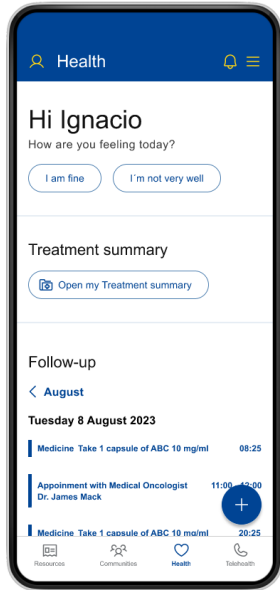
1. The uploading and tracking of **medical information** (such as medication and treatment) and symptom and side effects into the app.
2. **Telehealth** functionality and the ability to communicate with peers.
3. Useful **informational resources**.
4. Support for **mental health and anxiety**.
5. **Accessibility features** (including multilingual support) to ensure the app is usable for all cancer survivors.
6. Importance of **data protection** and ensuring the user has control over their data.

What efficiencies is smartCARE looking to improve?

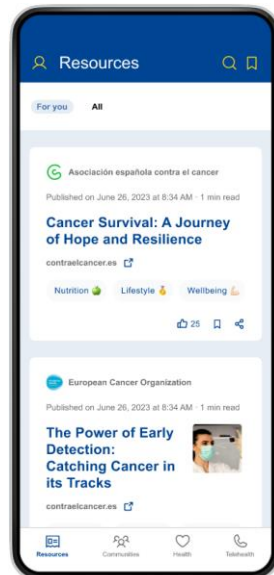
- The **storing of medical data** is crucial and can be hard for patients and even doctors to access.
- Patients are often required to **travel long distances to hospitals** for appointment and medical results.
- Easier access to and better **communication with healthcare providers**.
- Bridging the gap to **other cancer survivors, patients and caregivers** to share experiences.



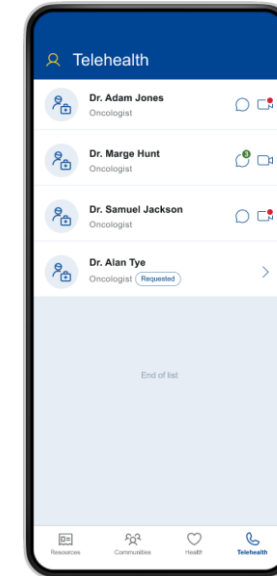
The Prototype Under Development



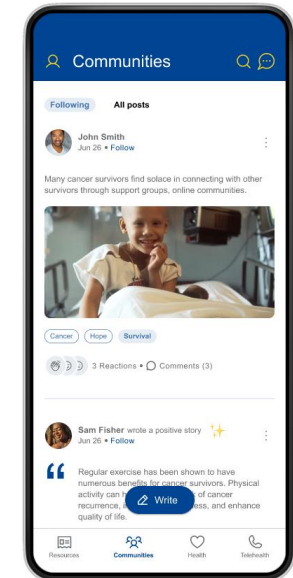
Storing of **health data** (i.e. tracking of medical events, symptoms & medicine), to be **taken to the doctor/across borders**.



Accurate, validated and **useful informational resources**

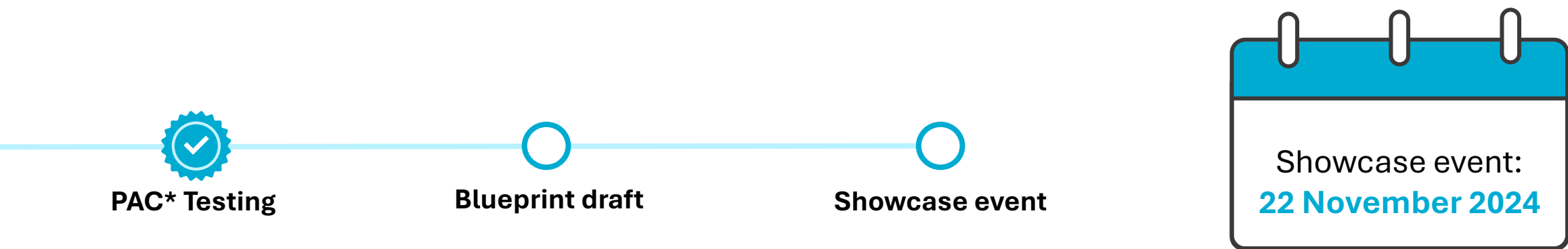


Communication between users and their **healthcare professionals**.



User interaction using an online forum/direct chat to **share experiences and get support**.

Next Steps



PAC testing: final in person review by the Patient Advisory Committee (Sept 2024)

Final Showcase event the day after the European Cancer Summit will feature:

- Two sessions featuring **interventions from leaders in oncology, patient advocacy, policymakers and app development** will reflect on the tangible work achieved in the project.
- **Two interactive workshops** that will give participants hands on experience with the smartCARE app prototype and gather their feedback that will be included in the final Blueprint document.

REGISTER NOW FOR FREE!

smartCARE 



**PROTECT
EUROPE.**

SHOWCASE EVENT

22 November 2024 – After the European Cancer Summit



Co-funded by
the European Union

The logo for the European Cancer Organisation is a white, irregularly shaped oval with a soft, glowing blue border. Inside the oval, the text "european cancer" is written in a bold, lowercase, blue sans-serif font, with "european" on the top line and "cancer" on the bottom line. Below "cancer", the word "ORGANISATION" is written in a smaller, uppercase, blue sans-serif font.

**european
cancer**
ORGANISATION

Let's stay in touch!

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