

# Cancer Care BEACON: Reducing disparities across the European Union

## OEI 46 – Oncology Days 2024



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the European Union**

# Reducing Disparities across the European Union



## Cancer Care Disparities

Cancer is the **second most prevalent cause of death** after cardiovascular disease in Europe.

In spite of this, **considerable disparities exist** between the quality of cancer care and clinical outcomes for cancer patients across European communities, hospitals, regions, and countries.

For instance, **cancer patients' survival differences go as high as 25% between different member states** for the same disease and stage of illness.

**Inequalities** in cancer **screening** vary by region, with significantly **lower morbidity and mortality in Western Europe**, where prevention programs and screening facilities are better developed, **compared to Central and Eastern Europe**, with underdeveloped screening infrastructure and procedures

Despite significant advances in cancer therapy, **there is still a long road ahead to improve disparities** in

- cancer screening
- diagnosis
- treatment
- quality of life
- management of survivorship
- palliative care



# Reducing Disparities across the European Union



## Cancer Care Disparities

Among the challenges encountered within and across Europe, **the most common disparities** are observed in

- **accessing information**,
- spiraling **costs** of healthcare,
- accessing **optimal treatment options** with complete treatment modalities and optimal outcomes,
- ensuring the **best Quality of Life** for patients during and after the treatment process,
- **integrating cancer research and innovative cancer care**,
- accessing networked, **multidisciplinary** cancer care **teams**.

Also, **outcomes** for patients with **rare cancers** are even **worse** than for patients with more common cancers mainly because of

- (1) the **delays** in obtaining accurate **diagnoses**,
- (2) **inadequate treatments**,
- (3) **restricted opportunities** for patients to participate in **clinical trials**.



For such cases, **there are substantial regional differences across EU countries in survival from rare cancers**, both for which there are no effective treatments and for those ones which respond well to treatment.

....This scenario suggests variations in the quality and availability of diagnosis and follow-up and differences in the use of effective treatment protocols



## Aim

- The 'EU Cancer Treatment Capacity and Capability Mapping' action aims to **map and share** the different **capabilities** and **expertise** available across the Union.

## Activities

- The action will **support** the **identification** of the different **capabilities** and **expertise** available across the Union, and build the foundation to regularly **identify gaps** and **needs** to be addressed at **national and regional levels across the Union**. At the same time, the **EU Network** of Comprehensive Cancer Centres will be **updated** on cancer care **innovation** as well as on cancer **workforce training**.

## EU4H-2021-PJ-11: Action grants for ‘EU Cancer Treatment Capacity and Capability Mapping’ project - Network of Comprehensive Cancer Centres



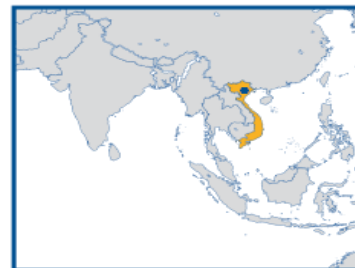
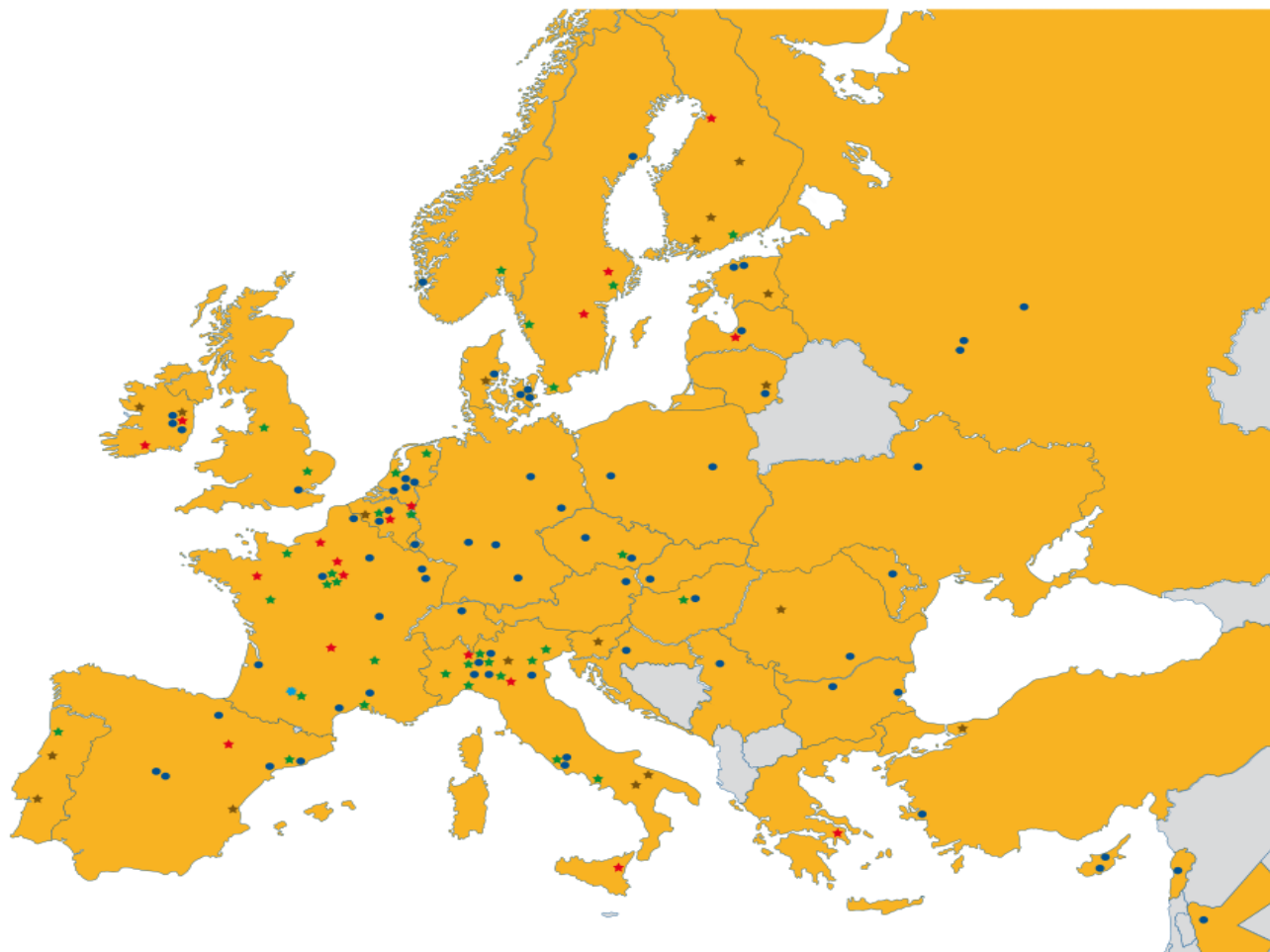
### Background

- “The European Guide on Quality Improvement in Comprehensive Cancer Control recommends as a **priority** the **establishment of Comprehensive Cancer Care Networks** [...] in all Member States as well as the **networking** of these centres at **Union level.**”
- “**Establishment** by 2025 of an **EU Network** linking recognised **National Comprehensive Cancer Centres** [...] to **facilitate the uptake of quality-assured diagnosis and treatment**, [...], including training, research and clinical trials across the Union”

# The OEICI Network



CANCER CARE  
— BEACON —



# Objectives - Endpoints



## Specific Objectives

- **OB1: Mapping** of capacity and capabilities across cancer centers in the European Union
- **OB2:** Creating and updating a **data repository** to **assist researchers** in **data access** and **sharing** and other **stakeholders** in gaining **useful information**
- **OB3:** Creating **decision support tools** that will assist our four stakeholders: **patients, providers, researchers** and **policymakers**

## Three main end products:

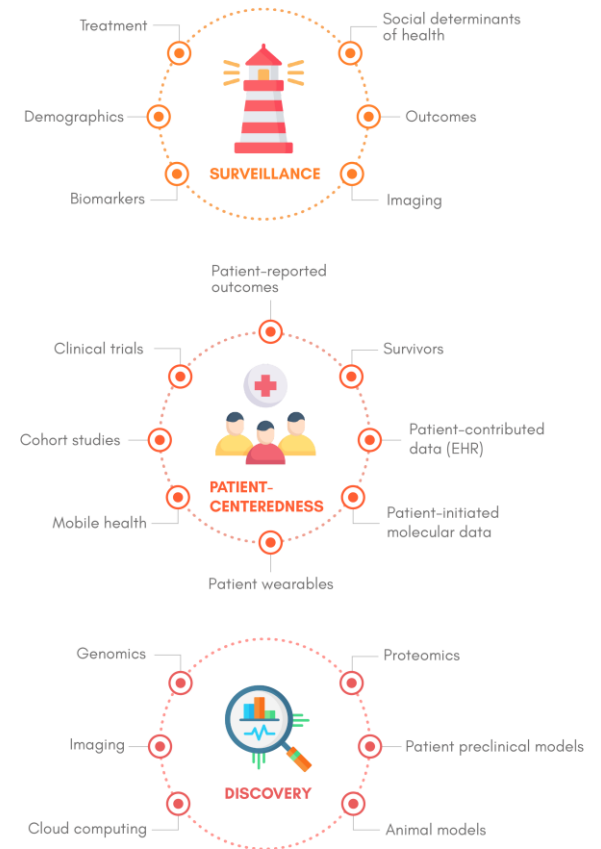
- (a) proposed **roadmap to scale** current **capacity and capabilities** in order to address existing cancer disparities
- (b) a plethora of reports, including both static documents and **interactive Web applications**, aimed at **supporting decision-making** for our four stakeholders
- (c) a **sustainability plan** on how we intend to directly work with our partners to **keep the project alive** and active beyond the two-year duration of the funding by EU4H.

# Focus Endpoint

## Online informative decision support tool

### To help:

- ➔ Patients in **finding** the **nearest** oncological **centre** and experiencing **easier access to comprehensive cancer care**
- ➔ Healthcare providers in **sharing resources, expertise and information** both with colleagues and patients
- ➔ Researchers in **sharing** and having **access to data**
- ➔ Policy makers in **aligning funding allocation with patients' priorities**





# Developing the Decision Support Tool: The Beacon Wiki



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Cancer Center

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## Cancer Beacon

(Redirected from Main Page)

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## Cancer Centers

This is a list of countries with cancer centers and other organizations that are part of Cancer Beacon.

### Contents [hide]

- 1 European Union
- 2 Austria
- 3 Belgium
- 4 Bulgaria
- 5 Croatia
- 6 Czech Republic
- 7 Denmark
- 8 Estonia
- 9 Finland
- 10 France
- 11 Germany
- 12 Greece
- 13 Hungary
- 14 Ireland
- 15 Italy
- 16 Latvia
- 17 Lithuania
- 18 Luxembourg
- 19 Malta
- 20 Poland
- 21 Portugal
- 22 Republic of Cyprus
- 23 Romania
- 24 Slovakia
- 25 Slovenia
- 26 Spain
- 27 Sweden
- 28 The Netherlands

# Developing the Decision Support Tool: The Beacon Wiki

## Italy [\[ edit | edit source \]](#)

[Centro di Riferimento Oncologico di Aviano](#)

[IRCCS Ospedale Policlinico San Martino](#)

[European Institute of Oncology](#)

[Fondazione IRCCS- Istituto Nazionale dei Tumori di Milano](#)

[Istituto Oncologico Veneto IRCCS-IOV](#)

[Humanitas Research Hospital](#)

[Istituto Nazionale Tumori -IRCCS 'Fondazione G.Pascale'](#)

[Azienda Unità Sanitaria Locale di Reggio Emilia - IRCCS Istituto in Tecnologie Avanzate e Modelli Assistenziali in Oncologia](#)

[Istituto Tumori Giovanni Paolo II, Istituto di Ricovero e Cura a Carattere Scientifico](#)

[IRCCS Centro di Riferimento Oncologico della Basilicata](#)

[Ospedale San Raffaele](#)

[Candiolo Cancer Institute](#)

[Mediterranean Institute of Oncology](#)

[Sacro Cuore - Don Calabria Hospital](#)

[IRCCS - Romagna Institute for the Study of Cancer 'Dino Amadori'](#)

[Fondazione Policlinico Universitario Agostino Gemelli IRCCS](#)

[Istituto Nazionale Tumori Regina Elena & Istituto Dermatologico San Gallicano](#)

[Fondazione I.R.C.C.S. Policlinico San Matteo](#)

## Latvia [\[ edit | edit source \]](#)

[Riga Eastern Clinical University Hospital](#)

## Lithuania [\[ edit | edit source \]](#)

[National Cancer Institute](#)



## Countries and Cancer Centers [\[ edit | edit source \]](#)

List of Countries and Cancer Centers included in Cancer Beacon

## Resources Integration [\[ edit | edit source \]](#)

### Tags Data Dictionary [\[ edit | edit source \]](#)

### Disparity maps [\[ edit | edit source \]](#)

### Glossary [\[ edit | edit source \]](#)

## Welcome to the BEACON Wiki [\[ edit | edit source \]](#)

The Cancer Care BEACON project, funded by the European Commission, is a groundbreaking initiative aimed at enhancing cancer care across the European Union by mapping cancer centers' capacities and compiling oncology datasets, among other cancer-related resources, and present them in an interactive, accessible application for all stakeholders. Designed to support patients, researchers, policymakers, and healthcare providers, the BEACON Decision-Support Application offers a comprehensive platform for informed decision-making and facilitates transatlantic collaborations and clinical trials. This concise resource empowers all stakeholders in the cancer care continuum with essential information to improve care and address disparities within the EU.

The Cancer Care Beacon Wiki is the collaborative platform where all information the BEACON project collects is stored, and it can be viewed and edited by all stakeholders. Through community effort, the Wiki aims to provide the highest-quality and accurate information about cancer care possible, and empower stakeholders to be a part of cancer care advances.

## Why contribute to the BEACON Wiki? [\[ edit | edit source \]](#)

Joining and contributing to the BEACON wiki offers a special chance for patients and hospitals to truly make a difference in cancer care.

**Patients** can help others by sharing their own stories and information, building a community where everyone has access to the knowledge they need.

**Hospitals and providers** can show off what they do best, making sure everyone knows about the great care they provide and working together to make cancer care better for everyone.

**Researchers and policymakers** also play a crucial role, by contributing cutting-edge findings and shaping supportive policies, they help

# Some crucial results: Access and Provision of cancer care

Main themes emerged from focus groups discussions (Italy, Croatia and Slovakia)



## Waiting lists and bureaucracy

Long waiting times

Corruption, personal connections

Bureaucratic hurdles

## Geographical and regional disparities

Physical and spatial limitations

Insufficient training, resources and instrumentations

Underserved rural areas

## The cancer financial burden

Travel costs

No treatment in Europe without private insurance

Healthcare privatisation

## Psycho-oncological support

Neglect of mental health

Stigma and prejudice

Lack of awareness and education

## Shared decision-making

No attentiveness and support from doctors

No trained and informed GPs

Neglect of side effects

## Information needs and use of Internet

Unclear, unaccessible and unhelpful information or reliable sources

Mistrust in online sources or professionals

# Disparities in Psycho-oncological support



## Team of psychologists and researchers (IEO, UNIPA)

➔ Focus on **disparities in Psycho-oncological care**:

- . **Cancer patients** have a **higher prevalence of mental disorders** compared to the general population across various tumor types
- . **Emotional distress** and psychiatric morbidity in cancer patients are linked to **reduced quality of life, impaired social relationships, longer rehabilitation time, lower treatment compliance, and shorter survival**
- . Providing **psycho-oncological support** is **crucial**, as it effectively reduces anxiety and depressive symptoms, **improves treatment adherence**, and **enhances the quality of life** for cancer patients, survivors, and their families
- . **Disparities persist** between European countries and within regions, with barriers hindering cancer patients and their families from accessing vital psycho-oncological support.

# ESMO Clinical Guidelines



## Assessment:

- Regular screening at diagnosis, during treatment, and at follow-up.
- Use of standardized tools like HADS or PHQ-9.

## Depression Treatment:

- Psychotherapy (psychoeducation, CBT, supportive-expressive, MBT).
- Medications (ADs).
- Combination therapy for optimal outcomes.

## Anxiety Treatment:

- Psychotherapy (MBT, CBT, supportive-expressive).
- Medications (ADs, Anxiolytics)
- Relaxation techniques (deep breathing, progressive muscle relaxation).



SPECIAL ARTICLE

### Anxiety and depression in adult cancer patients: ESMO Clinical Practice Guideline<sup>†</sup>

L. Grassi<sup>1</sup>, R. Caruso<sup>1</sup>, M. B. Riba<sup>2,3</sup>, M. Lloyd-Williams<sup>4,5</sup>, D. Kissane<sup>6</sup>, G. Rodin<sup>7</sup>, D. McFarland<sup>8,9</sup>, R. Campos-Ródenas<sup>10</sup>, R. Zachariae<sup>11,12</sup>, D. Santini<sup>13</sup> & C. I. Ripamonti<sup>14</sup>, on behalf of the ESMO Guidelines Committee<sup>\*</sup>

<sup>1</sup>Institute of Psychiatry, Department of Neuroscience and Rehabilitation, University of Ferrara, Ferrara, Italy; <sup>2</sup>Department of Psychiatry, University of Michigan, Ann Arbor; <sup>3</sup>University of Michigan Rogel Cancer Center, University of Michigan, Ann Arbor, USA; <sup>4</sup>Academic Palliative and Supportive Care Studies Group (APSCSG), Primary Care and Mental Health, University of Liverpool, Liverpool; <sup>5</sup>Department of Supportive and Palliative Care, Liverpool John Moores University, Liverpool, UK; <sup>6</sup>Department of Psychiatry, Monash University and Monash Medical Centre, Monash Health, Clayton, Australia; <sup>7</sup>Department of Supportive Care, Princess Margaret Cancer Centre, Toronto, Canada; <sup>8</sup>Department of Psychiatry, University of Rochester, Rochester; <sup>9</sup>Wilmont Cancer Institute, University of Rochester Medical Center, Rochester, USA; <sup>10</sup>Department of Psychiatry, Hospital Clínico Universitario Lozano Blesa, University of Zaragoza, Zaragoza, Spain; <sup>11</sup>Unit for Psychooncology and Health Psychology, Department of Oncology, Aarhus University Hospital, Aarhus; <sup>12</sup>Department of Psychology and Behavioural Sciences, Aarhus University, Aarhus, Denmark; <sup>13</sup>UOC Medical Oncology, AUSL Latina, Sapienza University of Rome, Aprilia; <sup>14</sup>Oncology-Supportive Care in Cancer, Department of Oncology & Haematology Fondazione IRCCS, Istituto Nazionale dei Tumori di Milano, Milan, Italy



Available online 14 March 2023

Key words: anxiety, depression, cancer, oncology, psychiatry, psycho-oncology

# Some crucial results: Disparities in access, use and provision of psycho-oncological support



## Disparities in psycho-oncological support

### Economic factors and Resource allocation

only 37% of European countries allocate a specific budget for POS

### Knowledge and Awareness

Lack of understanding about the impact of POS on health and quality of life of cancer patients and their families

### Socio-Demographic factors

Older, males, lower education and income receive less POS

### Cancer Type

Breast cancer patients tend to receive more POS than prostate (possibly related to gender)

### Geographical disparities and ruralness of residence

Eastern and Southern European countries lower-quality cancer care compared to Nordic

### Certification and Quality standards

Differences in screening measurements, national quality standards, policies, institutional capacities, training programs and specialised staff availability

# Results informing the Decision support tool



## Waiting lists and bureaucracy

Clear information on procedure, rights and timing

## Geographical and regional disparities

Mitigating regional disparities through information dissemination on nearby healthcare facilities and services (e.g., Medici nella tua città)

Geolocalisation of nearby centres

## The cancer financial burden

Data to inform better resource allocation and funding for financial support and its awareness

## Psycho-oncological support

Providing information on Psycho-oncology services, where to find them and how to access them

## Shared decision-making

Provide training on communication

Empathy, communication skills, time

## Information needs and use of Internet

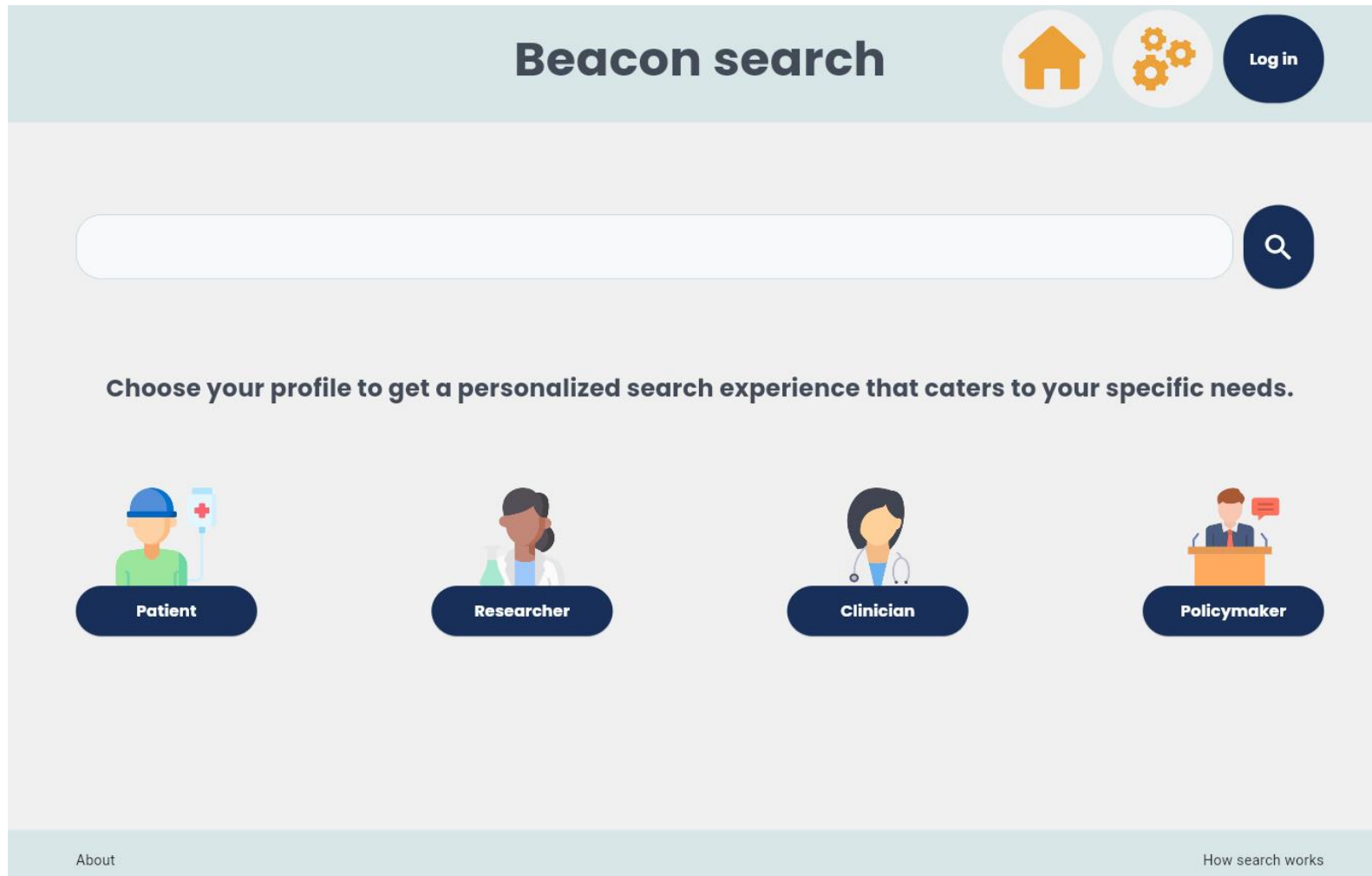
Information on rights, hospitals/centres, exams/treatments

Updated information on therapeutic procedures

List of reliable sources



# Decision support tool - Overview



The screenshot shows the main interface of the Beacon search tool. At the top, there is a light blue header with the text "Beacon search" on the left and three icons on the right: a home icon, a gear icon, and a "Log in" button. Below the header is a large white search bar with a magnifying glass icon on the right. Underneath the search bar, a text prompt reads: "Choose your profile to get a personalized search experience that caters to your specific needs." Below this prompt are four profile selection buttons, each with an icon and a label: "Patient" (with a person wearing a blue cap and a green shirt), "Researcher" (with a person in a white lab coat holding a flask), "Clinician" (with a person in a white lab coat and a stethoscope), and "Policymaker" (with a person in a suit speaking at a podium). At the bottom of the interface, there are two links: "About" on the left and "How search works" on the right.



Welcome to  
Beacon App



Enter your username or email address

Enter your Password

Beacon search

Reset your password

Log in

Sign up



# Psycho-Oncology in Beacon



Beacon search

Home Settings Log in

Q "psycho-oncology"

**Filters**

Clear all filters X

Type of Information v

Countries ^

- Italy 3
- Belgium 1
- Spain 1
- Others 25
- Germany 1
- France 1

**European Institute of Oncology**

**Type of information:** Surgery Prevention And Oncological Genetics Oncohematology Program **Psycho-oncology** Radiology Interventional Radiology Breast Radiology Radiotherapy Second

**Technical details:** 22951KB (368 words) - 12:57, 12 May 2024

**Institut Jules Bordet**

**Type of information:** Go back to Cancer Centers list.

**Technical details:** 7949KB (6 words) - 12:52, 02 May 2024

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# Progress and further steps

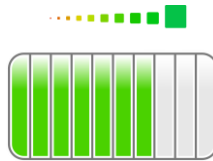


Development of Mobile Application as Decision support tool:

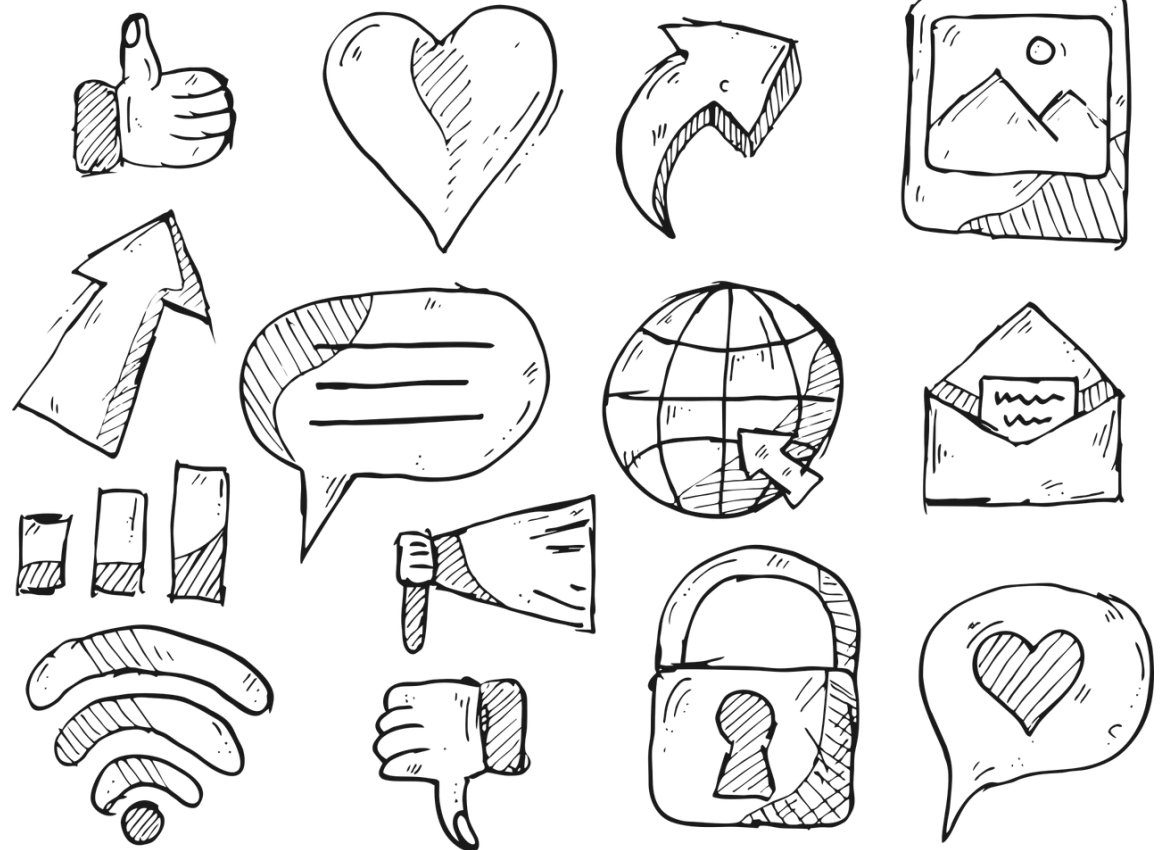
.Use cases



.Usability testing



.User experience



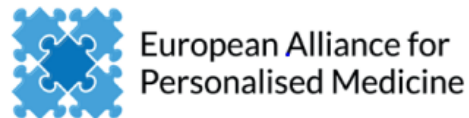
# Thank you! Questions?



The BEACON Consortium



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