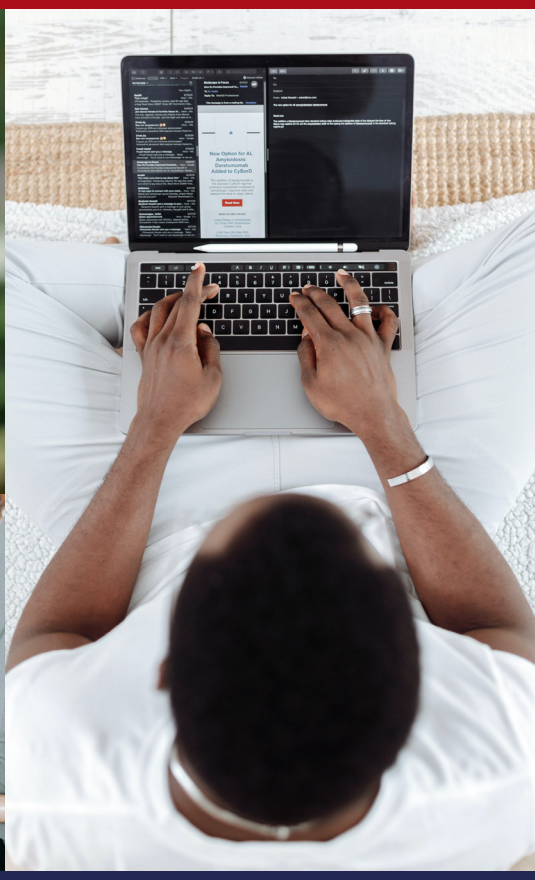
ECL PATIENT SUPPORT WORKING GROUP

A BETTER LIFE FOR CANCER PATIENTS AND SURVIVORS

Cancer leagues' reflections on comprehensive cancer rehabilitation



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ABOUT THE ECL PATIENT SUPPORT WORKING GROUP

Since 2007, the Patient Support Working Group (PSWG) of the Association of European Cancer Leagues (ECL) has been bringing together cancer care experts to collaborate on topics such as access to insurance and financial services, return to work, caregiver support, cancer rehabilitation and palliative care. PSWG members share best practices and develop guidelines and other sources of information to help raise awareness, improve quality of care, and strengthen the patients' voice in national and European policy-making.

The PSWG subgroup on Cancer and Rehabilitation was established in 2019 to share knowledge and best practices among cancer leagues in the WHO European region around cancer rehabilitation programmes. The PSWG collected information on the variety of much-needed rehabilitation programmes provided by cancer leagues in their communities and then developed two editions of the Cancer Rehabilitation Atlas. The latest edition is an inventory of 61 rehabilitation programmes carried out by ECL members, which provides information about these programmes and their activities that support the physical and psycho-social rehabilitation of patients and caregivers. This publication may also serve to inspire other cancer leagues, healthcare professionals and stakeholders.

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1. INTRODUCTION

The European Commission Joint Research Center (JRC) estimates that about four million new cancer cases were diagnosed in Europe in 2020 and projects the number of new cases per year to increase to 5.2 million by 2040 (1). More optimistically, cancer survival rates are also continually increasing, due to improvements and innovation in screening programmes, treatment, and care (2). Nonetheless, both the disease trajectory and treatment remain associated with significant negative effects, including late and long-term effects. About 40% of cancer survivors suffer from depression or anxiety (3), and many experience fatigue and physical ailments including pain, lymphedema, sexual and cognitive problems (4).

That is why it is of paramount importance to provide cancer patients and survivors with rehabilitation services that support their quality of life beyond the acute treatment phase, addressing long-term and late effects, and integrating psychosocial considerations. Well-designed rehabilitation services can greatly contribute to positive health, social and professional outcomes for cancer survivors, while also reducing long-term care needs and overall healthcare costs. Effective cancer rehabilitation is therefore not only beneficial to cancer survivors as individuals, but also to their community and to society at large.

Addressing long-term and late effects after cancer

Besides deteriorating people's physical and mental wellbeing in general, reducing their opportunities for social contact and negatively impacting their quality of life, cancer and cancer treatment can cause side effects that might appear during, immediately after or even years after treatment. These **late and long-term effects may further impair the physical wellbeing of cancer survivors**, negatively impacting their cardiovascular, endocrine, neurocognitive, sexual and reproductive functions among others. These can in turn harm their **psychosocial wellbeing**, often to the detriment of relational and professional satisfaction. Moreover, it is important to consider that, while creating specific needs for all age groups, late and long-term effects especially take a toll on those who experienced cancer as **children, adolescents and young adults** (5). Therefore, **European Cancer Leagues reaffirm the central role played by rehabilitation services in tertiary prevention, calling for the recognition and inclusion of early diagnosis and treatment of late effects as a key component of the cancer care trajectory**.

What is cancer rehabilitation?

According to the World Health Organisation (WHO), rehabilitation is "*a set of interventions needed when a person is experiencing or is likely to experience limitations in everyday functioning due to ageing or a health condition [...]. Examples of limitations in functioning include difficulties in thinking, seeing, hearing, communicating, moving around, having relationships, or keeping a job. Rehabilitation enables individuals of all ages to maintain or return to their daily life activities, fulfill meaningful life roles and maximize their wellbeing*" (6).

Cancer rehabilitation must consider the multidimensionality of cancer survivorship, as cancer has an array of implications that affect the whole person, not just their body, but also their mental health and their social and even spiritual well-being. **Effective cancer rehabilitation is built upon constructive communication with patients and survivors and requires a set of multidisciplinary team interventions**. Rehabilitation activities will most often be a collaborative effort between the patient or survivor and relevant health care professionals, with carers and relatives also playing a role.

Rehabilitation is a rather new but growing field in cancer care, and cancer leagues across Europe play an important role in offering innovative and comprehensive programmes.

2. WHAT MAKES CANCER REHABILITATION COMPREHENSIVE? AN OVERVIEW OF THE LITERATURE

Assessing cancer rehabilitation needs

Cancer patients and survivors may experience high levels of distress, including physical distress, psychological hardships and negative experiences in the spiritual, social and emotional spheres. These factors often act together and negatively affect the quality of life of cancer patients (7, 8, 9, 10).

The early and systematic detection of the distress and related needs of cancer patients and survivors is a stepping stone for rehabilitation programmes. The **CanCon Guide** recommends that rehabilitation activities start with a **multidimensional needs assessment** (5), while the **ESMO Handbook on Rehabilitation** suggests developinga **survivorship care plan** to prepare the patient for the post-treatment phase by addressing rehabilitation needs as well as late effects occurring in the follow-up period (6).

Needs assessments should be offered to all cancer patients and incorporated in routine clinical activity at all healthcare levels. To be most effective, they should start as early as possible in the cancer trajectory, becoming an integral part of diagnosis, treatment, rehabilitation and follow-ups, until the end of life (5, 11). In some cases, a needs assessment conducted at the time of diagnosis could point to prehabilitation needs - namely, result in the identification of services to be offered before treatment, such as physical training, dietary and smoking cessation interventions.

Such assessments should be as comprehensive as possible, covering physical aspects (i.e., functional assessment and symptom burden, pain, gastrointestinal and urological complications, sexual and reproductive issues), social aspects (i.e., relational and occupational issues), and psychological aspects, including emotional and spiritual issues (5, 7). They should be based on regular monitoring carried out through well-designed, validated tools that are brief, rely on good performance parameters (both qualitative and quantitative) and are acceptable for the front-line staff (5, 11). Assessment through Patient-Reported Outcome Measures (PROMs) should also be included (12).

Elements in a cancer rehabilitation programme

When professional care is necessary after the needs assessment, the interrelation and complexity of needs should be determined to provide appropriate information and/or referral to specific psychosocial, training and rehabilitation services, including specialised and interdisciplinary services (7, 11, 13). Importantly, information should be provided in a clear, timely and appropriate manner with the aims of improving health literacy, empowering patients and survivors and fostering the adoption of effective self-management behaviours (14, 15).

During their rehabilitation programmes, patients and survivors should learn about positive lifestyle changes like improving their diet, quitting the use of tobacco products and getting more physical activity, all of which could contribute to their rehabilitation and improve their health. Getting adequate physical activity is especially beneficial to those undergoing or recovering from treatment. Programmes for physical rehabilitation should be **individually tailored**, while generally consisting of moderate aerobic training and progressive resistance training, to improve muscle strength and reduce cancer-related fatigue (7, 11, 13). The growing body of evidence on the effects of High-Intensity Training (HIT) approaches should also be considered (16, 17, 18, 19).

Psychosocial support, psychoeducation and different types of psychotherapy should also be provided to address common issues such as fatigue, anxiety, depression, fear of recurrence, and sleep disorders (11, 20, 21).

Literature (22) shows that the use of complementary and alternative methods (CAM) has grown among cancer patients in Europe. Therefore, **further attention and research should be devoted to integrative oncology**, the evidence-based incorporation of complementary medicine modalities into conventional cancer care (23, 24, 25).

Rehabilitation programmes should be cognisant of the issues cancer patients and survivors often face with regards to returning to work, and systematically include this aspect as a component of rehabilitation services. Occupational physicians and social workers in particular can play a central role in supporting survivors in this area - providing, together with other healthcare professionals, timely interventions geared towards individual needs that can improve medical and functional recovery so as to facilitate the return to work (11, 20, 26).

Attention to sexual and reproductive health should also be paid, including a focus on the broad spectrum of sexuality and intimacy issues that cancer survivors may experience. Gaps in healthcare professionals' training in this realm should be adequately addressed, patients should be encouraged to address this topic, and adequate referral should be provided as needed (27).

Other recommended interventions are related to symptoms and late effects such as **pain, cognitive problems** and **lymphedema** and aim at improving the general quality of life for cancer survivors. Some cancers such as **head and neck cancer** will require **specialist rehabilitation programs** focusing on nutritional needs, neuromuscular problem management, speech therapy, lymphedema management and dental care (20).

Inequalities in rehabilitation needs and care

Inequalities are ubiquitous in healthcare, and the field of cancer rehabilitation is no exception. The determinants of inequalities in demanding and accessing cancer rehabilitation services can most often be traced back to systemic barriers rather than individual choices. Similarly, the literature shows inequalities in the ability of rehabilitation programmes to effectively meet the needs of individuals from different social classes and structures. These factors should be considered and addressed when setting up comprehensive programmes for cancer rehabilitation.

Across the European Union (EU), **healthcare systems may still face barriers in implementing effective rehabilitation** programmes for cancer survivors due to challenges in resources, infrastructure and perceived relevance of rehabilitation as part of the care pathway (28). In addition, **the inclusion of rehabilitation in national cancer plans varies** and specific **guidelines for cancer rehabilitation services** are **not always available** (29).

Deterioration of physical, mental and social quality of life in survivorship is strongly connected to precarious living situations, which are often common among underserved, vulnerable individuals with limited financial resources (5). Cancer patients with a low income at the time of diagnosis and treatment tend to participate less frequently in rehabilitation activities, if these are available, and may have more rehabilitation needs - which are often determined by pre-existing, unmet healthcare needs (30).

Gender and age, together with employment and education status of cancer survivors, figure as key factors in determining both the participation in rehabilitation activities and the ability of cancer rehabilitation programmes to meet the needs of patients (30, 31). Overall, studies suggest that participation in rehabilitation programmes tends to be more limited among survivors who have a lower socio-economic and educational status (30), while results on gender and age vary (30, 1). Unmet needs appear to be higher among cancer survivors who live alone, regardless of gender (30), and among older survivors (31).

3. CASE STUDIES: WHAT CAN BE LEARNED FROM THE EXPERIENCE OF CANCER LEAGUES?

Improved cancer care allows patients to transition from in-patient primary care to follow-up care and rehabilitation - which is provided in different settings across the EU, often including out-patient services. In this newly emerging context, **cancer leagues** - as non-profit organisations acting in the best interest of the public to ensure better cancer control and care - **are uniquely positioned to address patients' unmet needs that arise from the gaps witnessed in public health services across Europe** (29).

In 2021, building on the results of a survey carried out in 2019, ECL published the 2nd Rehabilitation Atlas, which provides an overview of 61 rehabilitation programmes carried out by 16 of the 31 cancer leagues represented by ECL (32). The Atlas aims at creating a non-exhaustive inventory of cancer leagues' action in the realm of cancer rehabilitation and related contact points, hoping to guide patients and caregivers and to inspire healthcare professionals active in the field.

Further reflecting upon and providing new insights on the role that cancer leagues play in rehabilitation, this section provides a snapshot of the key characteristics of four rehabilitation programmes offered by cancer leagues in **Denmark, Spain, Slovakia** and **Belgium**. These case studies are presented to illustrate pragmatic approaches that are currently adopted in different European countries to address the complex rehabilitation needs of cancer patients. At the end of the section, key learning points emerging from expert discussions and opinions on the lessons learned from these programmes are summarised.

Body & Cancer Programme

- The Danish Cancer Society

Since its establishment in **2001**, more than **2000 cancer patients** from different diagnostic groups who were undergoing chemotherapy have participated in the Body and Cancer Programme. This rehabilitation programme, carried out by the Danish Cancer Society in collaboration with oncology departments at ten Danish hospitals, offers **physical training, including aerobic and resistance training, to cancer patients receiving chemotherapy, supplemented by massages, training on relaxation and body awareness**.

Patients attend training in **groups of 12 to 16 participants**, with **four sessions per week over six weeks that are tailored to the needs of individual patients**. To assess these needs as well as patients' progression, participants are tested for strength, fitness and weight during the programme. A randomised study comparing participants to non-participants shows that the programme reduces fatigue and increases physical capacity, energy, and emotional wellbeing (33).

Kids' rehabilitation programme

- Catalan Federation Against Cancer (FECEC)

For more than 30 years, the Association of Family and Friends of Oncological Children of Catalonia (AFANOC) has been implementing a **rehabilitation programme targeting children, with 900 pediatric oncological patients participating each year**. The programme, carried out in partnership with Barcelona's leading hospitals, takes place in the Casa dels Xuklis - **a reception house with 25 apartments** where children and adolescents undergoing treatment and their families receive free temporary accommodation.

Access to the programme is determined through an **ad-hoc assessment of medical and social needs** that requires collaboration between healthcare staff and social workers. AFANOC works within reference hospitals and has direct contact with all families from the moment of diagnosis, providing them with stable psychosocial support.

The programme includes activities that cover the **psycho-pedagogical and psychomotor needs** of young cancer patients, as well as **socio-educational games and workshops, family meetings, and summer camps**. In addition, social and **emotional monitoring and support** throughout the cancer treatment is provided.

Activities in Cancer Help Centers

- League Against Cancer Slovakia (LPR)

Cancer Help Centers (CHCs) have been established in Bratislava, Košice and Martin in 2008, 2009 and 2010, respectively. The Centers currently offer a safe place where a wide spectrum of **care and supportive services** are provided to cancer patients, their carers and close loved ones, from diagnosis onward, **free of charge**. **Community building is a key driver** for the CHCs, to break taboos and the common belief that cancer equals the end of normal life.

In CHCs, **multidisciplinary teams provide advice and counseling tailored to individual needs through individual consultations, psychological therapy, and group meetings**. These services are available for patients and carers alike, and are provided by psychologists experienced in the field. The CHCs also offer physiotherapy and rehabilitation sessions for patients with trained physiotherapists, with a minimum package of ten sessions per patient.

Group programmes focus on teaching **techniques to reduce anxiety and feelings of helplessness**, support psychological and physical adjustments following cancer diagnosis, and create a feeling of wellbeing. The Centers also offer yoga classes, Pilates, Nordic walking, artwork, art therapy, language courses, social events, trips, and excursions. The aim is to support patients with making social connections, improving their mental health, building resilience and improving their overall health.

RECONNECT Platform

- Foundation Against Cancer Belgium

RECONNECT is a free online platform developed by the Foundation Against Cancer Belgium to **support employers welcoming back to work employees during or after their cancer treatment**. With over 26000 people of working age diagnosed with cancer every year in Belgium, the Platform facilitates a positive return to work by **providing information on the different steps to successfully reintegrate employees who have been undergoing cancer treatment**. This information is available to users as exercises, videos and testimonials that have been developed based on case studies and on the expertise of the Foundation Against Cancer Belgium. Furthermore, the Platform includes a directory that links users to a network of coaches trained by the Foundation, to offer personalised support to employees, teams or employers.

WHAT DID WE LEARN?

Based on the programmes listed above, expert representatives of the cancer leagues involved in these programmes identified some key learning points to consider for comprehensive cancer rehabilitation:

- Rehabilitation should be **part of the entire patient pathway** and start as early as possible, ideally from the moment of diagnosis or, at the latest, during treatment.
- Cancer rehabilitation is a complex issue, and a **one-size-fit-all approach is not effective**.
- Interventions should be adjusted to the **needs of the individual patient**, therefore, relevant professionals should be empowered to design flexible programmes that can effectively reach and support different target groups.
- Rehabilitation programmes must strive to **be holistic**, taking into account biological, psychological and social considerations that relate to cancer diagnosis, treatment and survivorship. Rehabilitation programmes should therefore adopt a systemic approach and provide:
  - Support to individuals, their carers and families, and other relevant actors in the lives of cancer patients.
  - Services that focus on physical, psychological and social wellbeing and that are adjusted to the different needs arising throughout the whole cancer journey - from housing during treatment to return to work.
- When applicable, **progress** during rehabilitation **should be evaluated** with relevant tests and assessments of symptoms, needs and perceived quality of life.
- Rehabilitation programmes benefit from **multidisciplinary, one-stop-shop approaches**, with patients and carers able to access a wide array of services in one location where they feel at ease and safe, and where they can build relations of trust with the staff.
- Integration of digital tools can also be beneficial and should be further explored.

4. WHAT SHOULD STAKEHOLDERS DO NEXT?

Although rehabilitation plays a key role in the cancer survivorship journey, **rehabilitative services are not systematically considered as part of the cancer pathway in the EU**. When services exist, these are not always tailored to the complexity of the individual needs of patients and their carers, and can be hard to access - especially for vulnerable, marginalised and underserved groups.

Building on their extensive experience in bringing rehabilitation at the forefront of considerations on cancer survivorship, the ECL Patient Support Working Group's subgroup on Cancer and Rehabilitation formulated a number of recommendations.

RECOMMENDATIONS FOR HEALTHCARE MANAGERS AND PROFESSIONALS

1. Assess patients' needs as early as possible (i.e., cancer diagnosis), in cooperation with healthcare professionals working along the cancer care pathway.

2. All patients should complete a needs assessment, which should be carried out at the moment of diagnosis. A plan or support should be devised based on existing prehabilitation needs and these needs must begin to be addressed while the treatment plan is being set up.

3. Ensure that additional and regular follow ups are carried out, assessing potential new needs and adjusting rehabilitation services accordingly.

4. Adopt a comprehensive view of the individual, including considerations of the physical, psychosocial and spiritual aspects that the cancer diagnosis and treatment may affect.

5. Adopt a multidisciplinary and multimodal approach to rehabilitation, tailored to individual needs. Teamwork and a collaborative approach are essential, therefore, include several disciplines and medical approaches represented in rehabilitative services.

6. When accompanying patients along the survivorship journey, empower patients to take control of their rehabilitation and support them in addressing issues related to intimacy, fertility, employment and/or returning to work.

7. Continuously evaluate the progress made by patients in their rehabilitation journey.

Despite health care policy, organisation and delivery being a national competence of national governments, **several instruments are available at EU level to strengthen cancer rehabilitation programmes across the Union**.

Cancer leagues recommend EU decision-makers to **put rehabilitation services under the spotlight of efforts aimed at strengthening national healthcare systems, achieving a better integration between health, social care and long-term care, and moving towards a more person-centered care**. The benefits of a greater focus on rehabilitation services would extend beyond cancer care to non-communicable diseases more broadly, being especially significant in the context of an aging European population and of improved treatment outcomes for a wide array of conditions.

Cancer leagues welcome the Europe's Beating Cancer Plan (EBCP)'s recognition of the importance of ensuring that cancer patients have the highest possible quality of life throughout the disease pathway and beyond. In particular, we appreciate the Plan's comprehensive approach to patients' physical, social, and psychological rehabilitation recognising the importance of patients' centricity in follow-up care. **The EBCP's quality of life pillar should be strengthened, through a greater focus on cancer survivorship in the Horizon Europe's Mission on Cancer and the EU4Health programme**. The current status and best way forward for supportive care and comprehensive rehabilitation programmes should be explored in parallel to the ongoing development of quality of life indicators and Patient-Reported Outcome Measures (34) and as a key tenet of the 2023 Flagship Technical Support Project 'Towards person-centred integrated care'.

RECOMMENDATIONS FOR EU POLICYMAKERS

i) Under relevant funding frameworks - notably, the EU4Health Programme (2021-2027) and Horizon Europe, **launch a call for proposals for action grants in support of research projects aimed at collecting standardised data on rehabilitation services** (including accessibility, affordability, availability, quality and inequalities in cancer rehabilitation services) **across the EU**.

   Stratified, standardised data on availability, access to and effectiveness of cancer rehabilitation programmes should be collected in a harmonised and detailed manner across Member States. In the long term, cancer leagues recommend setting up a data collection framework on cancer rehabilitation that aligns with the Data Quality Criteria set for the European Cancer Inequalities Registry (ECIR). This data could then feed into the Registry, creating a strong evidence-base to guide future action tackling inequalities in cancer survivorship (i.e., shaping measures allowing the effective inclusion and retention of low-income patients in rehabilitation services).

ii) **Commission a study** related to cancer rehabilitation and survivorship care, **mapping national and regional initiatives and policies, and identifying obstacles and challenges for setting up comprehensive cancer rehabilitation**, overseen by the European Commission's General Directorate for Health and Food Safety (DG SANTE) and the European Health and Digital Executive Agency (HaDEA).

iii) Set up a **Joint Action** or launch a **call for proposals for action grants** under the EU4Health Programme, in support of a study aimed at **collecting** existing **best practices in rehabilitation services for cancer (and NCDs)**, to complement the efforts of the 2023 flagship project on integrated care.

iv) In the context of EU-level action to strengthen the healthcare workforce, **devise curricula for inter-specialty training in cancer rehabilitation** as part of Innovative Collaboration for Inter-specialty Cancer Training across Europe - INTERACT-EUROPE.

v) **Provide sustainable funding to Member States in order to meet the ambitious goals within the EBCP's Quality of Life pillar**. Funding should be directed towards building or strengthening rehabilitation capacity, including infrastructural, human and monitoring capacity. Once gaps and best practices are identified, financing could be secured through several available mechanisms available, including the European Structural and Investment Funds and public-private partnerships financed by the European Investment Bank.

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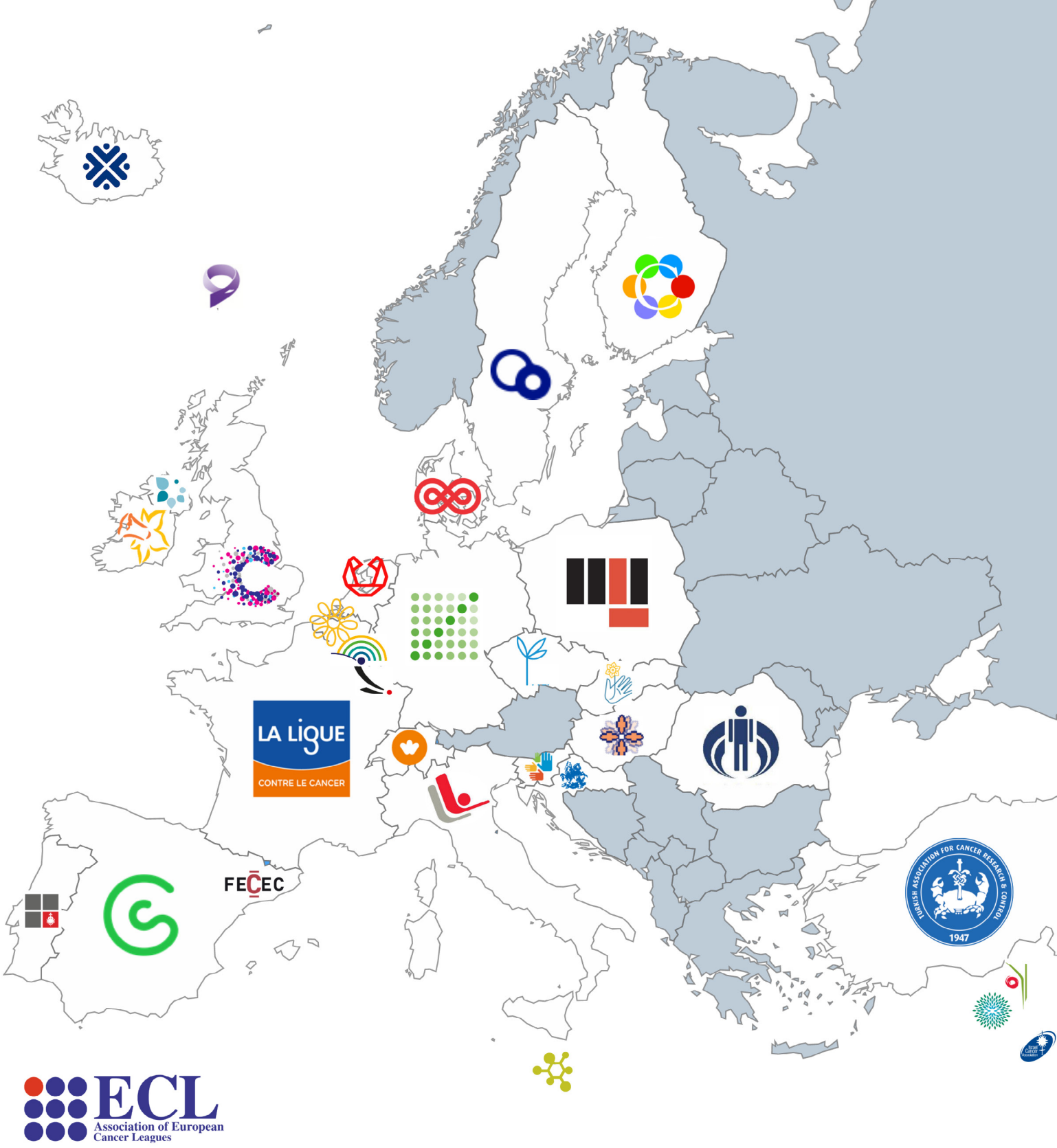

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