RARE CANCER ADVOCATES NETWORK

CALLING FOR A UNIFIED APPROACH TO THE INCLUSION OF CHILDHOOD CANCERS AND RARE ADULT CANCERS IN NATIONAL CANCER CONTROL PLANS IN EUROPE

EXECUTIVE SUMMARY

National healthcare plans are important official tools to implement dedicated measures to improve the organisation and delivery of care to patients in a defined healthcare area, as well as improve support services beyond clinical care. These plans are also necessary to foster the development of epidemiological studies and basic, translational, clinical and social research.

In Europe, many countries have adopted a National Cancer Control Plan (NCCP). However**, only a few of these plans include dedicated comprehensive sections on childhood cancers and on rare adult cancers** as demonstrated in different studies detailed in this paper. Some countries, however, have adopted and implemented specific actions that could serve as a source of inspiration.

The wide variability of NCCPs in Europe and their proposed measures emerged in a context of, and may possibly contribute to, structural inequalities in health care provision.

With a view to provide patients and survivors with equal access to quality care and improve their survival as well as quality of life, **the Rare Cancer Advocates Network (RCAN) asks that each NCCP in Europe includes dedicated and distinct sections on childhood cancers and on rare adult cancers respectively to address patients' and survivors' various challenges throughout their journey, and foster research for these disease groups.**

To that end, RCAN members have identified a set of joint patient-centred recommendations to be included in NCCPs.

RCAN members are patient advocates representing a specific patient organisation and are active partners of European Reference Networks (ERNs) relevant to rare cancers. Altogether, RCAN members cover the fields of childhood cancers *(that are all rare)*, rare adult cancers *(across haematological and solid cancers)*, hereditary cancers / genetic syndromes that predispose affected people to the development of cancer at an early onset.

They have ranked the development or review of NCCPs in European countries as one of their priorities to provide a unified and comprehensive approach to care for childhood cancer patients and for adult patients with a rare form of cancer, as well as support to their caregivers.

Within NCCPs, the respective dedicated sections on childhood cancers and on rare adult cancers need to include the following areas to cover the entire patients' and survivors' journey and stimulate research:

- Common definition, support to registries
- Access to centres of expertise and networks at both national and European level
- Prevention of hereditary cancers/genetic tumour risk syndromes
- Early detection
- Access to adequate care and treatments, including cross-border care
- Quality of life
- Patient-centred research
- Training for health professionals and supportive care providers
- Information and training for patients, survivors and caregivers
- Governance of NCCPs and inclusion of patient organisations as equal partners

The recommendations set out in this paper are equally important. National health authorities together with patient organisations and other stakeholders can decide which recommendations should be implemented in priority according to each national situation and healthcare system.

More details and background information are provided in the paper.

RARE CANCER ADVOCATES NETWORK

A unified approach to the inclusion of childhood cancers and rare adult cancers in National Cancer Control Plans in Europe

1 in 5 cancers is RARE

Incidence of rare cancers is less than 6 per 100,000 people a year. About 5.1 million people live with a rare cancer in Europe.

OBJECTIVE

The Rare Cancer Advocates Network (RCAN) asks that each National Cancer Control Plan (NCCP) in Europe includes dedicated and distinct sections on childhood cancers and on rare adult cancers respectively to address patients' and survivors' various challenges throughout their journey, and foster research for these disease groups. RCAN members have identified a set of **joint patient-centred recommendations** to be included in NCCP for each section on childhood cancers and on rare adult cancers.

Implement dedicated healthcare pathways and mandatory referrals to specialised multidisciplinary Centres of Expertise, or National Networks, and/or European Reference Networks (ERNs)	**Improve early detection: educate on warning signs, facilitate access to molecular diagnosis, integrate innovative diagnostic technologies**
Implement harmonised preventive measures needed for hereditary cancers/genetic tumour risk syndromes	**Ensure access to available best treatments, including innovative therapies and clinical trials at national level or in another European country where needed**
Support clinical registries developed by expert centres and European Reference Networks (ERNs)	**Develop and support dedicated patient-centred, needs-driven research programmes targeting respectively childhood cancers and rare adult cancers**
Provide needs-driven supportive care, psycho-oncology services, and adapted survivorship care planning	**Support specialised training programmes intended for health professionals and supportive care providers**
Ensure patients, survivors and their families receive the social aid they need. The Right to be Forgotten must be standardised and uniformly implemented	**Promote validated information and training programmes intended for patients, survivors and caregivers**

Foster European and international collaboration and synergies with other plans.

Childhood cancer and rare adult cancer patient organisations must be involved in the development of NCCP as equal partners

TABLE OF CONTENTS

I. RARE CANCERS REQUIRE A SPECIFIC APPROACH

Rare cancers, due to their uncommon nature and individual rarity, require a specific patient-centred approach from both national and European health competent authorities. Dedicated healthcare pathways for patients affected by a rare form of cancer are needed to improve patients' health outcomes, survival rate and quality of life.

Childhood cancers, which are all rare, also require specific approaches beyond those shared with rare adult cancers, in line with their distinct age-related biological, clinical and organisational needs and characteristics.

1. Definition and figures in Europe

Rare cancers, including all childhood cancers, are defined as those malignancies whose **incidence is less than 6 per 100,000 people per year,** based on the epidemiological study carried out within the EU co-funded project RARECARE, that looked at data on cancers from 89 population-based cancer registries in 21 European countries[1].

In the follow-up study RARECARENet, rare cancers in Europe amount to about **24% of new cancer cases per year** occurring from birth up to elderly age groups[2]. Researchers estimate that **5.1 million people** are living with a rare cancer across Europe and that 650,000 new rare cancers are diagnosed annually. In 2017, 5-year relative survival for all rare cancers was 48% compared with 63% for all frequent cancers[2].

Hereditary cancers / genetic tumour risk syndromes which are also rare, amount to **about 5 to 10% of all cancers**[3]. Genetic tumour risk syndromes are disorders in which inherited genetic mutations strongly predispose individuals to the development of tumours. The carriers are at a very high lifetime risk of developing an early-onset cancer, sometimes reaching 100%. At present, **only 20-30% of people with genetic tumour risk syndromes have been diagnosed**[3]. Depending on the specific genetic syndromes / mutations, tumours can develop in childhood, adolescence, or adulthood.

With regard to childhood cancers, every year in Europe, **35,000 children and young people are diagnosed with cancer**[4]. The burden of childhood cancers in Europe constitutes the leading cause of children's death by disease over the age of one, with 6,000 lives lost annually. Although survival rates are now up to 80%[5], there are prevailing issues in the pace of development of treatments for childhood cancers[6]. Additionally, while there are an estimated **500,000 childhood cancer survivors** in Europe today, with numbers growing substantially each year, **at least two-thirds of them experience long-term adverse side-effects into adulthood**:[7] "These post treatment complications often necessitate life-long follow-up care and hinder equal participation in the economy and society. Adequate and continued psychosocial and medical support to improve the quality of survivorship are of paramount importance" (SIOPe/CCI-E Manifesto for the European elections 2024[8]).

2. The specific challenges faced by patients and their caregivers

Patients affected by a rare cancer, across all ages, as well as their caregivers, face the **challenges linked to the rarity of the disease, sometimes with fatal consequences:** delayed diagnosis, or misdiagnosis, lack of or inadequate treatments, and lack of referrals to centres of expertise and to medical experts. Specialised healthcare units for various rare cancers are scarce and scattered across Europe which render their access more difficult.

Moreover, for many rare cancers, there is a lack of understanding of the underlying science and insufficient clinical registries/databases and research. The difficulties in conducting well-powered clinical studies in small populations of patients with a wide geographical distribution add a layer of complexity in developing and then accessing new, innovative therapies.

There is also insufficient monitoring of treatments' long-term side effects and a lack of recognition of long-term disabilities, which may not be "visible enough", e.g. chronic fatigue, difficulty sleeping, chronic pain, mobility impairment, cognitive impairment, and decreased sexual interest.

Rare cancer patients often feel alone, isolated and experience greatly reduced quality of life. Their caregivers can also be significantly and negatively impacted.

The Dutch Rare Cancer Patients Platform conducted a survey and has identified seven most important bottlenecks in care for patients with rare adult cancers, now displayed in a graphic map[9] to inform the Dutch Rare Cancer Plan: 1) delayed diagnosis, 2) few or no treatment options, 3) difficulty in finding the experts, 4) lack of contact points for care coordination, 5) difficulty in finding reliable information), 6) need to improve the follow-up care pathway, and 7) need to better define palliative care between the 'palliative' and 'terminal' phase.

Children and adolescents face challenges linked to their specific age range. They must be directed to dedicated childhood cancer centres to receive adequate medical care as well as specific psychological support and follow-up care. Also, research in childhood cancers necessitates investments to develop targeted therapies aiming at both improving cure rates and decreasing toxicity.

3. National Cancer Control Plans: the place of childhood and rare adult cancers

A National Cancer Control Plan (NCCP) is a "public health programme designed to reduce the incidence and mortality of cancer and improve the quality of life of cancer patients in a particular country or state, through the systematic and equitable implementation of evidence-based strategies for prevention, early detection, treatment, and palliation, making the best use of available resources." (World Health Organization: National Cancer Control Programmes: Policies and managerial guidelines, page 113[10]).

Many countries in Europe have adopted a NCCP. However, the inclusion of rare adult cancers and childhood cancers – when these groups are included - can greatly vary and may not cover each step of the patients' journey as demonstrated by studies.

As regards **rare adult cancers**, an analysis of 15 NCCPs and 18 Rare Disease National Plans was conducted within the framework of the EU Joint Action on Rare Cancers (JARC, 2016-2019). The published results in June 2020[11] indicated that these rare cancers were seldomly addressed in NCCPs and not addressed in Rare Disease National Plans. Of the 15 NCCPs analysed (Austria, Belgium, Czech Republic, Estonia, France, Germany, Ireland, Italy, Malta, Netherlands, Portugal, Slovenia, Spain, Sweden, UK-England), **only 8 contained some elements on rare adult cancers, and only 3 [France, Italy, Malta] described specific measures to address this disease group or took a comprehensive approach**.

Since the end of the JARC, some countries in Europe have revisited their respective NCCP and some have adopted a NCCP - or are in the process of developing one - for the first time.

Amongst the 15 NCCPs analysed in the JARC, a few countries - Czech Republic[12], Ireland[13], the Netherlands[14], Slovenia[15], Spain[16] - have either included elements for rare adult cancers in their NCCP, or further elaborated previous healthcare measures. Additionally, Poland[17] has integrated a section on rare adult cancers in its NCCP. Romania adopted a Law in 2022 for cancer control, LEGE 293 03/11/2022 - Portal Legislativ[18], that has a dedicated chapter on rare cancers.

However, **measures for rare adult cancer patients are uneven across NCCPs**. Only **a few countries are providing comprehensive specific measures to treat these patients throughout their journey**, as for instance in the Netherlands, and also in France[19] and Italy [20] who both adopted national networks for these rare cancers. Hence, further efforts are much needed

by national health authorities to ensure that rare adult cancer patients are treated equally across countries.

As regards **childhood cancers**, an article was published in February 2025 in the Lancet Regional Health – Europe displaying the results of a study on NCCPs. This study considered the NCCPs of 41 European countries in relation to children, adolescents and young adults. Only 22 provided data for full analysis in the study period (2022): Albania, Austria, Croatia, Cyprus, Czechia, Denmark, Estonia, France, Ireland, Italy, Latvia, Luxemburg, Norway, Poland, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, Turkey, UK-Northen Ireland. Only four NCCPs (Czechia, Estonia, France, Spain) were categorised in this study as having comprehensive paediatric oncology content.

The analysis of these 22 NCCPs in relation to children, adolescents and young adults highlighted that there was a clear emphasis on access to specialist care and multidisciplinary teams (MDTs). However, the approach was not always complete, and important elements of the care continuum and health system organisation specific to paediatric oncology were often missing. It is important to note that supportive care was amongst the weakest area in the 22 NCCPs.

In light of the results of these studies and latest findings, RCAN members want to reach a further step to ensure childhood cancer patients and rare adult cancer patients have equal access to prevention, early detection, care and follow-up care throughout their journey. Also, adequate support must be provided to caregivers.

Hence, RCAN members are calling for joint and harmonised measures across NCCPs in Europe that are relevant to the specific and distinct needs of childhood cancer patients and rare adult cancer patients to ultimately reduce health inequalities and improve health outcomes.

Additionally, synergies between NCCPs and Rare Disease National Plans are recommended to jointly address, for instance, access to orphan medicinal products and other innovative therapies intended for small populations of patients, and integration of European Reference Networks (ERNs) into national healthcare systems.

II. INTEGRATING CHILDHOOD CANCERS AND RARE ADULT CANCERS IN NCCPs

4. Recommendations from the Rare Cancer Agenda 2030, Rare Cancers Europe and European Parliament

The **Rare Cancer Agenda 2030**[22], published in September 2019, sets out key recommendations to improve dedicated research and adapted networked care throughout the patients' journey in the fields of both childhood cancers and rare adult cancers.

These recommendations are the result of three years of work within the EU Joint Action on Rare Cancers (JARC), that brought together over 60 partners from various stakeholder groups, including patient organisations.

Notably, the JARC partners built their work upon the results of the previous EU co-funded epidemiological projects, RARECARE and RARECARENet, as well as the outcomes of the European Partnership for Action Against Cancer (EPAAC), and the EU Joint Action on Cancer Control (CanCon).

As regards NCCPs, **one of the key recommendations from the Rare Cancer Agenda 2030** (9.1.4, p.110) **is as follows:** "National cancer planning should be viewed as an important tool to link the national with the EU level. **National cancer control plans should always involve a**

dedicated section on rare cancers in adults, as well as a dedicated section on childhood cancers, and develop synergies with national plans for rare diseases. Innovative instruments should be devised to improve consistency across national cancer plans."

In 2021, **Rare Cancers Europe (RCE)** issued a "**Call to Action on Rare Cancers in All Policies**"[23] to present policy recommendations and ensure that the final report from the European Parliament's Special Committee on Beating Cancer (BECA) would not overlook rare cancers. The recommendation #11 on NCCPs reinforces the above recommendation from the **Rare Cancer Agenda 2030**.

The **European Parliament Resolution of 16 February 2022**[24] on "strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy" (2020/2267(INI)), based on the BECA report, incorporates the recommendations from the childhood cancer and rare adult cancer communities. As regards NCCPs, the Resolution includes the following recommendation:

"151. Calls on the Member States to include a specific section on the management of rare adult cancers in their NCCPs (along with a dedicated section on cancers in children) as recommended in the Rare Cancer Agenda 2030; considers that these specificities should be acknowledged in dedicated sections in all NCCPs, including relevant synergies with rare disease national plans, to foster research and improve care management and care pathways for these patients, from primary care up to highly specialised multidisciplinary healthcare centres that are a part of or in close contact with the relevant ERNs; notes that, to date, many of the Member States' NCCPs do not sufficiently include rare cancers in adults and paediatric cancers."

5. Recommendations from the Rare Cancer Advocates Network

RCAN members are active partners of European Reference Networks (ERNs) relevant to rare cancers and also belong to, or co-lead, various (childhood, rare) cancer and/or rare disease projects, working groups and committees.

The four main ERNs (amongst a total of 24) relevant to rare cancers are PaedCan[25] (paediatric cancers), EURACAN[26] (rare adult solid cancers), EuroBloodNet[27] (rare haematological diseases including rare adult haematological malignancies) and GENTURIS[28] (genetic tumour risk syndromes).

RCAN members contributed their expertise to the development of the Rare Cancer Agenda 2030. They also shared their perspectives to be included in the **RCE Call to Action** and shared their amendments to the Members of the European Parliament BECA committee in view of the **Resolution** on fighting cancer.

They have ranked the development or review of NCCPs as one of their highest priorities to include measures relevant to their specific and distinct needs across the patients', survivors' and also caregivers' journey.

It is important to highlight the key role of patient organisations in the development of NCCPs to identify patients' unmet needs in the areas of childhood cancers, rare adult cancers and also genetic tumour risk syndromes, as well as to explore best solutions to address their challenges.

Based on the above policy recommendations as well as studies of NCCPs related to the place of rare adult cancers, and to children, adolescents and young adults, **RCAN members have combined their knowledge and experience to develop joint patient-centred recommendations for a set of items to be included in NCCPs with a view to ensure a comprehensive, coherent and standardised approach to care for both childhood cancer patients and rare adult cancer patients across European countries.**

The items that are deemed important to be included in the respective dedicated sections on childhood cancers and on rare adult cancers are as follows:

- Common definition of rare cancers, and support to registries
- Access to centres of expertise and networks at both national and European level
- Prevention of hereditary cancers/genetic tumour risk syndromes
- Early detection
- Access to adequate care and treatments, including cross-border care
- Quality of life
- Patient-centred research
- Training for health professionals and supportive care providers
- Information and training for patients, survivors and caregivers
- Governance of NCCPs and inclusion of patient organisations as equal partners

5.1. Common definition of rare cancers, and support to registries

The standard definition of rare cancers is an **incidence of less than 6 per 100,000 people per year.** This definition is the result of the work performed by researchers within the EU-funded project RARECARE[1]. It is now widely used in Europe, and even beyond, for all types of rare cancers, childhood and rare adult cancers alike.

RCAN members deem it very important that all NCCPs use the same definition to ensure that no rare cancer patient is left behind. Applying the same definition ensures a harmonised approach to care and research across countries in the fields of both childhood and rare adult cancers.

As regards the collection of information on various rare tumours, a standard definition enables a coherent development of registries for both childhood and rare adult cancers. Indeed, collecting accurate data is of paramount importance to better understand the natural history of various rare tumours, predictive and prognostic factors and monitor the quality of care and treatments.

The ERNs play a crucial role in bringing together existing clinical registries and supporting the development of new ones to ultimately cover all rare cancers and make data interoperable. This work requires a considerable amount of resources and efforts. Patient advocates involved in ERNs actively contribute to the development of these registries.

RCAN members recommend national authorities to provide support to expert centres contributing to the development of clinical registries for different groups of rare cancers. These centres, institutions can be either full or affiliated member of ERNs, or collaborate with ERN member centres at national level.

Recommendations from the Rare Cancer Advocates Network

Use the same standard definition of rare cancers; support the development and maintenance of childhood cancer and rare adult cancer registries

- The standard definition of rare cancers is to be used: incidence of less than 6 per 100,000 people per year.
- National authorities must support centres contributing to the development of clinical registries for different groups of rare cancers, including childhood cancers and rare adult cancers (haematological, solid, hereditary cancers). These centres can be either full or affiliated member of ERNs, or collaborate with ERN member centres at national level.

5.2. Access to centres of expertise and networks at both national and European level

The entire rare cancers community, including patients and survivors across all ages, caregivers as well as healthcare professionals, unanimously underscores the **vital need** to refer a patient affected by a rare cancer to relevant cancer centres of expertise with minimum delay from the first appearance of symptoms.

The centralisation of care for complex, rare, or ultra-rare diseases allows to concentrate the expertise and the experts to treat these patients, and to increase their knowledge and experience which result in improved clinical outcomes.

Indeed, these centres provide the necessary multidisciplinary expertise and equipment to help detect rare forms of cancers and provide adapted care based on current available knowledge.

RCAN members emphasise that NCCPs must include **mandatory and timely referrals** of patients with a suspicion of a rare cancer **to relevant designated centres of expertise**. To that end, **dedicated healthcare pathways for childhood cancer patients and for rare adult cancer patients** are relevant to coordinate referrals from primary care up to specialised care at both national level and European level where necessary.

Though healthcare systems vary considerably from one European country to another, the **identification of centres of expertise at national level for (a group of) rare cancers is key** to provide patients who may have a rare cancer with the best chance to access the specific expertise they need in a timely fashion.

These centres of expertise have a pivotal role:

- at national level, they need to be well connected with other centres taking care of patients with a rare form of cancer as well as with primary care services;
- at European level, they need to be well connected with ERNs to increase knowledge sharing for the treatments of rare tumours due to their complexity.

In addition, the **transition of young cancer patients to adult cancer care services** is often raised as a concern by young patients and their parents. Several NCCPs offer specific recommendations that can be implemented.

The development of **national network(s) for rare cancers** bringing together centres of expertise (hub) and other centres (spoke) could facilitate the rapid exchange of knowledge to diagnose and treat complex cases.

Centres of expertise, national networks for rare cancers (where relevant) need to be well connected with ERNs. These European reference networks constitute an innovative step forward to enhance collaboration amongst highly specialised healthcare providers, patient organisations and research institutions across countries in Europe to ultimately leverage standards of care and reduce health inequalities.

With the objective to well inform patients, caregivers, patient organisations and healthcare professionals, a **map** of national centres of expertise for rare cancers, and other specialised centres treating rare cancers, national networks (where relevant) and ERNs must be made **publicly available** by national health authorities, for instance on their website.

a. <u>Designation of national centres of expertise for rare cancers</u>

Based on the recommendations of the **Rare Cancer Agenda 2030**[22]:
A national centre of expertise treating a group of rare cancers needs to provide:

- a high degree of multidisciplinary clinical expertise / multidisciplinary tumour boards in the field of diagnosis, treatment and follow-up care;
- high-tech facilities;

- open clinical studies;
- proof of number of cases treated in the centre, and research publications.

A national centre of expertise:
- coordinates the delivery of care to a patient affected by a rare cancer;
- contributes to the development of, or endorses state-of-the-art clinical practice guidelines;
- provides training to (new) experts;
- is involved in translational and clinical research;
- contributes to the development of clinical registries;
- collaborates with patient groups in the field of information, research and production of lay versions of clinical guidelines;
- collaborates with other national expert centres and with European Reference Networks.

The designation criteria for national centres of expertise for childhood cancers and for rare adult cancers might vary from one country to another in Europe. In the frame of a collaborative approach, these designation criteria could be shared amongst countries to inform on designation processes with a view to harmonise criteria while respecting each country's national competence and rules.

b. Transition of young cancer patients to adult cancer care services

The article published in February 2025[21] in the Lancet Regional Health – Europe highlights the following elements: the transition to adult cancer care services can be particularly stressful for both young patients and their caregivers due to undercainties related to treatment and support. Nine NCCPs, during the study period (2022), mentioned improving young cancer patients' transition to adult services as a goal. For instance, "different initiatives were put forward: therapeutic guidelines for the transition from childhood to adulthood (Poland), specific transition pathways (Luxembourg), individualised treatment plans (Czechia), and coordinated transition (Latvia, Norway)."

c. National networks of centres of expertise for rare cancers

The establishment of national networks for rare cancers bringing together national centres of expertise and other centres at regional and local level, can be viewed as an optimised system to facilitate timely, adequate referrals for diagnosis, treatment plans and monitoring of patients. Additionally, patients may not have to travel too often to national centres of expertise and instead be treated in a regional or local centre, belonging to or connected with a network, close to his/her home. As an example, France has established national networks for rare adult cancers. There are currently 17 national networks whose mandate will expire in July 2025. A new call has been launched by the French Cancer Institute (INCa) for the extension or potential reorganisation of these networks, as well as potential new networks[29].

Such national networks for rare cancers can facilitate interactions and knowledge-sharing with ERNs. RCAN members recommend that **the grouping of rare cancers in national networks should mirror the same grouping as in ERNs.**

Some countries, however, may not have the necessity to establish national networks according to their size and healthcare system. In that case, centres treating rare cancer patients must be well referenced at national level, connected with each other (if there are more than one specialised centre) and with ERNs.

It is interesting to note that Luxemburg and Malta have both designated a national healthcare centre acting as a hub and coordinating exchanges and collaborations with healthcare professionals across ERNs.

The **Rare Cancer Agenda 2030** provides in-depth information and recommendations related to the best use of networking for the delivery of care to rare cancer patients.

d. Collaboration and interaction with ERNs relevant to rare cancers

Due to the scarce and scattered expertise on rare conditions, no one country alone can tackle the many complex issues of rare cancers and rare diseases. Hence, a strong collaboration at the European level and at the international level is crucially needed between expert centres to share cases, discuss, elaborate and disseminate optimal care guidelines.

The rare diseases and rare cancers community have strongly advocated for the establishment of ERNs bringing together highly specialised centres across European countries with a view to facilitate access to timely, accurate diagnosis and treatments.

In March 2017, the European Commission launched 24 ERNs[30] covering each main clusters of rare diseases. These **ERNs are virtual networks** that connect specialised multidisciplinary healthcare providers in the EU, UK and Norway to discuss rare and/or complex cases requiring a high degree of knowledge and resources. Within ERNs, the expertise travels rather than the patient. The ERNs' mission also includes the development of clinical guidelines, clinical registries, training programmes for experts and the conduct of research studies.

As previously mentioned, there are four main ERNs relevant to rare cancers: PaedCan, EURACAN, EuroBloodNet, GENTURIS. Some rare cancers are also covered in a few other ERNs such as, for example, a range of rare endocrine tumours in ENDO-ERN[31]. The ERN experts have established partnerships to foster exchanges.

RCAN members recommend that **NCCPs, in each of their respective section dedicated to childhood cancers and to rare adult cancers, place an emphasis on European collaboration and interaction with ERNs.** The connection between national centres of expertise for rare cancers, other hospitals treating rare cancer patients and ERNs must be facilitated to ensure that the latest standards of care for treating different types of rare tumours are shared, thus maximising patients' chance of survival.

Additionally, **NCCPs should ensure that national centres of expertise that are members of ERNs relevant to rare cancers, and thus selected against stringent criteria, are well integrated in national healthcare systems and receive adequate support**. To that end, the EU Joint Action JARDIN[32] on the integration of (all) ERNs into national healthcare systems will support the provision of recommendations to optimise healthcare pathways and referrals from primary and secondary care to specialised multidisciplinary teams in ERNs.

The ERN EURACAN (rare adult solid cancers) has also issued a Position[33] in ESMO Open to support the integration of EURACAN member centres in national health care systems in Europe. The proposals therein emphasise the interaction with national networks of rare adult cancers (where they exist), continuous development of collaborations and networking of national centres of expertise with institutions and organisations at a pan-European scale, and increased knowledge and data sharing. This Position's proposals could also serve as a source of inspiration for other ERNs.

In parallel, Europe's Beating Cancer Plan includes two important flagship initiatives:

- the creation of a European network of Comprehensive Cancer Centres;
- the establishment of Networks of Expertise across cancers on transversal issues such as, for instance, survivorship or omics.

Several EU Joint Actions (CraNE, EUnetCCC, JANE and JANE-2)[34] are supporting the development of these initiatives.

RCAN members commend such European initiatives. The interaction between ERNs, the EU Network of Comprehensive Cancer Centres and Networks of Expertise need to be clear, transparent, and well defined.

e. Raising awareness of centres of expertise and ERNs relevant to rare cancers

The organisation of national cancer services for rare cancers, in children and adolescents, and in adults, must be well known to physicians, patient organisations, and patients and caregivers. **A map of national centres of expertise for rare cancers, and other specialised centres treating rare cancers, national networks (where relevant) and ERNs must be made publicly available by national health authorities.** This map could be, for instance, displayed on national health authorities' website.

"The rare cancer community has stressed the importance of increasing awareness of rare cancers (including inherited cancers/genetic tumour risk syndromes) amongst primary and secondary healthcare professionals. National authorities must support the implementation of adequate referrals to specialised multidisciplinary expert centres at both national and European level (European Reference Networks) for childhood cancers, rare adult solid cancers, rare adult blood cancers and patients with genetic tumour risk syndromes. The development of decision-making aides, training for GPs and specialised clinicians, and public health campaigns can increase awareness of rare cancers among health professionals. Such initiatives would surely dramatically increase rare cancer patients' life expectancy and quality of life." (European Cancer Organisation 2024 Manifesto: 'Time to Accelerate: Action on Rare Cancers'[35]).

Recommendations from the Rare Cancer Advocates Network

Implement dedicated healthcare pathways and mandatory referrals to guarantee equal, timely access to childhood cancer and rare adult cancer centres of expertise and networks at national level, and at European level via ERNs

- NCCPs must include mandatory and timely referrals of patients with a suspicion of a rare cancer to relevant designated centres of expertise and networks at both national level, and at European level via ERNs where necessary.
- Designation criteria for national centres of expertise could be shared amongst European countries to inform on designation processes with a view to harmonise criteria while respecting each country's national competence and rules.
- National health authorities need to ensure a smooth transition from childhood to adult cancer care services. Different initiatives can be shared to help inform and improve the transition process.
- National networks for rare cancers bringing together national centres of expertise and other centres at regional and local level, can be viewed as an optimised system to facilitate timely referrals. The structure of national networks should mirror the structure of ERNs for rare cancers to facilitate interactions and collaborations.
- NCCPs, in each of their respective section dedicated to childhood cancers and to rare adult cancers, must include a section on European collaboration and interaction with ERNs.
- ERNs need to be well integrated in national healthcare systems. National centres of expertise that are a member of an ERN (and thus selected against stringent quality criteria) need to receive adequate support from national health authorities.
- A map of national centres of expertise for rare cancers, and other specialised centres treating rare cancers, national networks (where relevant) and ERNs must be made publicly available by national health authorities (e.g. website) to help navigate the system.

5.3. Prevention of hereditary cancers/genetic tumour risk syndromes

Prevention in the field of rare cancers may be applicable to people with a **genetic predisposition to cancer**. Hereditary cancers amount to about 5 to 10% of cancers[3]. A specific healthcare pathway is needed for detecting hereditary cancers at an early stage. Harmonised procedures across European countries should be implemented.

The national health authorities should include measures in their NCCP to guarantee access to genetic testing and adequate genetic counselling for people with a suspicion of hereditary cancer/genetic tumour risk syndrome. When the test result is positive, the carriers need to be referred in a timely fashion to specialised centres for appropriate monitoring. Moreover, these carriers, as well as their family, need to receive adapted psychological support to better live with their condition and face the challenges linked to it.

Children with a genetic predisposition to cancer must be taken care of by specialised paediatric units with multidisciplinary teams, including psychosocial support.

Newborn screening (NBS) programmes would need to consider including genetic syndromes leading to tumours. The EU IHI project Screen4Care[36] (2021-2026) explores an innovative research approach to accelerate diagnosis based on two central pillars: genetic newborn screening and digital technologies. The outcomes of this project will contribute to feed the discussion on the development of NBS programmes.

The national list of hereditary cancers / genetic tumour risk syndromes would need to take into consideration the list of syndromes covered by the ERN GENTURIS to avoid discrepancies amongst European countries and ensure a harmonised approach to this disease group.

Lastly, existing and arising digital tools must be considered to a) facilitate access to relevant information for potential carriers, patients, families and health professionals, and b) help monitor treatments and medical appointments. As an example, the EVITA Platform[37] a citizen-to-citizen initiative based on identified real needs, provides a risk assessment questionnaire, educational material, remote access to genetic counselling and psychological support. This platform also facilitates active involvement in research and Health Technology Assessment (HTA) process, besides the possibility of centralising the clinical process inside the platform to overcome the lack of interoperability. Evidence-based health literacy and information regarding recruiting clinical trials in EU Member States are provided. The main concept of the EVITA Platform is to empower users to assume the responsibility of their health and their data.

Recommendations from the Rare Cancer Advocates Network

Implement harmonised preventive measures needed for hereditary cancers / genetic tumour risk syndromes

- Guarantee access to genetic testing and adequate genetic counselling for people with a suspicion of genetic predisposition to cancer.
- Refer carriers to specialised centres for appropriate monitoring.
- Provide adapted psychological support to carriers and their family.
- Children with a genetic predisposition to cancer must be taken care of by specialised paediatric units with multidisciplinary teams, including psychosocial support.
- The national list of hereditary cancers / genetic tumour risk syndromes would need to take into consideration the list of syndromes covered by the ERN GENTURIS for consistency.
- Use existing and arising digital tools for information and monitoring of treatments.

5.4. Early detection of rare cancers

The uncommon form of rare cancers makes them very difficult to be detected at an early stage. **The specificity of each rare tumour absolutely requires the involvement of relevant experts**. As highlighted in 5.2, timely referrals to experts can be vital for providing the patients with an accurate diagnosis, and as such, the best available treatment.

In the field of both childhood cancers and rare adult cancers, early detection and symptoms awareness are key as the symptoms can be non-specific and resemble more common benign diseases.

Some NCCPs in force for childhood cancers report campaigns or training programmes targeting relevant stakeholders — paediatricians, general practitionners (GPs) and parents — to avoid late detection[21]. Similar campaigns on symptoms awareness for rare adult cancers must also be put in place (see section 5.8).

The centres of expertise for childhood cancers and for rare adult cancers possess trained medical experts and high-tech facilities to perform and analyse relevant imaging (scanner, MRI, PET-scan etc.). Additionally, these centres have either in-house or liaise with highly specialised pathologists who can perform tests on tissue and/or body fluids that can be determinant for an accurate diagnosis.

Scientific and technological advances in the field of diagnosis such as for instance **genome sequencing**, bring a lot of hope to patients as these might significantly help reduce their diagnosis odyssey and improve their chance of survival.

The Dutch Rare Cancer Plan[14] includes the implementation of a mechanism to provide **uniform and comprehensive molecular diagnosis** for people with a rare form of cancer. It is recommended to set the preconditions determining for which tumour types a molecular diagnosis is desirable. In this area, **research on biomarkers** needs to be further supported.

The use of **Artificial Intelligence (AI)** will also bring breakthroughs in precision diagnosis. Specific algorithms could improve the accuracy of early diagnoses and predictive risk algorithms could help estimate the risk of a patient developing a rare cancer. **Registries** can also be powerful tools to monitor variations in diagnosis times and access to tests to support evidence-based recommendations for improving diagnosis (Time to Accelerate: Action on Rare Cancers[35]).

A precise diagnosis is critical to provide the patients with the best available treatment for his/her rare cancer.

Recommendations from the Rare Cancer Advocates Network

Improve measures for early detection of childhood cancers and rare adult cancers

- Better inform and educate GPs, other health professionals and family members on early symptoms.
- Diagnosis of a specific childhood cancer or a rare adult cancer needs to be confirmed in relevant centres of expertise and/or networks concentrating highly specialised medical teams, including expert pathologists, and high-tech equipment.
- Standardised molecular diagnosis for patients with a rare form of cancer must be accessible. National health authorities can exchange best practices regarding the preconditions determining for which tumour types a molecular diagnosis is desirable.
- Research on biomarkers needs to be fostered.
- New diagnostic technologies, such as the use of AI, need to be integrated in the healthcare systems.

5.5. Access to adequate care and treatments, including cross-border care

A **specialised multidisciplinary tumour board** is necessary to provide the patient affected by a rare cancer with the most adapted treatment plan based on his/her specific diagnosis and condition. As previously underlined, specialised medical experts are located in centres of expertise for childhood cancers and rare adult cancers, members of, or connected with an ERN.

Within ERNs, consultations for expert advice can take place via the Clinical Patient Management System (CPMS). This is a virtual tool aimed at sharing complex patient cases on a highly secured web-based platform. If a centre is not a member of an ERN, the medical team can seek advice from an ERN member centre by sending a request via the CPMS.

Depending on the type of treatment prescribed by the multidisciplinary tumour board, the patient could be treated in a centre located not far away from his/her place of living, connected with a centre of expertise. Where possible, it is always better for the patient (and caregivers) to be treated in a centre not far away from his/her home.

However, if the patient requires specialised care, he or she needs to be directly treated in a specific centre of expertise. Indeed, some complex treatments including surgeries and innovative therapies can only be performed/ administered in certified centres for quality and safety reasons. In the case of children and adolescents, childhood cancer centres can help accommodate accompanying parents either in the hospital or next to it (home for parents).

It might happen that the recommended/ most efficient existing treatment is not available in the patient's home country. In the European Union (EU), the Regulation (EC) 883/2004 on the coordination of social security systems and the Directive 2011/24/EU on patients' rights in cross-border healthcare are the legislative instruments to access healthcare services in another EU country.

Due to the difficulty to treat rare tumours and to ensure equal rights to care, **RCAN members ask national health authorities to facilitate the transfer of patients to another EU Member State to access the therapy and/or surgery they need where relevant. ERN experts' advice must be taken into consideration**.

Additionally, **experimental treatments/clinical trials must be accessible in specialised healthcare units under safe conditions, even if the trial is taking place in another European country.** The patients, across all ages and rare tumour types, should be offered the maximum chance of survival and as such be able to access a recommended experimental treatment. In some circumstances, clinical trials might be the only chance to access potential life-saving new treatments. The medical team needs to provide patients – including parents of patients in the case of minors – with necessary information on the trial in a lay language, including its potential benefits as well as potential risks before signing the 'informed consent form'.

Currently, accessing an experimental treatment taking place in another European country is possible but still very difficult. A study on "cross-border access to clinical trials in the EU: exploratory study on needs and reality"[38] revealed that "cross-border participation in clinical trials occurs in practice, however very rarely. Ninety-two percentage of survey respondents and the majority of interviewees perceived as needed the possibility to access clinical trials abroad".

The current EU legislations on access to cross-border healthcare do not include specific reference to cross-border clinical trials. Detailed rules or guidelines governing access to cross-national clinical trials are needed for all patients. Such rules or guidelines could also address challenges associated with participation in clinical trials such as bureaucracy, translation of documents, travel and housing cost coverage.

As regards the shared objective to reduce healthcare inequalities, an equitable access to **compassionate use** of treatments must be provided to European patients affected by a severe, life-threatening rare form of cancer.

Moreover, due to the difficulty to treat rare cancers and sometimes the lack of authorised medical products, the use of off-label drugs (use of drugs in ways not covered under existing terms of the marketing authorisation e.g. indication, age, dosage, duration of use) is not only common in medical practice but vital for rare cancers. Yet the use of off-label treatments is not always reimbursed. National health authorities should implement mechanisms for the **reimbursement of off-label use** of treatments that have proven to be efficient for some rare cancers while supporting the collection of real-world data.

In any circumstances, the patients, or the parents of patient in the case of minors, must understand the protocol/ treatment plan and **patients' preferences/choice must be respected.**

In parallel to supporting fair access to existing (experimental) treatments for patients in Europe, **clinical practice guidelines and decision-making support tools for rare cancers need to be further developed.** Some guidelines produced by learned societies/ institutions already exist for a number of childhood cancers and rare adult cancers. Nevertheless, a lot of work remains to be done to cover all rare cancers.

One of the ERNs' missions is to develop or endorse state-of-the-art clinical practice guidelines for the different rare cancers they cover, as they concentrate and connect highly specialised experts. The patient representatives involved in ERNs contribute as well, by providing their experience and expertise. **RCAN members recommend national health authorities to support the development and integration of ERNs' clinical practice guidelines in addition to those developed by learned societies / institutions.**

Recommendations from the Rare Cancer Advocates Network

Ensure that childhood cancer patients and rare adult cancer patients have equal access to available specialised care and best treatments as well as cross-border care and clinical trials where needed

- National health authorities must ensure that childhood cancer patients and rare adult cancer patients can receive the care they need in a fair and equal manner. To that end, national health authorities need to facilitate access to:
  - Multidisciplinary tumour board in relevant centres of expertise to provide childhood cancer patients and rare adult cancer patients with the most adapted treatment plan;
  - Innovative therapies and complex surgeries where needed. If these are not available in the patients' home country, national health authorities must facilitate the transfer of the patients to another country to access the therapy and/or surgery they need, using EU legislative mechanisms;
  - Experimental treatment via a clinical trial based on the recommendation of the medical team. A clinical trial taking place in another country than the patients' home country must be accessible to maximise chance of survival;
  - Compassionate use of a treatment.
- National health authorities should support the reimbursement of off-label use of treatments that have proven to be efficient for some rare cancers, while supporting the collection of real-world data.
- Clinical practice guidelines developed or endorsed by ERNs for rare cancers need to be integrated in national healthcare system, in addition to those developed by learned societies/institutions.

5.6. Quality of life

RCAN members emphasise that patients affected by a rare cancer, across all ages, and their caregivers, face a lot of anxiety, exacerbated by the rarity of the tumour. Survivors of a childhood cancer, or a rare adult cancer, may be confronted with short-term as well as long term specific and distinct challenges.

With a view to improve the quality of life of childhood cancer patients/survivors, rare adult cancer patients/survivors, and their caregivers, European countries should share national initiatives and programmes that have proven to be effective.

Missing initiatives identified by both the childhood cancer and rare adult cancer communities would need to be discussed with relevant national and European competent authorities, and other stakeholders.

a. <u>Supportive care services, rehabilitation programme and survivorship plan</u>

Childhood cancer patients and rare adult cancer patients, as well as well as survivors are impacted by the burden of treatments and their potential short-term and long-term side effects. These side effects might vary from one patient to another, and must be considered throughout the patient journey, even after the end of the treatment. It should also be considered that for some rare cancers, the disease may be incurable and treatment may be ongoing and chronic in nature for many years. A holistic approach to care is absolutely needed to improve quality of life.

Supportive care services are provided to manage pain, fatigue, help restore physical strength and mental well-being to cope with the burden of cancer. These services also include expert advice to adjust lifestyle (e.g. good nutrition, smoking cessation…) as well as advice on body image, sexuality and fertility protection. The latter has to be discussed with patients, and survivors (adolescents, young adults and adults of child-bearing age) due to the impact on their (future) family planning.

Based on the age and specific needs of the patient, the medical team needs to coordinate with other professionals such as psychologists, physiotherapists, speech and language therapists, occupational therapists and dietitians.

N.B.: 'Palliative care' is described by WHO as follows: "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual[39]*."*
In this paper, supportive care services, rehabilitation programme, survivorship care planning are used.

Supportive care can be provided via a cancer rehabilitation programme. **RCAN members recommend that in each country, patients should benefit from an adequate rare cancer rehabilitation programme based on their age, rare tumour type and specific needs.** The rare cancer rehabilitation programme would need to be adjusted throughout the patient's journey based on the patient's evolving health condition.

An emphasis must be placed on **psycho-oncology** as rare cancer patients often feel abandoned and isolated due to the rarity of their cancer. Age range is an important component to consider as patients face different challenges at different times in their life. Children and adolescents need to be treated by experts in paediatric psycho-oncology and also have the opportunity to be introduced to networks of survivors if they wish. They can exchange on common challenges and reach out for support, especially at an age where body image matters, mental health and socialisation are crucial.

Additionally, caregivers (often family members) need access to specific psychological support to cope with the severity and complexity of the disease, and the significant burden of care which they take on. As for networks of survivors, the role of support groups for caregivers, including parents of patients, is very important and need to be recognised.

Survivorship care planning, covering post-treatment follow-up and **monitoring of long-term side effects**, is also paramount in cancer care. Hence, following the completion of a treatment, **survivorship care planning must be provided and adapted to the age group and type of rare cancer of the survivor.**

In the field of childhood cancers, international guidelines for late side effects of childhood cancer exist (https://www.ighg.org/), however they need a wide dissemination across the community to help guide patients, caregivers and the supporting community. Those guidelines reflect an integrated strategy for the surveillance of chronic health problems and subsequent cancers in childhood, adolescent, and young adult cancer survivors. Additionally, a dedicated '**Survivorship Passport**' has been developed: "it is a tool to provide all European childhood cancer survivors with optimal long-term care. It provides instant access to the medical history of patients who ended a cancer therapy, making survivors and healthcare professionals aware of the potential risks or late effects stemming from the previous disease and treatment received" (SIOPe, Survivorship passport for European childhood cancers and survivors[40]). This innovative and much needed tool, should go hand in hand with an appropriate multidisciplinary infrastructure to tackle the health and psychosocial challenges of survivors.

In November 2024, a prototype for a **cancer survivor smart card** - in the form of a mobile app – has been launched. This "smart card" has been developed together with healthcare professionals, patient advocacy groups, and cancer survivors under the EU-funded project 'smartCARE'[41] (coordinated by the European Cancer Organisation and involving 42 organisations from 17 Member States and 3 non-EU countries). This promising digital tool will provide cancer patients and survivors with relevant medication details, symptom trackers, connection to their healthcare providers as well as access to fellow patients and survivors.

Also, some patient organisations have developed their own digital tools to enable patients and survivors to directly monitor their disease and care in liaison with different health professionals in a secure fashion. As example, the Chronic Myeloid Leukemia (CML) Advocates Network has developed the 'Know Your CML' application[42] for chronic myeloid leukaemia patients/survivors. The patient organisation EVITA for hereditary cancers has co-developed the EVITA digital platform[37] that provides safe access to genetic counselling for citizens, as well as targeted services to healthy carriers of inherited cancers, patients and survivors.

b. Social Services

Social workers and dedicated services are needed to provide relevant information on social care and financial aid available in the country where the patient is based. Social workers might not be well acquainted with patients affected by a rare form of cancer. They need to receive training to be better informed and adapt their services accordingly. In this respect, **RCAN members recommend establishing or strengthening relations between social services and rare cancer patient organisations as well as centres of expertise.** The age of the patient is of course an important factor for tailoring services to specific age-related needs.

As regards children and adolescents, the long-term nature of hospital treatments often disrupts the daily lives of young cancer patients, impacting their intellectual, social, and emotional development. The study of NCCPs in relation to children, adolescents and young adults[21] reveals that ten NCCPs recommend **integrated schooling** either at the bedside or at home, through special programmes, involvement of teaching staff, and/or digital solutions. Several NCCPs also highlight financial uncertainties. Social assistance and support may still fall short. For example,

in some countries, statutory sick leave benefits for parents may cover young children but not adolescents or young adults.

c. The Right to be Forgotten

Cancer survivors often face discrimination, especially financial discrimination, when survivors ask, for instance, for an insurance, a loan or a mortgage. Survivors can be confronted with financial discrimination even years or decades after the end of their treatment. The **Right to be Forgotten** enables cancer survivors to no longer be required to disclose their medical record and fill out a questionnaire after several years of cancer treatment completion.

As indicated in the 'ending discrimination against cancer survivors'[43], in the European Union as of December 2024, nine Member States have introduced measures in their national legislation to protect cancer survivors against financial discrimination: Belgium, Cyprus, France, Italy, the Netherlands, Portugal, Romania, Slovenia, Spain. However, the Right to be Forgotten is not homogeneously applied. Adults' medical history should be forgotten after **10 years** (Cyprus, Italy, the Netherlands, Portugal) or **7 years** (Romania, Slovenia) or **5 years** (Belgium, France, Spain) and without any evidence of relapse or recurrence. Some countries have developed special protection measures for people having cancer at a young age, offering shorter delays. In Romania, if cancer was diagnosed before the age of 18, the Right to be Forgotten would apply from 5 years after the end of treatment. In Belgium, Cyprus, the Netherlands, Portugal and Slovenia, a similar shorter period applies for a diagnosis before the age of 21.

European countries should have **a standardised approach to the Right to be Forgotten,** ensuring that all patients have access to the same rights. To that end, the European Society for Medical Oncology (ESMO) 'calls on EU countries to ensure equal financial rights for cancer survivors'[44]. The European Cancer Organisation has issued a Position Paper[45] calling for a common approach to the Right to be Forgotten at EU level and across European countries.

At the European Union institutional level, in October 2023 the Council of the European Union and the European Parliament adopted the 'Credit Consumer Directive'[46] where for the first time the Right to be Forgotten was established. The text puts forward two important wins: 1) Personal data concerning consumers' diagnoses of oncological diseases shall not be used for the purpose of an insurance policy related to a credit agreement after a period of time determined by each Member State. However, this time period may not exceed 15 years following the end of the consumers' medical treatment; 2) when assessing the creditworthiness of a consumer, creditors should not process information related to special categories of data, such as health data. Social networks should not be consulted either.

Europe's Beating Cancer Plan highlights the Right to be Forgotten as a key priority. In 2023-2024, the European Commission made efforts to establish a Code of Conduct aimed at standardising practices across Member States. However, discussions between the cancer patient community and financial institutions have not yet resulted in an agreement.

d. Monitoring programme of rare cancer patients' specific unmet needs

An initiative proposed by the Dutch Rare Cancer Plan[14] could be expanded to other countries in the future after its success has been shown: **a monitoring programme of rare cancer patients' specific unmet needs.** All along the patient's journey, from the onset of the disease, this programme is aimed at identifying those 'at risk' for unmet needs and lower quality of life, as well as their loved ones, and refer them to appropriate support. To date, research into support regarding unmet needs and quality of life has mainly focused on people with a non-rare form of cancer and their caregivers. There is too little knowledge about specific problems that people with a rare form of cancer, and their loved ones, face when it comes to unmet needs and quality of life.

Recommendations from the Rare Cancer Advocates Network

Share various measures, plans and programmes amongst European countries for improving childhood cancer and rare adult cancer patients' and survivors' quality of life, during and after treatment

- Children, adolescents, young adults, adults and elderly people who suffer from a rare cancer must be provided with adequate supportive care services, adapted to their age and rare tumour type. National authorities are encouraged to share their good practices so that each country can learn from each other.
- A harmonised rehabilitation plan to restore physical strengths and mental well-being should be offered to each patient with a rare cancer, adjusted to their age and type of tumour.
- An emphasis must be placed on psycho-oncology. Caregivers (often family members) also need to benefit from specific psychological services.
- Survivorship care planning must be provided. The childhood cancer community has paved the way with the Survivorship Passport. This initiative can be transferred and adapted to rare adult cancer patients.
- Available digital tools for monitoring care, including tools provided by patient organisations, need to be used and promoted.
- National authorities must ensure that childhood cancer patients, rare adult cancer patients, and their caregivers (usually the parents in the case of minors) receive the social aid they need.
- Social workers are recommended to establish or strengthen relations with rare cancer patient organisations as well as centres of expertise.
- The Right to be Forgotten must be standardised and uniformly implemented to eradicate discrimination.
- A monitoring programme of rare cancer patients' specific unmet needs can be explored.

5.7. Patient-centred research

Research on childhood cancers and rare adult cancers faces the challenges of the scarcity of data and does not attract sufficient financial investment. Due to the limited number of patients affected by the same rare cancer within a given age range, this research needs to be **conducted in specialised infrastructures and across borders** to collect, as much as possible, more patients' data on etiology, pathophysiology and responses to treatments. This is even more crucial for ultra rare cancers. Networking is again a critical factor for data sharing, in compliance with the EU General Data Protection Regulation.

The continuing evolution of basic, translational and clinical research, including **precision medicine**, research on **biomarkers**, can lead to the development of new diagnosis tools and transformative therapies that could dramatically improve patients' health outcomes and quality of life. Additionally, **drug repurposing** can bring significant breakthrough at a lower cost than novel therapies. There are ongoing pilots such as the EU project REMEDI4ALL[47].

RCAN members stress the importance of involving patients, survivors and caregivers in research studies intended for childhood cancers or rare adult cancers. They can share their real-life experience in coping with a specific type of rare cancer, contribute to study design and adherence to studies. This is notably highlighted in the **2020 Joint Declaration 'Europe: Unite against Cancer'**[48] issued by Germany, Portugal and Slovenia, in the frame of the trio of the EU Council Presidency: "Germany and the trio partners will initiate a process to systematically

involve patients in European cancer research since long-term and visible participation increases transparency and the benefit of research. Thus, it not only improves societal confidence in research, but can also bring about a lasting change in scientific culture."

The optimal use of **patient-reported outcomes measures (PROMs)** and **patient-reported experience measures (PREMs)** in clinical trials as well as in clinical practice is highly necessary due to the limited data available. The identification of childhood and rare adult cancer patients' and survivors' unmet needs can drive research to better address these specific unmet needs.

The ERNs and their associated partners, patient organisations included, play an active role in translational and clinical research, and the development of registries, for the group of rare cancers they each cover.

European and national public funding bodies should financially support academic research in the fields of both childhood cancers and rare adult cancers. Dedicated research programmes specifically targeting these groups of rare cancers need to be further developed. Additionally, mechanisms for public-private investment to enhance research efforts are very much needed. As a model to explore, the Dutch Rare Cancer Plan proposes to establish *'a pan rare cancer research platform supported by public and private funders, including industry'*[14].

In the field of childhood cancers, it is important to highlight that most anticancer drugs being used are often off label - meaning they were designed for adult cancers originally - which can cause acute and long-term toxicity. There is a pressing need for supporting the development of medicines against specific paediatric biological targets[49]. The ACCELERATE Platform brings together academic researchers, industry, parents and patient advocates, and regulators to find solutions for more and better innovative therapies for children and adolescents with cancer.

As regards **social research**, more studies need to be conducted within different age groups to measure the socio-economic disease burden of a rare cancer diagnosis on patients, survivors and caregivers. The collection of data could underpin the development of tailored supportive care services for targeted age groups. The participation of childhood cancer and rare adult cancer patient organisations as partners in social research studies is key to reach out to targeted patients, survivors and caregivers, and further identify their unmet social needs.

Recommendations from the Rare Cancer Advocates Network

Further develop and support dedicated patient-centred, needs-driven research programmes targeting respectively childhood cancers and rare adult cancers

- European and national public funding bodies should financially support academic research in the fields of both childhood cancers and rare adult cancers.
- Mechanisms for public-private investments need to be further explored.
- Basic, translational, clinical research on childhood cancers and rare adult cancers need to be conducted across-borders due to the small number of cases for each type of rare tumour. The work of ERNs in this area must be adequately funded.
- Researchers and clinicians must involve patients, survivors and caregivers in their research studies as they bring important information on coping with the disease and on unmet needs.
- The optimal use of patient-reported outcomes measures (PROMs) and patient-reported experience measures (PREMs) is highly necessary due to the limited data available.
- Social research in the fields of childhood cancers and rare adult cancers needs to be further developed with a view to better address patients, survivors and caregivers' specific social needs.

5.8. Training for health professionals and supportive care providers

Patients affected by a rare cancer not only face disease-specific challenges affecting their quality of life but also obstacles directly stemming from the lack of specialised knowledge of many health professionals and supportive care providers.

Rare cancers are usually not approached in undergraduate studies. Health professionals can acquire specialised knowledge in post graduate studies and/or via continuing professional development.

Health professionals such as oncologists, surgeons, radiotherapists and nurses develop necessary skills in treating certain types of rare cancers if they are working in a centre of expertise or other centres treating rare cancer patients. As already emphasised, a well-qualified multidisciplinary team of experts is necessary to treat rare cancers due to the challenges they pose.

Likewise, supportive care providers need to receive a specialised training to take care of children, adolescents, young adults, adults and elderly people with a rare cancer.

With a view to enhance knowledge and skills, there are different types of trainings that would need to be further expanded, supported and promoted:

- **Training provided by ERNs**

ERNs' training and educational programmes (both online and onsite) offer high-level information on a wide range of rare cancers, from childhood cancers to rare adult cancers, in the areas of solid tumours, haematological malignancies and hereditary cancers. These trainings need to be further supported and promoted by European and national health authorities to maximise their outreach and impact.

- **Training for health professionals working in institutions connected with centres of expertise**

As highlighted in the **Rare Cancer Agenda 2030,** the health professionals who treat rare cancer patients but who see less cases than in centres of expertise, must be adequately trained by specialists. Reinforcing skills is important to effectively collaborate with specialists and provide patients with quality-assured care. National health authorities must facilitate the development and access to specialised trainings for the staff working in institutions connected with centres of expertise.

The childhood cancer community notably highlights that "while there are well established, full medical careers in paediatric oncology, a comprehensive training pathway is lacking in many EU Member States. Paediatric oncologists are overall either paediatricians or medical oncologists. Some radiation oncologists and surgeons may specialise in treating some or all childhood cancers, in both cases without dedicated training pathways. Thus, a comprehensive educational strategy is being developed under the leadership of SIOP Europe" (Rare Cancer Agenda 2030, page 68).

- **Training for General Practitioners and other health professionals**

General Practitioners (GPs) are often the first entry point to care when patients experience first symptoms. GPs do not need to be specialised in rare cancers but they do need to be well informed about the different main types of rare cancers, specific early symptoms, as well as national relevant centres of expertise and networks in their country for timely and appropriate referral.

The same recommendation applies to other health professionals, even though they might not be the first entry point to care.

Additionally, the existence of ERNs must be well known to all health professionals.

- **Training for supportive care providers**

As underlined in section 5.6, supportive care providers, such as for instance psycho-oncologists, physiotherapists, occupational therapists, need to be adequately trained to better take care of childhood cancer patients/survivors and rare adult cancers/survivors. Training needs to be adapted to the different age groups: children, adolescents, young adults, adults and elderly.

Recommendations from the Rare Cancer Advocates Network

Support specialised training programmes on childhood cancers and on rare adult cancers for health professionals and supportive care providers

- Support and promote various training / educational programmes for:
  - Clinicians and nurses treating children and adolescents affected by a cancer, and rare adult cancer patients, in centres of expertise or in other centres,
  - GPs and other health professionals to educate them on warning signs, as well as on existing national centres of expertise and networks in their country, as well as on relevant ERNs for timely referral,
  - Supportive care providers.

5.9. Information and training for patients, survivors and caregivers

The rarity and severity of rare cancers lead patients and their families to search for the most up-to-date information on the best available treatment options and on clinical experts. The internet has been a major game changer in terms of access to such information. However, finding reliable and user-friendly information may be challenging.

European and national institutions, centres of expertise and ERNs have dedicated websites providing relevant information to patients, survivors, caregivers as well as to health professionals and supportive care providers.

Patient organisations covering childhood cancers or rare adult cancers, across solid tumours, haematological malignancies, and hereditary cancers **also provide patients, survivors and their caregivers with validated information** on their disease and various specialists. They can also offer advice on how to cope with the disease, manage (late) side effects of treatments, as well as on how to access social services. They can sometimes inform on ongoing research projects and clinical trials. Patient organisations often team up with clinical experts to develop brochures, leaflets and other material in lay language that can be easily understood by patients, survivors and their caregivers. In addition, patient organisations - notably those involved in ERNs - contribute to the production of lay summaries of clinical guidelines and facilitate their dissemination amongst relevant stakeholders.

Furthermore, patient organisations often offer tailored training programmes to patients, survivors and their caregivers. These programmes can cover a wide range of topics such as, for example, understanding research, clinical trials, health technology assessment, access to drugs and innovative therapies, long term side effects of treatments, and social care services.

They train as well **patient advocates** (usually patients, survivors, caregivers) who are willing to get further engaged in advocacy and voice their rare cancer patient community's needs and expectations. Patient advocates can participate in different committees at national and/or European level, in conferences, and can contribute to projects in the fields of research, public health and social care. They can become as well the trainers of future patient advocates.

Additionally, over these past years, patient fellowship programmes have been expanded to enable the participation of patient advocates in scientific conferences with a view to increase their knowledge and to network with other stakeholders.

Lastly, patient organisations can organise webinars and meetings with health professionals and supportive care providers to help them better understand the challenges faced by patients, survivors and their caregivers affected by the specific rare cancer(s) these patient organisations cover.

Patients, survivors and caregivers who are well informed feel more empowered to make informed choice about treatments, care and survivorship planning according to their own preferences.

Recommendations from the Rare Cancer Advocates Network

Promote initiatives that provide patients, survivors and caregivers with validated, accessible information and training programmes

- Direct patients, survivors and caregivers to reliable sources of information, e.g. websites of centres of expertise, ERNs, patient organisations, and national institutions.
- Support the development of user-friendly information material (e.g. brochures, leaflets…) including the development of lay summaries of clinical guidelines.
- Support and promote childhood cancer and rare adult cancer patient organisations' services and training programmes intended for patients, survivors, caregivers, and patient advocates.

5.10. Governance of NCCPs and patient organisations as equal partners

Patient organisations in the fields of childhood cancers and rare adult cancers bring invaluable experience on the various challenges faced by patients, survivors and caregivers. They are proactive in proposing concrete policy solutions to address these challenges.

Therefore, with the objective to adopt measures that best address patients' and survivors' needs in different age groups, as well as their caregivers, **national health authorities must involve childhood cancer patient organisations and rare adult cancer patient organisations as equal partners in the development or review of their NCCP.**

Additionally, once a NCCP is adopted, these patient organisations are also key actors to disseminate information about the Plan and actively participate in the implementation of dedicated measures for either childhood cancers or rare adult cancers.

Also, a section on European and international collaboration in NCCPs is crucial to promote cross-border partnerships as well as share best care practices for improving care. Systematic references to Europe's Beating Cancer Plan, Cancer Mission, European projects and ERNs must be included to ensure a coherent common approach to cancer care and research in Europe.

Lastly, it is important that relevant synergies are made between NCCPs, Rare Disease National Plans, and other plans/programmes as deemed relevant to optimise resources and services.

Recommendations from the Rare Cancer Advocates Network

Involve childhood cancer and rare adult cancer patient organisations as equal partners in the development and update of NCCPs; foster European and international collaboration as well as synergies with other plans

- Childhood cancer patient organisations and rare adult cancer patient organisations must be involved in the development and review of NCCPs as equal partners.
- NCCPs must include a section on European and international collaboration.
- Synergies with rare disease national plans and other plans as deemed relevant are recommended to optimise resources and services.

III. LIST OF RCAN RECOMMENDATIONS BY ITEMS

Members of the Rare Cancer Advocates Network (RCAN) calls for the recognition of childhood cancer and rare adult cancer patients' and survivors' specificities and challenges by national health authorities in Europe.

Due to the different age-related biological, clinical and organisational needs and characteristics of childhood cancer patients, NCCPs need to include distinct sections for childhood cancers and for rare adult cancers to provide measures relevant to these disease groups.

With the objective to reduce health inequalities and provide a comprehensive as well as a harmonised approach to care and research, RCAN members recommend that NCCPs include in the section dedicated to childhood cancers, and in the section dedicated to rare adult cancers, the following recommendations to cover the entire patients' and survivors' journey, and stimulate research for these rare cancers.

The recommendations are equally important. National health authorities together with patient organisations and other stakeholders can decide which recommendations should be implemented in priority according to each national situation and healthcare system.

Recommendations from the Rare Cancer Advocates Network

Use the same standard definition of rare cancers; support the development and maintenance of childhood cancer and rare adult cancer registries

- The standard definition of rare cancers is to be used: incidence of less than 6 per 100,000 people per year.
- National authorities must support centres contributing to the development of clinical registries for different groups of rare cancers, including childhood cancers and rare adult cancers (haematological, solid, hereditary cancers). These centres can be either full or affiliated member of ERNs, or collaborate with ERN member centres at national level.

Implement dedicated healthcare pathways and mandatory referrals to guarantee equal, timely access to childhood cancer and rare adult cancer centres of expertise and networks at national level, and at European level via ERNs

- NCCPs must include mandatory and timely referrals of patients with a suspicion of a rare cancer to relevant designated centres of expertise and networks at both national level, and at European level via ERNs where necessary.
- Designation criteria for national centres of expertise could be shared amongst European countries to inform on designation processes with a view to harmonise criteria while respecting each country's national competence and rules.
- National health authorities need to ensure a smooth transition from childhood to adult cancer care services. Different initiatives can be shared to help inform and improve the transition process.
- National networks for rare cancers bringing together national centres of expertise and other centres at regional and local level, can be viewed as an optimised system to facilitate timely referrals. The structure of national networks should mirror the structure of ERNs for rare cancers to facilitate interactions and collaborations.
- NCCPs, in each of their respective section dedicated to childhood cancers and to rare adult cancers, must include a section on European collaboration and interaction with ERNs.

- ERNs need to be well integrated in national healthcare systems. National centres of expertise that are a member of an ERN (and thus selected against stringent quality criteria) need to receive adequate support from national health authorities.
- A map of national centres of expertise for rare cancers, and other specialised centres treating rare cancers, national networks (where relevant) and ERNs must be made publicly available by national health authorities (e.g. website) to help navigate the system.

Implement harmonised preventive measures needed for hereditary cancers / genetic tumour risk syndromes

- Guarantee access to genetic testing and adequate genetic counselling for people with a suspicion of genetic predisposition to cancer.
- Refer carriers to specialised centres for appropriate monitoring.
- Provide adapted psychological support to carriers and their family.
- Children with a genetic predisposition to cancer must be taken care of by specialised paediatric units with multidisciplinary teams, including psychosocial support.
- The national list of hereditary cancers / genetic tumour risk syndromes would need to take into consideration the list of syndromes covered by the ERN GENTURIS for consistency.
- Use existing and arising digital tools for information and monitoring of treatments.

Improve measures for early detection of childhood cancers and rare adult cancers

- Better inform and educate GPs, other health professionals and family members on early symptoms.
- Diagnosis of a specific childhood cancer or a rare adult cancer needs to be confirmed in relevant centres of expertise and/or networks concentrating highly specialised medical teams, including expert pathologists, and high-tech equipment.
- Standardised molecular diagnosis for patients with a rare form of cancer must be accessible. National health authorities can exchange best practices regarding the preconditions determining for which tumour types a molecular diagnosis is desirable.
- Research on biomarkers needs to be fostered.
- New diagnostic technologies, such as the use of AI, need to be integrated in the healthcare systems.

Ensure that childhood cancer patients and rare adult cancer patients have equal access to available specialised care and best treatments as well as cross-border care and clinical trials where needed

- National health authorities must ensure that childhood cancer patients and rare adult cancer patients can receive the care they need in a fair and equal manner. To that end, national health authorities need to facilitate access to:
  - Multidisciplinary tumour board in relevant centres of expertise to provide childhood cancer patients and rare adult cancer patients with the most adapted treatment plan;
  - Innovative therapies and complex surgeries where needed. If these are not available in the patients' home country, national health authorities must facilitate the transfer of the patients to another country to access the therapy and/or surgery they need, using EU legislative mechanisms;
  - Experimental treatment via a clinical trial based on the recommendation of the medical team. A clinical trial taking place in another country than the patients' home country must be accessible to maximise chance of survival;
  - Compassionate use of a treatment.

- National health authorities should support the reimbursement of off-label use of treatments that have proven to be efficient for some rare cancers, while supporting the collection of real-world data.
- Clinical practice guidelines developed or endorsed by ERNs for rare cancers need to be integrated in national healthcare system, in addition to those developed by learned societies/institutions.

Share various measures, plans and programmes amongst European countries for improving childhood cancer and rare adult cancer patients' and survivors' quality of life, during and after treatment

- Children, adolescents, young adults, adults and elderly people who suffer from a rare cancer must be provided with adequate supportive care services, adapted to their age and rare tumour type. National authorities are encouraged to share their good practices so that each country can learn from each other.
- A harmonised rehabilitation plan to restore physical strengths and mental well-being should be offered to each patient with a rare cancer, adjusted to their age and type of tumour.
- An emphasis must be placed on psycho-oncology. Caregivers (often family members) also need to benefit from specific psychological services.
- Survivorship care planning must be provided. The childhood cancer community has paved the way with the Survivorship Passport. This initiative can be transferred and adapted to rare adult cancer patients.
- Available digital tools for monitoring care, including tools provided by patient organisations, need to be used and promoted.
- National authorities must ensure that childhood cancer patients, rare adult cancer patients, and their caregivers (usually the parents in the case of minors) receive the social aid they need.
- Social workers are recommended to establish or strengthen relations with rare cancer patient organisations as well as centres of expertise.
- The Right to be Forgotten must be standardised and uniformly implemented to eradicate discrimination.
- A monitoring programme of rare cancer patients' specific unmet needs can be explored.

Further develop and support dedicated patient-centred, needs-driven research programmes targeting respectively childhood cancers and rare adult cancers

- European and national public funding bodies should financially support academic research in the fields of both childhood cancers and rare adult cancers.
- Mechanisms for public-private investments need to be further explored.
- Basic, translational, clinical research on childhood cancers and rare adult cancers need to be conducted across-borders due to the small number of cases for each type of rare tumour. The work of ERNs in this area must be adequately funded.
- Researchers and clinicians must involve patients, survivors and caregivers in their research studies as they bring important information on coping with the disease and on unmet needs.
- The optimal use of patient-reported outcomes measures (PROMs) and patient-reported experience measures (PREMs) is highly necessary due to the limited data available.
- Social research in the fields of childhood cancers and rare adult cancers needs to be further developed with a view to better address patients, survivors and caregivers' specific social needs.

Support specialised training programmes on childhood cancers and on rare adult cancers for health professionals and supportive care providers

- Support and promote various training / educational programmes for:
  - Clinicians and nurses treating children and adolescents affected by a cancer, and rare adult cancer patients, in centres of expertise or in other centres,
  - GPs and other health professionals to educate them on warning signs, as well as on existing national centres of expertise and networks in their country, as well as on relevant ERNs for timely referral,
  - Supportive care providers.

Promote initiatives that provide patients, survivors and caregivers with validated, accessible information and training programmes

- Direct patients, survivors and caregivers to reliable sources of information, e.g. websites of centres of expertise, ERNs, patient organisations, and national institutions.
- Support the development of user-friendly information material (e.g. brochures, leaflets…) including the development of lay summaries of clinical guidelines.
- Support and promote childhood cancer and rare adult cancer patient organisations' services and training programmes intended for patients, survivors, caregivers, and patient advocates.

Involve childhood cancer and rare adult cancer patient organisations as equal partners in the development and update of NCCPs; foster European and international collaboration as well as synergies with other plans

- Childhood cancer patient organisations and rare adult cancer patient organisations must be involved in the development and review of NCCPs as equal partners.
- NCCPs must include a section on European and international collaboration.
- Synergies with rare disease national plans and other plans as deemed relevant are recommended to optimise resources and services.

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