

Do national cancer control plans address care and research for children, adolescents, and young adults? A review of status, priorities, and recommendations across 41 European countries



Joan Prades,^{a,b} Olga Kozhaeva,^{c,*} Maria Otth,^{d,e,f} Pamela Kearns,^g Ruth Ladenstein,^{h,n} Carmelo Rizzari,^{i,o} Delphine Heenen,^{j,r} Uta Dirksen,^{k,p} Cormac Owens,^l Deyan Lazarov,^c Ciara Sheehan,^c Josep M. Borras,^{a,b} and Gilles Vassal^{c,m,q}



^aCatalan Cancer Plan, Department of Health, Av. Gran Via de l'Hospitalet, 199-203, 08908, L'Hospitalet de Llobregat, Barcelona, Spain

^bDepartment of Clinical Sciences, IDIBELL, University of Barcelona, Av. Gran Via de l'Hospitalet, 199, 08908, L'Hospitalet de Llobregat, Barcelona, Spain

^cEuropean Society for Paediatric Oncology (SIOPE), Clos Chapelle-aux-Champs 30, 1200, Brussels, Belgium

^dDivision of Oncology-Hematology, Children's Hospital of Eastern Switzerland, Claudiusstrasse 6, 9006, St. Gallen, Switzerland

^eDepartment of Oncology, University Children's Hospital Zurich, Steinwiesstrasse 75, 8032, Zurich, Switzerland

^fFaculty of Health Sciences and Medicine, University of Lucerne, Frohburgstrasse 3, 6002, Lucerne, Switzerland

^gInstitute of Cancer and Genomic Sciences, NIHR Birmingham Biomedical Research Centre, College of Medical and Dental Sciences, University of Birmingham, B15 2TT, Birmingham, United Kingdom

^hSt Anna Children's Hospital and Children's Cancer Research Institute, Zimmermannplatz, 10, 1090, Vienna, Austria

ⁱPediatrics, Fondazione IRCCS San Gerardo dei Tintori, Via G. B. Pergolesi, 33, 20900, Monza, Italy

^jKickCancer, Av. des Arts 50, 1000, Brussels, Belgium

^kPediatrics III, West German Cancer Center, University Hospital Essen, Hufelandstrasse 55, 45147, Essen, Germany

^lDepartment of Oncology, Children's Health Ireland at Crumlin, Cooley Rd, Crumlin, Dublin, D12 N512, Ireland

^mGustave Roussy Comprehensive Cancer Centre, Rue Edouard-Vaillant 114, 94 805, Villejuif, France

ⁿMedical University of Vienna, Spitalgasse 23, 1090, Vienna, Austria

^oUniversità di Milano-Bicocca, Piazza dell'Ateneo Nuovo, 1, 20126, Milan, Italy

^pUniversity of Duisburg-Essen, Universitätsstrasse 2, 45141, Essen, Germany

^qParis-Saclay University, Rue Georges Clemenceau 14, 91400, Orsay, France

^rChildhood Cancer International – Europe, Lerchenfelderstrasse 74/3/2, 1080, Vienna, Austria

Summary

Paediatric cancers, although rare, are the leading cause of disease-related mortality in European children above one year. A key pillar of the European Health Union, Europe's Beating Cancer Plan (EBCP) puts a spotlight on childhood cancer. National Cancer Control Plans (NCCPs) have a key role but did not address childhood cancers sufficiently previously. This study considered the NCCPs of 41 European countries in relation to children and adolescents and young adults (AYAs). Twenty two NCCPs informed a structured narrative analysis. Four NCCPs were categorised as having comprehensive paediatric oncology content. Findings emphasise access to care through centralisation combined with local delivery of low-risk interventions and the role of multidisciplinary teams. Survivorship, AYA care, registries, and voluntary associations were addressed to varying degrees. Supportive care was among the weakest areas in the 22 NCCPs. Recommendations were presented to strengthen paediatric oncology in NCCPs and enrich the EBCP vision towards improved survival and reduced inequalities across Europe.

The Lancet Regional Health - Europe

2025;49: 101155

Published Online 18

December 2024

<https://doi.org/10.1016/j.lanepe.2024.101155>

Copyright © 2024 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC license (<http://creativecommons.org/licenses/by-nc/4.0/>).

Keywords: Childhood cancer; National cancer control plans

Background

In 2015, the European Society for Paediatric Oncology (SIOPE) launched its strategic plan with the goal to cure more children, cure them better, and tackle inequalities.¹ Despite being rare, paediatric cancers remain the first cause of mortality by disease among young people in Europe with 6000 deaths per year.²

Over 60 percent of the estimated 400,000 survivors experience long-term complications.^{3,4}

In 2021, the European Union (EU) unveiled Europe's Beating Cancer Plan (EBCP) including a spotlight section on childhood cancer.⁵ According to the subsidiarity principle, EU Member States have primary responsibility for national health policy. Country-level action is therefore central to advance the EU agenda for childhood cancer. The EBCP may also serve as a blueprint for non-EU countries with candidate or association status.⁶⁻⁸

*Corresponding author.

E-mail address: olga.kozhaeva@siope.eu (O. Kozhaeva).

The EU Joint Action on Rare Cancers (2016–2019, 724161/JARC) was an effort of the European Commission, national governments and stakeholders to advance quality of care and research on rare cancers. The JARC conclusions emphasised the role of National Cancer Control Plans (NCCPs) in linking European and country-level initiatives.⁹ It also recognised specificities of childhood cancers and called for distinct provisions for them in NCCPs.

NCCPs are policy instruments “designed to reduce cancer incidence and mortality and improve quality of life of cancer patients, through the systematic and equitable implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment, and palliation, making the best use of available resources”.¹⁰ The World Health Organization (WHO) and the EU recommend that countries develop NCCPs to guide cancer control, including in childhood cancer.^{11–13}

Due to the focus on childhood cancer in EU policy, it is essential to evaluate how NCCPs address childhood cancers and to formulate recommendations to strengthen coordinated efforts around the EBCP.

A 2018 global review of NCCP documents observed that paediatric cancer was only specified in 42 percent of 158 countries, mainly in the Eastern Mediterranean and European regions of the WHO.¹⁴ In Europe, a 2018 JARC study analysed the content on rare adult and childhood cancers in 15 NCCPs.¹⁵ The findings pointed to a lack of comprehensive approach to childhood cancer, with only 4 NCCPs containing detailed information.

Most of the NCCPs considered in the previous JARC work were no longer in force in 2022. The current study aimed at updating the JARC analysis while expanding the scope to additional European countries and focusing exclusively on childhood cancers. For the present purposes, this includes childhood, adolescent and young adult (CAYA) cancers, and the terms paediatric, child (hood), and CAYA are used interchangeably.

Methods

A documentary analysis¹⁶ of information on paediatric cancers in European NCCPs was performed (Box 1). Seventeen childhood cancer control areas were identified and enabled to structure the review (Fig. 1). A high-level summary of results is followed by a narrative description organised around key themes derived from NCCP data (Box 1).

Results

Overview of childhood cancer content of NCCPs

Out of a total of 41 countries, there was no active NCCP in 13 countries during the study period, and one NCCP could not be accessed (Table 1). Some COTs retrieved NCCPs outside of the reference period, and five NCCPs had no paediatric cancer content. Specific situations and underlying reasons varied (Supplement D); three

scenarios can be highlighted: (1) the use of instruments other than NCCPs in national cancer control (e.g., Belgium, Netherlands); (2) NCCP considered applicable to the entire population but with no explicit information on CAYA (e.g., Germany), and (3) NCCPs with information on CAYA but either expired or not yet adopted during the study period (e.g., Malta, Portugal). Twenty-two NCCPs provided data for full analysis (Supplement E).

From the total of 22 eligible countries, the number of NCCPs covering each cancer control area ranged from two (for area ‘Pain management’) to 18 (for area ‘Evidence-based medicine, clinical decision-making, and care delivery’) (Fig. 1). Most NCCPs included content on epidemiology, survivorship, and care organisation at the national level. International cooperation as well as research, workforce, and early diagnosis were each featured in about half of the NCCPs. Less than one third addressed psychosocial care. Fourteen NCCPs had a dedicated section on paediatric oncology.

Four NCCPs addressed over 75 percent of childhood cancer control areas and were classified as level one with a comprehensive approach (Table 2). An equal number of NCCPs were on the other end of the spectrum with a limited approach. The stepwise and ad hoc approaches were each implemented by seven NCCPs.

Access to high quality care

Centralisation and networking

Seventy percent of NCCPs suggested the need for care centralisation in paediatric oncology. This was motivated by seeking the volume effect or fostering equal access to quality services and outcomes at the national level. Several NCCPs highlighted problems of access to expert centres due to ineffective referral systems or lack of integration of care and expertise, or described a negative trade-off between geographical proximity and access to high-quality care. When diagnosis and treatment are centralised in an expert centre and local institutions cannot provide low-risk interventions (e.g., transfusions of blood products), patients and families may have to travel long distances during interim periods of treatment. Two NCCPs (Ireland, Norway) proposed centralisation and networking of services. Here, paediatric cancer centres oversee diagnosis, treatment planning, and follow-up, while local units may provide components of treatment and essential supportive care under the former’s supervision.

The analysis of NCCPs indicates that a shared care service model may be explored under some conditions, three of which are recurrent. Firstly, the positioning of paediatric oncology expert centres should be formalised at the health system level. Secondly, expert centres should be responsible for the whole process of care — and not just diagnosis and treatment — in a coordinating role and be responsive to regional centres, general practitioners (GPs), patients, and families. Finally,

effective referral pathways facilitating patient access to expert centres should be in place.

Early diagnosis and symptom awareness

Early diagnosis was a clear priority in half of the examined NCCPs. Most highlighted difficulties in identifying signs and symptoms as these can be non-specific and resemble more common benign diseases. Specific knowledge is required to minimise the time between symptom onset, diagnosis, and treatment start. One NCCP (Cyprus) emphasised the importance of timely diagnosis for optimising the chance of cure and rehabilitation. NCCPs reported campaigns or training programmes targeting relevant stakeholders — paediatricians, family doctors, and parents — to avoid late detection. One NCCP (Latvia) put forward a specific algorithm on “red flag symptoms” with the rationale that many professionals may see a child with cancer once in their entire working life, making it impossible to accumulate sufficient experience in recognising cases.

Multidisciplinary care as the cornerstone for research and social aspects

Integration of care and research

There is no defined boundary between standard and clinical trial treatment of CAYAs with cancer since integration of care and research is a hallmark of paediatric oncology. Better access to clinical trials and innovation was defined as a priority in nine NCCPs. Relevant initiatives included setting minimum numbers of trial recruitment (Northern Ireland), better information about the option to participate in clinical trials through user-friendly tools (France, Norway), policies to boost collaboration by means of homogeneous clinical trials and treatment protocols (Italy), networking between centres involved in clinical research (Austria), or

Box 1.

Search strategy and selected criteria

The study was coordinated by a Steering Committee composed of health professional representatives from SIOPE and parents, patients and survivor representatives from Childhood Cancer International—Europe (CCI Europe). The geographic scope consisted of 41 countries covered by the SIOPE and/or CCI Europe membership, including all 27 EU Member States and 14 non-EU countries; the latter were either EU candidate countries and/or those with associated or transition status enabling participation in relevant EU programmes (Supplement A).

NCCPs officially in force, or active, between May and December 2022, defined as the study period, were the primary source documents. NCCPs were obtained and data retrieval and validation performed by one Country Operating Team (COT) per country. Each COT included a senior paediatric oncologist, an early career investigator (Young SIOPE member), and a patient advocate (parent or survivor). Processes were standardised by means of a data extraction form and COT training.

The NCCPs were gathered in a database. A grounded-theory study with inductive thematic analysis of NCCP data was performed using the constant comparative method. Atlas-ti 9 software was used to create codes and identify 17 cancer control areas (Supplement B).

Individual NCCPs were classified in relation to each cancer control area according to whether relevant action-oriented initiatives were included. Building on the approach in the JARC NCCP analysis, the level of childhood cancer content was derived from the proportion of cancer control areas covered: comprehensive ($\geq 75\%$), stepwise (50–74%), ad hoc (25–49%), and limited ($\leq 24\%$).

Through the above thematic analysis approach, cancer control areas were consolidated into broader categories of NCCP data, and a conceptual framework integrating all key findings was developed to structure the narrative analysis (Supplement C): macro- or health system-level aspects, service delivery aspects, and emerging areas of particular interest based on current trends in paediatric oncology.

developing research activities in tumour working groups (Croatia). Barriers to access were also described, such as extensive administrative requirements for participation in international academic trials (Czechia, Estonia).

Improvements in overall accessibility and speed of access to medicines were sought at both the national (Romania, Croatia, Estonia) and international levels. Supporting access to innovation was seen as relevant in this context. One NCCP (France) emphasised the setup

Country* / Cancer control area	AL	AT	HR	CY	CZ	DK	EE	FR	IE	IT	LV	LU	NO	PL	RO	RS	SK	SI	ES	SE	TR	UK	NI	Number of countries per cancer control area
1. Epidemiology and prognosis measures	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	16
2. Early diagnosis and symptoms awareness	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10
3. Long-term effects and survivorship care	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	16
4. Centralisation and networking at national level	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	16
5. Evidence-based medicine, clinical decision-making and care delivery	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	18
6. Precision medicine and genetic counselling	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
7. Rehabilitation	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	9
8. Psychosocial care	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	6
9. Palliative care	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	13
10. Pain management	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	2
11. Transition to adulthood services and AYA care	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
12. Research and access to clinical trials	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	11
13. Access to drugs and innovative diagnostics & therapeutics	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	8
14. Patient and family needs	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
15. Data availability, digitisation and cancer registries	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	14
16. Professionals' education and wellbeing, and certification of centres	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10
17. International cooperation and European networking	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	11
Number of cancer control areas per country	2	10	11	8	13	7	16	14	11	12	8	9	6	10	7	4	4	13	5	4	7			

* Country codes: AL: Albania, AT: Austria, HR: Croatia, CY: Cyprus, CZ: Czechia, DK: Denmark, EE: Estonia, FR: France, IE: Ireland, IT: Italy, LV: Latvia, LU: Luxembourg, NO: Norway, PL: Poland, RO: Romania, RS: Serbia, SK: Slovakia, SI: Slovenia, ES: Spain, SE: Sweden, TR: Turkey, UK NI: UK Northern Ireland

Fig. 1: Childhood cancer control areas covered by National Cancer Control Plans (NCCPs) (n = 22).

Country	NCCP status ^a
Included NCCPs	
Albania	Active (2021–2031)
Austria	Active (2014–onwards) ^b
Croatia	Active (2020–2030) ^b
Cyprus	Active (2019–onwards) ^b
Czechia	Active (2022–2030) ^b
Denmark	Active (2016–onwards)
Estonia	Active (2021–2030) ^b
France	Active (2021–2030) ^b
Ireland	Active (2017–2026) ^b
Italy	Active (2022–2027) ^b
Latvia	Active (2022–2024)
Luxembourg	Active (2022–2024) ^{b,c}
Norway	Active (2018–2022) ^b
Poland	Active (2020–2030)
Romania	Active (2022–2027/2030) ^b
Serbia	Active (2020–2022)
Slovakia	Active (2021–2025)
Slovenia	Active (2022–2026)
Spain	Active (2021–onwards) ^b
Sweden	Active (2018–2025)
Türkiye	Active (2021–onwards) ^b
UK-Northern Ireland	Active (2022–2032) ^b
Non-included NCCPs	
	No active NCCP in the study period
Belgium	
Bosnia and Herzegovina	
Bulgaria	
Finland	
Greece	
Iceland	
Israel	
Malta	
Montenegro	
Netherlands	
Portugal	
Switzerland	
UK-England	
	Active NCCP with no content on paediatric oncology
Germany	
Lithuania	
North Macedonia	
UK-Scotland	
UK-Wales	
	NCCP not accessed
Hungary	

^aSpecific situations for a number of countries are summarised in [Supplement D](#).
^bNCCP with a section on paediatric oncology. ^cCombined with geriatric oncology.

Table 1: National Cancer Control Plans (NCCPs) in the scope of the study in the reference period May to December 2022 (n = 41) and reasons for non-inclusion in full analysis.

of ad hoc national committees or supporting healthcare professionals through more effective dissemination of innovative therapeutic strategies. From an international perspective, NCCPs pointed to the need for biomedical research and industry to invest in and develop medicines to treat paediatric cancer patients, including those with a poor prognosis (France, Spain).

NCCPs systematically associated expert, established multidisciplinary teams (MDTs) with quality decision-making processes in paediatric oncology. Together with probability of survival, a vision based on quality-of-life aspects such as treatment toxicity, side effects, and therapeutic appropriateness makes a trained and specialised MDT a requirement to guide diagnosis and treatment. Practices described in NCCPs to support the development and evaluation of MDTs and services for CAYAs included: harmonising specifications, certifying expert centres/units, providing uniform therapy protocols, or creating national programmes aiming at specific goals such as treatment de-escalation (France).

Successive layers of intervention — and not only diagnosis, treatment and follow-up — are associated with specialised MDTs. First, many NCCPs mentioned the importance of cross-border consultation and cooperation with experts — e.g., in the framework of the European Reference Network on Paediatric Cancer¹⁷ — for effective patient access to optimum planning strategies and research networks. Second, there is a need for timely translation of positive scientific results into diagnostic and therapeutic protocols and streamlining the care-research interface. While MDTs are encouraged to play a pivotal role, three NCCPs (Estonia, Norway, Sweden) emphasised the lack of human resources across all relevant groups of physicians and nurses.

Quality of hospital stay and schooling

The long-term nature of hospital treatments is a disruption to daily life and may impact academic progress of CAYAs with cancer. An age-appropriate environment is a key component of quality of hospital stays. Outpatient treatment may also imply being away from peers for extended periods, and the health status of young cancer patients may hinder their socio-educational advancement. Parents' efforts alone may be not sufficient to counteract these challenges. Ten NCCPs recommended integrated schooling at the bedside or at home through special programmes, teaching staff involvement, and/or digital solutions. Education is an integral part of CAYAs' social life and their intellectual, social and emotional development, thus efforts should be made to foster their participation.

Several NCCPs highlighted that cancer may bring financial uncertainty due to direct and indirect costs incurred, such as for transport, rehabilitation, or care arrangements, including abroad. Social assistance may be inadequate. For instance, statutory sick leave for

Level of information on paediatric oncology	Country	Proportion of cancer control areas covered
Level 1. Comprehensive approach^a: 75–100%		
	Estonia	94%
	France	82%
	Spain	76%
	Czechia	76%
Level 2. Stepwise approach^b: 50–74%		
	Italy	71%
	Latvia	71%
	Ireland	65%
	Croatia	65%
	Austria	59%
	Romania	59%
	Norway	53%
Level 3. Ad hoc approach^c: 25–49%		
	Cyprus	47%
	Luxembourg	47%
	Denmark	41%
	Serbia	41%
	UK—Northern Ireland	41%
	Poland	35%
	Sweden	29%
Level 4. Limited approach^d: 1–24%		
	Slovakia	24%
	Slovenia	24%
	Türkiye	24%
	Albania	12%

^aLevel 1—Comprehensive approach (≥75%): Paediatric cancer care is conceived as a specific and integrated area of intervention, involving health system arrangements to ensure quality in the main stages of the process of care as well as access to innovation and international cooperation. ^bLevel 2—Stepwise approach (50–74%): Most of the paediatric cancer control issues are covered within NCCPs, and the main stages of the process of care (diagnosis, treatment, and follow-up) as well as the main organisational components (e.g., early referral, centralisation and/or expert tumour boards) are generally present. ^cLevel 3—Ad hoc approach (25–49%): NCCPs cover different paediatric cancer control issues, although a global health system perspective or some degree of correspondence between close issues (e.g., healthcare organisation or supportive care as a whole) is missing. Innovative cancer control areas such as precision medicine, genetic counselling and/or access to innovative medicines are hardly present. ^dLevel 4—Limited approach (≤24%): Paediatric cancer care is a minor topic within the NCCPs, and the few areas covered are an extension of or complementary aspects to adult cancer care.

Table 2: Grouping of National Cancer Control Plans (NCCPs) in accordance with the level of information on paediatric oncology (n = 22).

parents may cover young children but not adolescents and young adults, leading to difficult decisions for some. One NCCP (Estonia) emphasised the need for social protection to avoid a decline in the affected families' living standards.

Adapted supportive care

In the examined NCCPs, supportive care for CAYAs was overall the most underdeveloped area (Fig. 1). Supportive care can be described across two domains: psychosocial care and rehabilitation, and palliative care and pain management. Overall, NCCPs described the need to adapt supportive care to each patient and family while keeping an age-related perspective and to improve collaboration between these professionals and paediatric cancer MDTs.

Psycho-rehabilitation care

Psychosocial care encompasses different specialities such as psychologists, psychotherapists, teachers, and/or physical and occupational therapists. Five NCCPs described lack of such trained professionals and limited ambulatory services. Measures to improve psychosocial care and provide an adapted supportive care approach were mentioned: providing of such care from the time of diagnosis (Austria), engaging clinical psychologists and certified units (Spain), and coordinating interventions across levels of care, from primary to teaching hospitals (Croatia).

The concept of rehabilitation includes both clinical (e.g., psychomotor, orthopaedic) and psychosocial (e.g., cognitive, educational) aspects. NCCP proposals included the development of rehabilitation pathways and/or guidelines by cancer type and setting up collaborating rehabilitation centres.

Palliative care and pain management

NCCPs emphasised that palliative care for adults is not directly suitable for children due to the latter's particular needs, and that any model of paediatric palliative care should be defined to ensure equity, avoid fragmentation of services, and promote information regarding counselling and bereavement. There is no common strategy in NCCPs to address the dignity of children and families or describe their involvement before and after a patient death, as these aspects have different connotations. However, most NCCPs agree that the child should spend as much time as possible at home/in a familiar environment. To support this, multi-disciplinary mobile palliative teams working across health system levels have been created in Austria, Czechia, and Estonia. For instance, home care may be delivered in primary care while specialised settings are needed in case of uncontrolled or high intensity symptoms.

Beyond this model, five NCCPs called for structural measures such as proper funding of national palliative services, developing children-specific palliative care education, and evaluating the nationwide offer of children's hospice facilities. Strikingly, only two NCCPs (France, Italy) included pain management.

Consolidation of AYA oncology and transition to adult services

The content of the examined NCCPs strongly suggested that traditional models of cancer care did not meet

Adolescents and Young Adults' (AYA) needs. One NCCP (Italy) highlighted the lack of substantial progress in survival rates for this group in the last decades — regardless of the type of tumour — and access to clinical trials that was inferior to that of access of adults and children. Some NCCPs distinguished adolescents (age range of 15–19) from young adults (upper age limit of 24, 29, 39 and even further), while other NCCPs included all under the label of “AYA” or “young people”.

To enshrine their needs, many specific initiatives and recommendations could be noted, including appropriate psychosocial support, specialised MDTs, and assistance to young adults to cope with financial and educational issues, career, and family life. One NCCP (Denmark) was particularly rich in proposals; for instance, developing a communal living for AYAs undergoing treatment and creating a Young Cancer Network for not hospitalised AYAs to foster a sense of community. Across NCCPs, the approach to creating AYA units was to run services either in adult facilities or in children's hospitals.

Improving patients' transition to adult services was a goal mentioned in nine NCCPs, as this process can be stressful for young people and caregivers due to uncertainty regarding treatment and support available. 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).

Impact of precision oncology

While survival rates for some paediatric tumours are particularly low, NCCPs highlighted that progress would only be possible through a greater understanding of individual tumour biology and access to new medicines for first-line treatment. However, only eight NCCPs included related content, and one NCCP (Italy) noted that even if precision oncology was considered a new standard in cancer care, its impact remained limited and the gap between clinical knowledge and the application of genomics in cancer treatment was widening.

Improving access to biomarkers and delivering translational bench-to-bedside care was a common goal in four NCCPs. They emphasised the need to expand multi-omics tests performed by molecular biology platforms in paediatric solid tumours and increase testing capacities for comprehensive diagnostics in childhood cancers. One NCCP (Slovakia) envisaged the setup of diagnostic algorithms for the examination of tissue and liquid biopsies to identify predictive factors for targeted treatment and immunotherapy as a national standard.

Clinicians are increasingly confronted with sophisticated genetic information. The molecular profiling of tumour samples and exponential expansion of genomic “big data” makes the interpretation progressively complex. The need to include genomics across the patient pathway to optimise effectiveness and sustainability as

well as the development and consolidation of molecular tumour boards were articulated in two NCCPs (Italy, Luxembourg). One NCCP (France) put forward an adapted financial model for innovative molecular tests combining real-life follow-up and periodic evaluation. Finally, two NCCPs (France, Spain) encouraged industry and biomedical research sectors to invest in poor prognosis or incurable paediatric tumours.

Tracking long-term effects and survivorship care

Sixteen NCCPs addressed long-term effects and survivorship care. NCCPs proposed tracking and responding specifically to long-term effects. One example is early screening of children to detect and intervene on subtle cardiac abnormalities (Northern Ireland). NCCPs also elaborated proposals to ensure follow-up that is specialised, personalised, and delivered through a formal framework. Examples include a ‘Survivorship Passport’ (Austria, Croatia, Italy), nationally agreed pathways and guidelines (Czechia, Estonia, Italy, Luxembourg, Northern Ireland, Slovenia), follow-up clinics integrated in paediatric cancer centres (Czechia, Denmark, France, Ireland, Latvia, Romania, Slovenia), and involving GPs (Czechia, Denmark, France, Ireland, Latvia, Romania, Slovenia). Each of these approaches was aligned with the goal of ensuring systematic surveillance and preventive measures in the context of late effects.

Role of voluntary associations

Five NCCPs recommended that voluntary associations should support clinical activities in alignment with healthcare services. One NCCP (Croatia) encouraged engaging “competent volunteers” to contribute towards improving the quality of life of patients and families and the working conditions of healthcare professionals. This NCCP also suggested setting up rehabilitation camps for young survivors with the help of voluntary associations. Requirements to underpin the engagement of voluntary associations included clear task descriptions, volunteer contracts, and rigorous selection and training.

Two NCCPs regretted the absence of a nationwide parent association or volunteer network, pointing to their potential role in substantially facilitating the representation of patient and family interests in the dialogue with health authorities on social and practical issues.

The importance of childhood cancer registration

Eleven NCCPs emphasised the importance of population-based childhood cancer registration and the use of the International Classification of Childhood Cancers (ICCC). Childhood cancer registration may contribute to making data uniform and facilitate benchmarking and research to investigate differences in survival across Europe. Indeed, one NCCP (Latvia) noted that 5-year survival was 10–20 percent lower in Eastern Europe compared to Northern and Western Europe.

NCCPs mentioned clinical outcome registries (Norway) and tracking late effects (Sweden). There was agreement that any outcome registry or survey should be connected to paediatric cancer registries. Such registries should be supported by improved clinical data digitalisation to facilitate multidisciplinary care and international cooperation.

Discussion

This review provides a between-country thematic analysis of NCCP content on paediatric cancers. Most NCCPs included centralisation approaches combined with the need for multi-disciplinary expert teams. Supportive care emerged as a gap across the analysed documents, while survivorship care was well addressed. A limitation is that the analysis is based exclusively on NCCP content during the study period and does not include initiatives underway nationally through other channels or prior NCCPs.

Comparison with prior European analysis

Generally, countries with higher levels of information on paediatric cancers in their NCCPs in 2018 kept their position in this study, while three NCCPs which previously contained no or very limited information adopted the most developed comprehensive approach (Supplement F). This suggests that national-level buy-in can be mobilised in a short period given political will. Indeed, half of the analysed NCCPs in this study were classified as levels one and two, where paediatric oncology is approached from a health system perspective and most cancer control areas are covered.

Recommendations

While international coordination provides high added value for paediatric cancers due to their rarity, it is national level action that can make the difference by contextualising policies and shaping the services offered to patients and families. To this end, the role of NCCPs is considered highly relevant in international and EU health policy discourse.^{11–13} As seen in this study, countries may employ approaches other than NCCPs to organise national cancer control (e.g. Belgium, Netherlands). In any case, where NCCPs are in place, there is value in designing them to address childhood cancers in a specific manner and through a comprehensive approach.^{9,18} Inclusion in NCCPs may also serve to build the visibility of and the political commitment to these rare malignancies.¹⁹

Dialogue between the EU and international institutions and national governments is particularly important for rare diseases such as paediatric cancers.⁹ The understanding and comparison of national priorities and strategies can be an invaluable source of knowledge to further reinforce the shared European vision such as based on the EBCP.

In 2019, SIOPE Board experts formulated consensus policy recommendations on the inclusion of childhood cancer in NCCPs, which were reflected in the JARC conclusions.⁹ These recommendations have been maintained in SIOPE's advocacy strategy and further adapted to reflect current findings (Box 2, Panel 1). The SIOPE advocacy strategy also includes more granular consensus recommendations on fostering integrated research and care at both national and European levels (Box 2, Panel 2). Overall, the recommendations may provide a guide to policymakers and other stakeholders

Box 2.

Recommendations for policy development in paediatric oncology

1: Priorities for National Cancer Control Plans (NCCPs) stemming from JARC

- NCCPs should include a clearly designated section on children, adolescents and young adults (CAYAs) in line with the approach of Europe's Beating Cancer Plan (EBCP) which contains a Spotlight section on childhood cancer.
- NCCPs should be patient-centric and inclusive of families and caregivers, and the clinical and social aspects of CAYA cancer care should be integrated.
- NCCPs should integrate specific information and provisions on childhood cancers spanning at least the following areas:
 - 1 Epidemiology and registration.
 - 2 Healthcare organisation and quality control.
 - 3 Access to multimodal multidisciplinary standard diagnosis and treatment.
 - 4 Access to clinical research, innovative diagnostics, and therapeutics, including precision medicine.
 - 5 Access to pain management, palliative and psychosocial care addressing the needs of patients and families.
 - 6 Quality of life and survivorship care, including long-term follow-up and Survivorship Passport.
 - 7 Organisation of AYA care and transition to adult services.
 - 8 Data contributing to a European Childhood Data Strategy.
 - 9 Specialised and continuously educated workforce.
 - 10 International cooperation.
- Dedicated resources, funding and auditing should be defined for the implementation of NCCPs, including specific provisions for their childhood cancer section.

2: Priorities for coordinated approach at the European and national levels stemming from the SIOPE advocacy strategy

- Rapid referral to expert centres within countries and cross-border should be established for appropriate diagnosis and treatment planning and to ensure equal access to the best standard treatment and research.
- Centralisation of paediatric cancer procedures in expert centres should be combined with networking and shared care for low-risk interventions or services (e.g., blood tests, oral chemotherapy or essential supportive care) in coordination with other hospitals containing children's wards and under the supervision of an expert centre (the Hub and Spoke model).
- All paediatric cancer cases in Europe should be discussed in an expert regional, national or international multidisciplinary tumour board, which should in turn relate to other levels of care at the national and/or international level, avoiding silo-based models.
- A European childhood cancer accreditation programme should be established to ensure high-quality care delivery across Europe.
- Comprehensive Paediatric Cancer Infrastructures should be fostered to accelerate access to research and innovation and to amplify twinning programmes.
- Systematic and comprehensive childhood cancer registration using the International Classification of Childhood Cancer should be established across Europe to monitor the impact of policies such as NCCPs and the EBCP.
- A paediatric cancer country profile should be available for each country in the European Cancer Information System.

regarding the inclusion of paediatric oncology in NCCPs and strengthening coordinated approaches to childhood cancer control.

A unique effort in the global landscape on childhood cancers

The WHO Global Initiative for Childhood Cancer (GICC)²⁰ launched in 2018 aims for at least 60% childhood cancer survival globally and reduced suffering for all by 2030. Its operational framework¹³ addresses national cancer planning in cooperation with key stakeholders. In this context, the Pan American Health Organization developed a regional approach for the development of national plans in Latin America and the Caribbean, and nine countries were implementing national laws inclusive of childhood cancer in 2023.²¹ Efforts in other regions including Africa and Eastern Mediterranean are also ongoing.^{22,23}

European Union: towards an integrated approach

The EBCP contributes to global efforts on cancer control in the EU and may serve as a blueprint in the broader European region.²⁴ Alignment between the EBCP and NCCPs is set to foster progress towards the goal to cure more CAYAs with cancer, to cure them better, and to reduce inequalities across Europe.

Yet, gaps can be identified in the EBCP approach. One example is the lack of specific infrastructural EU and Member State support of the European paediatric oncology network delivering care and research, which is necessarily different from the European Network of Comprehensive Cancer Centres envisaged for adult patients. The European Reference Network on Paediatric Cancer¹⁷ has been an important step forward and requires sustainable support. Further major needs are the systematic registration of paediatric cancers using the appropriate classification and supportive care including pain management, palliative and psychosocial care, which should be a consistent part of commitment to the needs of CAYAs with cancer.

Conclusion

In the global policy environment where childhood cancer is increasingly in the spotlight, the EBCP and its dedicated Section on Childhood Cancer added important momentum to address the specific needs of CAYAs with cancer across Europe. Alignment and cross-dialogue with national cancer policies are key to realising and further enriching this vision. This review shows that paediatric cancers are addressed in 22 European NCCPs, with a clear emphasis on access to specialist care and MDTs. However, the approach is not always complete, and important elements of the care continuum and health system organisation specific to paediatric oncology are often missing. The EU policy term 2024–2029 and the renewal or establishment of NCCPs

at the country level are opportunities to build on the impetus for childhood cancer and ensure comprehensive integrated care and research underpinned by solid infrastructures for the benefit of each young patient and survivor.

Contributors

Conceptualisation: GV, JB, JP, MO, PK, RL, CR, DH, UD, CO, OK, DL. Methodology: GV, JB, JP, MO, PK, RL, CR, DH, UD, CO, OK, DL. Project administration: JP, DL, OK, GV, JB. Data collection, curation, and validation: JP, DL, OK, GV, JB. Formal analysis: JP, OK, CS. Writing—original draft: JP, OK. Writing—review and editing: JP, OK, GV, JB, MO, PK, RL, CR, DH, UD, CO, DL, CS; Supervision: GV and JB. Final approval was obtained from all authors. All authors confirm that they had full access to all the data in the study and accept responsibility to submit for publication.

Declaration of interests

OK: All support for the present manuscript (e.g., funding, provision of study materials, medical writing, article processing charges, etc.): The European Society for Paediatric Oncology (SIOPE) is set to contribute to the article processing fee. Other financial or non-financial interests: Currently employed by SIOPE.

MO: Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid: SIOPE Board member.

PK: Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid: ACCELERATE–Board member of Not for profit organisation, no payments involved; SIOPE–Board member of Not for profit organisation; No payments involved; ITCC – Board member of Not for profit organisation; No payments involved.

RL: Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid: SIOPE Board member.

CR: Consulting fees: Amgen Servier, Clinigen, Amgen, Jazz. Payment honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events: Amgen Servier, Clinigen, Amgen, Jazz. Support for attending meetings and/or travel: Amgen Servier, Clinigen, Amgen, Jazz. Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid: SIOPE Board.

UD: Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid: SIOPE Board (unpaid), GPOH Board (unpaid), German Childhood cancer foundation board (unpaid), German Sarcoma Association board (unpaid).

CO: Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid: SIOPE Board member.

GV: Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid: SIOPE Board member; ITCC Board member; ITCC-P4 gGmbH Chief Operating Officer; Accelerate Chair.

The other authors report no conflict of interest related to this work.

Acknowledgements

Country Operating Team members: Supplement G.

Office support: Andreu Albiach [Catalonian Cancer Strategy], Agata Kusiak [previously SIOPE], Caroline Queiroz [SIOPE].

Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.lanepe.2024.101155>.

References

- 1 Vassal G, Schrappe M, Pritchard-Jones K, et al. The SIOPE strategic plan: a European cancer plan for children and adolescents. *J Cancer Policy*. 2016;8:17–32.
- 2 Ferlay J, Ervik M, Lam F, et al. *Global Cancer Observatory: Cancer Today*. Lyon: International Agency for Research on Cancer; 2024:c2024 [cited 2024 Feb 7]. Available from: <https://gco.iarc.who.int/today/>.
- 3 Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006;355(15):1572–1582.

- 4 Hjorth L, Haupt R, Skinner R, et al. Survivorship after childhood cancer: PanCare: a European Network to promote optimal long-term care. *Eur J Cancer*. 2015;51(10):1203–1211.
- 5 European Commission. Europe's Beating Cancer Plan. European Commission [cited 2024 July 22]. Available from: https://health.ec.europa.eu/document/download/26fc415a-1f28-4f5b-9bfa-54ea8bc32a3a_en.
- 6 European Commission. EU enlargement [cited 2024 Oct 15]. Available from: https://commission.europa.eu/strategy-and-policy/policies/eu-enlargement_en.
- 7 European Commission. List of participating countries in the EU4Health programme [cited 2024 Oct 15]. Available from: https://ec.europa.eu/info/funding-tenders/opportunities/docs/2021-2027/eu4h/guidance/list-3rd-country-participation_eu4h_en.pdf.
- 8 European Commission. List of participating countries in Horizon Europe [cited 2024 Oct 15]. Available from: https://ec.europa.eu/info/funding-tenders/opportunities/docs/2021-2027/common/guidance/list-3rd-country-participation_horizon-euratom_en.pdf.
- 9 JARC – Joint Action on Rare Cancers. In: Casali PG, Trama A, eds. *Rare Cancer Agenda 2030: Ten Recommendations from the EU Joint Action On Rare Cancers*. Lecce: Youcanprint; 2019:131 [cited 2024 July 22]. Available from: <https://siope.eu/media/documents/rare-cancer-agenda-2030.pdf>.
- 10 World Health Organization. National cancer control programmes. World Health Organization [cited 2024 Feb 16]. Available from: <https://www.who.int/publications-detail-redirect/national-cancer-control-programmes>.
- 11 Seventieth World Health Assembly. *Cancer prevention and control in the context of an integrated approach*. Geneva: World Health Organization; 2017 [cited 2024 Oct 15]. Available at: https://apps.who.int/gb/ebwha/pdf_files/WHA70/A70_R12-en.pdf.
- 12 European Union. Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions on Action Against Cancer: European Partnership [cited 2024 Oct 15]. Available at: <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A52009DC0291>.
- 13 World Health Organization. CureAll framework: WHO global initiative for childhood cancer. Geneva: World Health Organization [cited 2024 Apr 15]. Available from: <https://iris.who.int/bitstream/handle/10665/347370/9789240025271-eng.pdf?sequence=1>.
- 14 Romero Y, Trapani D, Johnson S, et al. National cancer control plans: a global analysis. *Lancet Oncol*. 2018;19(10):e546–e555.
- 15 Joint Action on Rare Cancers. Priorities and recommendations on rare cancers in adults and children in National Cancer Control Plans (NCCPs). Innovative Partnership for Action Against Cancer (iPAAC) [cited 2024 July 22]. Available from: <https://www.ipaac.eu/res/file/roadmap/id138-a1.pdf>.
- 16 Glaser BGS, Strauss AL. *The discovery of grounded theory: strategies for qualitative research*. Chicago, IL: Aldine; 1967.
- 17 ERN PaedCan [cited 2024 Feb 16]. Available from: <https://paedcan.ern-net.eu/>.
- 18 Jelenc M, Weiderpass E, Fitzpatrick P, Albrecht T. Developments in national cancer control programmes in Europe: results from the analysis of a pan-European survey. *Cancer Control*. 2021;28.
- 19 Prades J, Weinman A, Le Cam Y, Trama A, Frezza AM, Borrás JM. Priorities on rare cancers' policy in national cancer control plans (NCCPs): a review conducted within the framework of EU-JARC joint action. *J Cancer Policy*. 2020;24.
- 20 The Global Initiative for Childhood Cancer [cited 2024 July 22]. Available from: <https://www.who.int/initiatives/the-global-initiative-for-childhood-cancer>.
- 21 Loggetto P, Jarquin-Pardo M, Fuentes-Alabi S, et al. Regional collaboration for the development of national childhood cancer plans in Latin America and the Caribbean. *Rev Panam Salud Pública*. 2023;47:1.
- 22 Siddiqui AK, Belgaumi AF. Paediatric oncology in the Eastern Mediterranean region (EMR): the current state and challenges. *Ecancermedicalscience*. 2024;18:1677.
- 23 WHO Regional Office for Africa. *Zimbabwe updates National Cancer Control Plan to mitigate the increase of cases in the country*; 2022 [cited 2024 Apr 12]. Available from: <https://www.afro.who.int/countries/zimbabwe/news/zimbabwe-updates-national-cancer-control-plan-mitigate-increase-cases-country>.
- 24 World Health Organization. *WHO discusses approaches to strengthen cancer efforts with members of the European Parliament*. Geneva: World Health Organization; 2021 [cited 2024 Oct 15]. Available from: <https://www.who.int/news/item/09-11-2021-who-discusses-approaches-to-strengthen-cancer-efforts-with-members-of-the-european-parliament>.