

Recommendations for Equitable, Diverse, and Inclusive Cancer Care in Europe



Co-funded by the European Union

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

Acknowledgments

Authors:

Carmen Monge-Montero
Stewart O'Callaghan
Katie Rizvi
Urška Košir
Victor Gîrbu

Reviewers:

Johan De Munter
Karl Smith-Byrne
Maria Cristina Trifulescu

Graphic Design:

Andrea Ruano Flores

Additional contributors
listed in alphabetical order

Literature reviews & Surveys

Ana Amariutei, Regvita Janavičiūtė,
Giorgia Manuzi, Varduhi Sargsyan,
Anna Zettl

Multi-stakeholder consultation:

Inclusive Employers for facilitating the
consultation event and workshop

We thank everyone who helped to deliver
this project including survey and workshop
participants and translators.

We also acknowledge the Beneficiary
and Associated Partner organisations
of the larger consortium and especially
the members of the WP5 working group
of EU-CAYAS-NET and all those who
contributed to the EDI workstream.

Suggested citation: Monge-Montero, C., O'Callaghan, S., Rizvi, K., Košir, U., & Gîrbu, V. (2024). Recommendations for Equitable, Diverse, and Inclusive Cancer Care in Europe. Youth Cancer Europe; European Commission co-funded project: EU-CAYAS-NET EU4H-2021-PJ-04:101056918

Work led by:



Contributing consortium partners:



Recommendations for Equitable, Diverse, and Inclusive Cancer Care in Europe

“Identifying reasons why people either don’t feel heard or supported or feel disadvantaged is very important if our goal is to try and improve survival and well being among patients.”

Karl Smith-Byrne, Rectal Cancer Patient, Senior Molecular Epidemiologist, University of Oxford

The right of everyone to access healthcare is enshrined in Article 35 of the European Union’s Charter on Fundamental Rights¹ but cancer care access and outcomes for young people can vary greatly depending on a multitude of factors.

Some of these factors are demonstrated by the EU Commission’s Inequalities Register² which provides data on disparities between Member States and regions; and the European Network of Equality Bodies³, which reports on inequalities known to affect health outcomes across the EU. However, certain key dimensions are not fully captured, including ethnicity, migrant status, gender identity, sexual orientation, or for example neurodiversity; all of which have been found to be important predictors of cancer treatment outcomes.⁴⁻⁶

Attaining equity in cancer care remains an elusive goal for institutions, healthcare providers, researchers, and patient communities alike. As we navigate the complexities of addressing cancer inequalities, it becomes imperative to collectively explore immediate, mid-term and long-term possible solutions.

This document is meant to serve and shape the discourse by reporting on a multi-stakeholder and collaborative process aimed at unveiling actionable recommendations designed to be aspirational, achievable, and transformative.



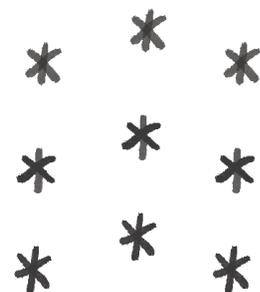
Equity, Diversity, and Inclusion in cancer care

Equity, Diversity, and Inclusion (EDI) in cancer care encompasses the principles of fairness, accessibility, and respect for individual differences to ensure that all individuals receive appropriate and timely support and services to achieve optimal health outcomes.

This includes addressing systemic barriers and disparities in healthcare access, delivery, and outcomes based on factors such as race, ethnicity, socioeconomic status, gender identity, sexual orientation, disability, or geographic location. EDI in cancer care involves promoting equitable access to cancer prevention, screening, diagnosis, treatment, and supportive care services for diverse populations, including underserved and marginalised communities. It also entails fostering culturally competent care practices, providing patient-centred communication and decision-making, and creating inclusive healthcare environments that accommodate the unique needs and preferences of all individuals affected by cancer. Ultimately, EDI in cancer care aims to reduce disparities, promote health equity, and improve the quality of care and outcomes for all individuals impacted by cancer.

To address this, Youth Cancer Europe introduced an EDI workstream into the European Commission co-funded European Network of Youth Cancer Survivors project (EU-CAYAS-NET EU4H-2021-PJ-04:101056918).

A scoping literature review and grey literature review examined articles, narrowing down to those meeting specified criteria; an online cross-sectional Patient Survey was conducted in 12 European languages, and a second survey for healthcare providers explored existing EDI policies and practices within healthcare institutions. In late 2023 a multi-stakeholder consultation in Romania looked at key considerations for EDI educational and training needs in the cancer care ecosystem.



The process was steered by a diverse working group of individuals from various backgrounds and professions, the majority of whom are young people living with and beyond cancer.

Based on our findings, we focused on four important areas to ensure fairness and inclusivity in cancer care and grouped our recommendations as follows:

1. RACE, ETHNICITY, CULTURE, REFUGEE, OR MIGRANT STATUS:

To address disparities and ensure equitable access to cancer care for individuals from diverse racial, ethnic, and cultural backgrounds, including refugees and migrants.

2. GENDER IDENTITY AND SEXUAL ORIENTATION:

To promote awareness and support for LGBTIQ+ individuals affected by cancer, ensuring they receive respectful and inclusive care regardless of their gender identity or sexual orientation.

3. AGE, PHYSICAL AND MENTAL DEVELOPMENT, AND WELLBEING:

To recognize the unique needs of individuals at different stages of life, including children, adolescents, and young adults, and recognise mental health status and neurodiversity as important determinants of health outcomes.

4. EDUCATION, CAREER, AND SOCIOECONOMIC STATUS:

To address social determinants of health and ensure that individuals from all socioeconomic backgrounds have access to quality cancer care, regardless of their education level, career status, or living conditions.



41% of young people with cancer don't feel represented by booklets and other information provided to them by healthcare facilities

Equality

means everyone gets the same things or treatments. It's like giving everyone the same-sized shoes, even if some people need bigger or smaller shoes.



Equity

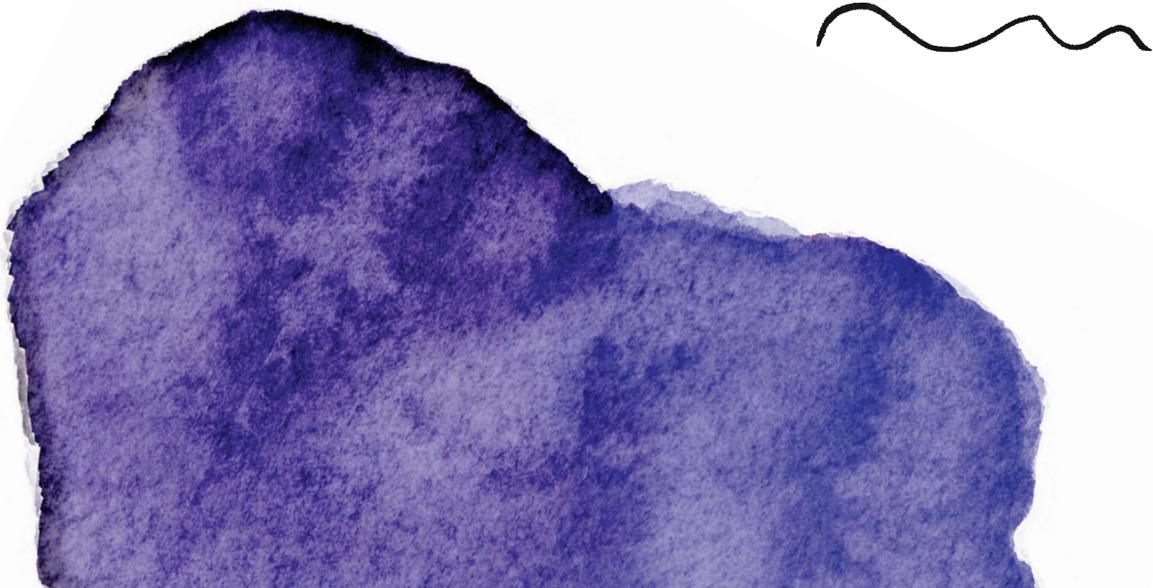
Means everyone gets what they need to be fair. It's like giving different-sized shoes to different people so that everyone's shoes fit them just right.



In cancer care

this could mean providing free or low-cost cancer screenings in underserved communities where people may have less access to healthcare. It could also mean offering language interpretation services or transportation assistance to ensure everyone can access cancer treatments, regardless of their language spoken or ability to travel. It would mean recognizing and respecting individual preferences, beliefs, and values related to health and healthcare, or for example providing information in easy language written formats, using visual diagrams, and creating environments that are conducive to the needs of neurodiverse individuals, such as minimising noise, bright lights, and crowded waiting areas.

Striving for equity in cancer care is striving for everyone to have the best chance at getting better.



Article 21 Charter of Fundamental Rights¹ of the European Union forbids discrimination on grounds of sex, race, colour, ethnic or social origin, genetic features, language, religion or other belief, political opinion, membership of a national minority, property, birth, disability, age or sexual orientation.

There are 9 grounds for discrimination:

1. **Gender:** includes man, woman, or transgender
2. **Civil status:** includes single, married, separated, divorced, widowed people, civil partners and former civil partners
3. **Family status:** this refers to the parent of a person under 18 years or the resident primary carer or parent of a person with a disability
4. **Sexual orientation:** includes gay, lesbian, bisexual and heterosexual
5. **Religion:** means religious belief, background, outlook, or none
6. **Age:** this does not apply to a person aged under 16
7. **Disability:** includes people with physical, intellectual, learning, cognitive or emotional disabilities and a range of medical conditions
8. **Race:** includes race, skin colour, nationality, or ethnic origin
9. Membership of the **Traveller community**

These are known as the protected grounds.

For example...

Under EU law a transgender person who experiences discrimination arising from their gender reassignment, or transition, is protected under the gender ground.

How does this relate to cancer care?

Transgender individuals may postpone seeking healthcare due to fear of discrimination or stigma, leading to delayed cancer diagnosis and treatment initiation. Some cancer treatments may interact with gender-affirming hormone therapy commonly used by transgender individuals, potentially complicating treatment regimens or causing adverse effects.

When transgender individuals encounter healthcare providers who lack knowledge or sensitivity regarding transgender health issues, it may lead to suboptimal care or inappropriate treatment recommendations. They may also experience additional psychological distress related to cancer diagnosis and treatment, compounded by existing stigma, discrimination, or social isolation.





Our approach

LITERATURE REVIEW

A scoping literature review and a grey literature review was conducted and examined 1,519 articles, narrowing down to 914 for inclusion through age, category, and region criteria. When applying the 'Europe specific' region criteria, 90 articles were accepted for inclusion and 45 were used in this document. 31% of papers specifically centred on childhood, and 11% on adolescents and young adults (AYA). Topics such as gender and sexuality, family, and education or career were not well represented in European literature compared to global literature. From grey literature, 27 relevant sources were identified, including official webpages (48%) and reports (28%), with the majority focusing on "Race & Ethnicity" and "Gender & Sexuality".

ONLINE SURVEYS

An online cross-sectional survey (Patient Survey) was launched in 12 European languages (English, Italian, Spanish, French, German, Dutch, Russian, Ukrainian, Romanian, Lithuanian, Slovenian, and Croatian). Participation from minority groups was encouraged through targeted survey promotion in organisations focusing on minority populations. A total of 128 respondents with a lived experience of cancer (average age 30.9), from 25 different countries completed the anonymous survey. Descriptive analyses were used to summarise demographic and medical information and qualitative content analysis for the coding of short-answer responses to the open ended questions. Results were triangulated by 3 independent researchers and informed the writing of recommendations.

A second survey explored existing EDI policies and practices within healthcare institutions (HCP Survey). The survey was completed by 77 respondents (average age 51 years), from 22 EU countries. The majority, 97% of respondents, came from cancer-specific health roles including paediatric haemato-oncologists, nurses, paediatric residents, radiation oncologists, researchers, and consultants. The survey responses revealed that European healthcare professionals recognize the importance of EDI but seek further education and engagement opportunities.

MULTI-STAKEHOLDER CONSULTATION AND WORKSHOP (WORKSHOP)

Held in Romania, the "From Prejudice to Progress: Equity, Diversity & Inclusion Round Table and Workshop" welcomed 37 participants representing 17 countries in various roles, including patient advocates, researchers, healthcare providers, academics, and local interest groups, health policy experts and policymakers. Among them, representatives of the Cluj-Napoca City Hall, the Cluj-Napoca International Council, the Babeş-Bolyai University Public Health faculty, the Prof. Dr. Ion Chiricuță" Oncology Institute, the Medical University of Vienna, the European Oncology Nursing Society (EONS), the Global Inclusion Department of the Global Institute for Peace (PATRIR), patient groups Alike and Little People Romania and advocacy groups OUTpatients and Queer Sisterhood participated. Key learnings from discussions highlighted the necessity for a pan-European perspective in developing educational content tailored to healthcare providers, researchers, and patient advocates. Inclusive language, interactive content, real-world application through case studies, and involving individuals with lived experience in content creation were emphasised.

Recommendations

* **STRENGTHENING EDI IN RESEARCH: IMPROVING PATIENT DATA COLLECTION AND ENHANCING RESEARCH TEAM DIVERSITY**

EU member states should systematically and within legal bounds improve the data they hold for ethnicity, LGBTIQ+ identity, psychosocial development, quality of life, physical and mental health, education, socioeconomic status and employment rights of cancer patients. The EU should work towards a standardised data collection that is shared via the EU Health Policy Platform alongside other major EU initiatives. An equal weight should be given to efforts to increase diversity and inclusion in healthcare and research personnel.



* **IMPROVING EDI IN CANCER SERVICES: PROVIDING CULTURALLY SENSITIVE CARE AND PROMOTING DIVERSE REPRESENTATION IN CARE TEAMS**

Cancer services should develop, improve, and implement culturally sensitive care, ensuring that patients receive support that respects their cultural, psychosocial, financial, educational, reproductive, and sexual needs. Inclusive cancer services also require the promotion of diverse representation in care teams to better reflect the communities they serve. Patients with lived experience should be actively engaged in health strategy development, funding decisions and building services and the co-creation of new policies related to their care, fostering a collaborative approach that prioritises their unique perspectives and needs.



* **FOSTERING DIVERSITY AND INCLUSION WITHIN PATIENT ORGANISATIONS**

Patient organisations should have a more proactive approach to achieving diversity and inclusion by actively recruiting individuals from diverse backgrounds, providing training on cultural competency and sensitivity, and implementing policies and practices that promote inclusivity and equity within the organisation. By embracing diversity and inclusion, patient organisations can better serve their communities and advocate for more equitable healthcare policies and services.

INTRODUCING AN INNOVATIVE INTERACTIVE CURRICULUM AND TRAIN-THE-TRAINER TOOLKIT AIMED AT TRANSFORMING CANCER CARE THROUGH DIVERSITY, EQUITY, AND INCLUSION PRINCIPLES

Soon to be launched within the European Network of Youth Cancer Survivors EU co-funded project, our comprehensive program is designed to equip clinicians, healthcare providers, patient and community organisations, researchers, and educational institutions with essential skills and awareness to address prejudice and tailor cancer care to underserved groups.

Modules will cover a range of topics including cultural competence, legal and cultural contexts of inequality, inclusive language, psychological safety, family support, patient autonomy, discrimination identification and challenge, holistic patient needs assessment, inclusive research practices, and effective advocacy.

More details to be announced on beatcancer.eu

For queries, please email

Victor Girbu victor@youthcancereurope.org and
Katie Rizvi katie@youthcancereurope.org

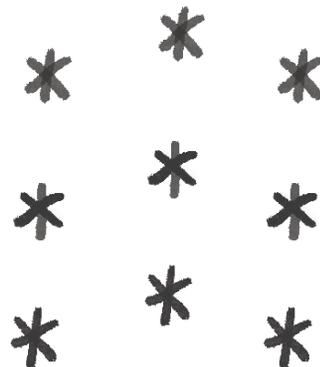


**60% of healthcare
professionals reported
not having heard about
EDI policies and practices
in their work environment**

Actions



To help EU members deliver on the three recommendations, the following section provides examples of targeted actions that have been designed to be measured, realistic, and achievable. These actions are grouped under four focus areas according to the recommendations. The table is illustrative; the actions extend across the four focus areas and are not mutually exclusive. This setup is particularly effective for addressing intersectionality, tackling issues that affect people in different and overlapping ways, and ensuring we address everyone's needs.



	Strengthening EDI in research: improving patient data collection and enhancing research team diversity	Improving EDI in cancer services: providing culturally sensitive care and promoting diverse representation in care teams		Fostering diversity and inclusion within patient organisations
↓ Focus areas	Data and monitoring	Representation and advocacy	Services and accessibility	Knowledge and education
Race, ethnicity, culture, refugees, and migrants	Integrate ethnicity and migration experiences into cancer research and data monitoring	Embed diverse community representation in decision making Improve public health messaging for diverse populations	Provide interpreters and translate public health messaging Provide culturally informed services	Provide cultural humility training for healthcare providers
Gender identity & sexual orientation	Encourage and support LGBTIQ+ research	Increase visibility and awareness Include sex, gender, and sexual orientation in health strategies	Provide comprehensive psychosocial support Design tailored interventions for reproductive and sexual health	Provide awareness and support strategies for gender, sexuality, fertility and family support
Age, physical and mental wellbeing	Implement psychosocial cancer care for all ages and all types of cancer Promote research on visible and invisible disabilities	Include young people in health decisions and co-create holistic care models Address negative bias in public health messaging	Create accessibility policies and audits to support people with disabilities Offer prehabilitation and rehabilitation	Co-produce training for age-appropriate communication with people with and beyond cancer
Education, career, and socioeconomic status (SES)	Create a taskforce within the EU Commission to monitor the education and employment rights of young cancer survivors	Legislate for inclusive employment policies for people living with and beyond cancer Co-create programmes to support patients and families facing financial difficulties and/or educational challenges	Expand health insurance coverage for young adults without stable jobs Promote best practices in cancer care to overcome geographic disparities	Educate patients and family about their employment rights and opportunities Improve public health messaging in rural and low SES populations

Table 1. Summary of recommended actions in four key focus areas to enhance EDI in cancer care

Actions for addressing disparities related to race, ethnicity, culture, migrant and refugee status

“It would have been easier if there had been more opportunities to involve my parents who live in another country and don’t speak the local language during conversations and not only afterwards.”

Online survey participant

DATA AND MONITORING

Integrating ethnicity and migration experiences into cancer research and data monitoring

In the Patient Survey, 12% of respondents received at least some of their treatment outside of their home country, suggesting that there is a need for enhanced inclusivity in European cancer research and data monitoring. Addressing this gap requires integrating detailed analyses of ethnicity, cultural backgrounds, and refugee experiences into research, with a focus on the implications of genetics, race, and treatment outcomes.^{4,7,8} Moreover, improving data collection policies, diversifying research teams, and standardising data across countries are essential steps to ensure person-centred care for all patients, particularly migrants.⁹

REPRESENTATION AND ADVOCACY

Embed diverse community representation in decision making

Create opportunities and structure for meaningful co-production with underrepresented and minority groups and include the patient voice through all levels of decision-making. To achieve this, involve intercultural facilitators/advocates who can provide healthcare professionals with insights into the needs of patients and their families, while also offering information, advice, and support.⁹



Improve specific support for diverse populations

Create specific support for different origins and ethnic populations. This work should also consider migrants, their biological characteristics, levels of education, and health approaches to develop tailored communication programmes but also respect their cultural norms and beliefs.⁹ These programmes must be developed by the communities themselves, for themselves, to ensure effectiveness in addressing their unique needs.

SERVICES AND ACCESSIBILITY

Provide interpreters and translate public health messaging

The HCP Survey clearly outlined a need for language support, including both interpretation and translation. The translation should be considered for not only informative leaflets and posters but also for surgical checklists, consent forms, medical records, and insurance information. Provision and promotion of events and support groups should also be provided in other languages, particularly for immigrants.¹⁰

Provide culturally informed services

Consider beliefs and values of the patients and their communities within services, including medical aspects of care and socio-economic determinants. This could be achieved by providing patient navigation programmes and intercultural support to assist in navigating the healthcare system.¹⁰ Demonstrate the feasibility and acceptability of these services through pilot studies, then scale these interventions to a national level to enhance healthcare accessibility and effectiveness.¹¹

KNOWLEDGE AND EDUCATION

Provide cultural humility training for healthcare providers

In the Patient Survey, 10% of the participants reported experiencing or witnessing discrimination related to race, ethnicity, nationality, culture, and religion. The HCP Survey demonstrated a high interest in training related to these factors. Training should move past 'cultural competency' which has the potential to suggest a finite or ultimate point of awareness and may lead to complacency. Instead, 'cultural humility' should be embraced as it recognises the importance of remaining open to learning.¹²



16% young people reported being exposed to racially charged or dehumanising language during or after their cancer care

Actions for addressing disparities related to gender identity & sexual orientation

“Fertility issues are a concern for all young people, not only females.”

Online survey participant

DATA AND MONITORING

Encourage and support LGBTIQ+ research

Engage researchers and healthcare professionals to prioritise diversity and intersectionality in LGBTIQ+ research, particularly its impact on cancer survivorship, well-being, and fertility issues.¹³ Survey responses from patients and healthcare professionals underscored a significant gap in information on this critical topic.

REPRESENTATION AND ADVOCACY

Increase visibility and awareness

In the Patient Survey and workshop, there were indications that discrimination against various genders within the healthcare system impacted patient engagement. Ensuring freedom from discrimination based on gender and sexual orientation must become a fundamental objective for all EU member states. Immediate actions should include the visible display of LGBTIQ+ affirming materials in healthcare settings and the recruitment of a diverse medical team.¹⁴

Include sex, gender, and sexual orientation in health strategies

Services must be accountable for addressing complaints about discrimination to reduce mistrust and avoidance of medical consultations. Policies and procedures should include multiple levels of engagement from patients, professionals, and policy leaders in the cancer space.¹⁴ Targets for patient reported experience measures and outcomes should be set and monitored for progress, potentially by national equality bodies.

SERVICES AND ACCESSIBILITY

Provide comprehensive psychosocial support

LGBTIQ+ patients have been shown to have poor quality of life, intersectional barriers, poor mental health, unmet needs, lower levels of social support, and financial hardship.¹⁵⁻¹⁷ Specific actions include targeted interventions for depression and anxiety, initiatives to increase social support, and support for employment and financial stability among LGBTIQ+ patients.

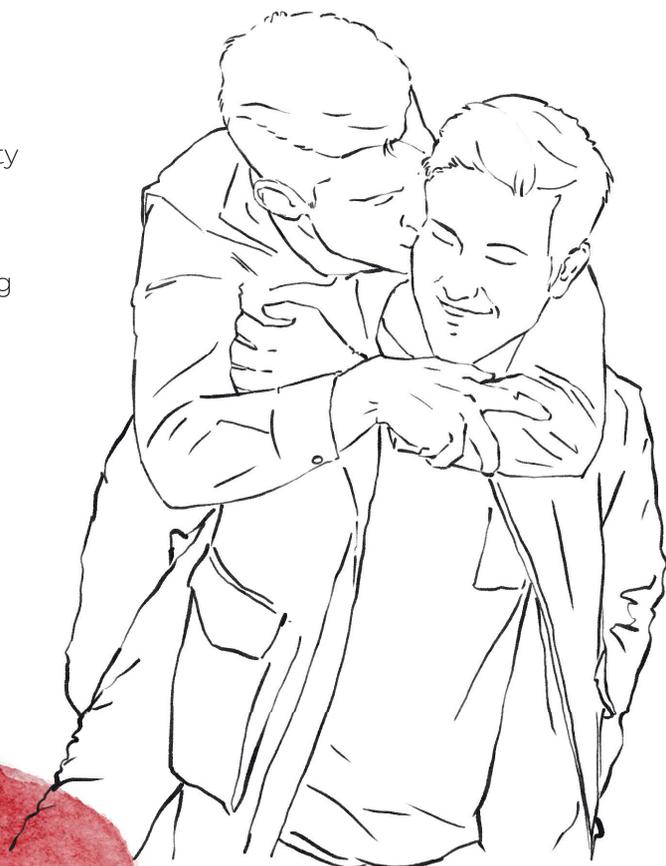
Design tailored interventions for reproductive and sexual health

Workshop findings and our patient survey revealed that the LGBTIQ+ community faces a significant information gap and stigma regarding fertility preservation and sexual health before, during, and after cancer treatments. Cancer services must provide fertility preservation and family planning options for all patients and prevent financial discrimination in accessing these services.

KNOWLEDGE AND EDUCATION

Provide essential training on awareness and strategies for gender, sexuality, fertility and family support

In the Patient Survey, respondents highlighted discrimination based on gender and sexuality by HCPs. The HCP Survey confirmed the need for specialised training on these issues. Essential training for HCPs should cover gender and sexuality awareness, the psychosexual effects of treatments, changes in physical appearance, ensuring fertility equality, and strategies for navigating family rejection.¹⁸



Actions for addressing disparities related to age, physical and mental wellbeing

“My biggest barriers to feeling more included or comfortable during my cancer experience were my psychosocial issues post-treatment (e.g. fatigue, depression) not being seen as a disability and late effects that still remind you that you are different from people your age because of your cancer journey”

Online survey participant

DATA AND MONITORING

Implement psychosocial cancer care for all

Monitor the psychosocial development, health-related quality of life and physical parameters from all types of cancers and create early detection strategies for developing issues.¹⁹⁻²¹ Address the critical need for investment in high-quality psycho-social research into survivor mental health, especially for rare cancers and long-term follow-ups across all ages.²²

Promote research on visible and invisible disabilities

Clinicians advocate for more research to refine care protocols for patients with intellectual and neurodiverse conditions.^{23,24} One example is autism, which is associated with higher diagnosis rates and poorer outcomes which may be linked to concurrent intellectual and developmental disabilities.⁶ Research is needed for both visible and invisible disabilities in cancer care.

REPRESENTATION AND ADVOCACY

Include young people in health decisions and co-create holistic care models

In the Patient Survey, 10% of respondents felt overlooked and underestimated in their cancer care, ignoring their unique needs. To address this, multi-stakeholder teams are needed in all clinical settings and develop a comprehensive holistic care model that emphasises psychoeducation, exercise, and peer support for patients of all ages and at all stages of cancer, extending into post-treatment survivorship.²⁵⁻²⁷

Address negative bias in public health messaging

Strategic public health messaging should avoid stigma-inducing, shock-based campaigns that can foster guilt, regret, and perceived blame among those diagnosed with cancer.²⁸ Instead, the focus should shift towards patient-centred, positive communications that promote positive health maintenance within the broader societal context.

SERVICES AND ACCESSIBILITY

Create accessibility policies and audits to support disabled people

The Patient Survey revealed that individuals with mobility impairments stress the need for accessible infrastructure and services which often fail due to inadequate patient consultation. Co-production of accessibility should also apply to neurodivergence and invisible disabilities considering adaptive equipment, communication aids, and supportive resources. Regular evaluations by equality bodies and patient groups are essential to ensure these facilities genuinely accommodate all patient needs.²⁹



Offer prehabilitation and rehabilitation

In a study in Sweden, over 25% of patients reported not receiving offers for cancer rehabilitation.³⁰ The Patient Survey showed similar results with one participant being denied the possibility of having rehabilitation even though they were entitled to it. Health providers should recognize the need for repeated and varied information dissemination to both patients and their families, guardians, and caregivers to make sure all services are advertised effectively.

KNOWLEDGE AND EDUCATION

Implement training for better age-appropriate communication with people with and beyond cancer

Improve age-appropriate communication through training that takes a multidisciplinary and intersectional approach to holistic support, for example, improving communication between paediatric oncology and primary care after childhood cancer.²⁰ Address the issue of medical staff underestimating young patients' understanding, as reported by 21% of Patient Survey respondents, to enhance informed decision-making and respect for AYAs in and beyond cancer treatment.³¹



Actions for addressing disparities related to education, career development, and socioeconomic status

“Many young adults are only students and don’t have enough savings ”

Online survey participant

DATA AND MONITORING

Create a taskforce within the EU Commission to monitor the education and employment rights of young cancer survivors

For many AYA patients, treatment often disrupts crucial development stages which can significantly impact their professional success, career progression, and competitive standing against peers and established professionals.

Implement a system for periodic updates and reviews of educational data, socioeconomic outcomes and employment rights for young cancer survivors.

REPRESENTATION AND ADVOCACY

Legislate for inclusive employment and prohibiting financial discrimination against cancer survivors

Many cancer survivors struggle to regain financial stability due to stigma and financial discrimination impacting their ability to secure health insurance or mortgages and build a solid foundation for their future. Advocate for inclusive employment policies to support cancer survivors' workforce re-entry, particularly in countries without strong advocacy, to ensure their needs are recognized on the political agenda.^{32,33}

Implement co-create programmes to support patients and families facing financial difficulties and/or educational challenges

Patient Survey results highlight young cancer patients' financial struggles, including access to specific tests, treatments, and transportation costs. Implement financial support measures such as travel bursaries, subsidised temporary accommodation, parental education on cancer impacts, assistance for school integration, and subsidies for fertility preservation to alleviate the financial burden on families affected by cancer.³⁴⁻³⁶

SERVICES AND ACCESSIBILITY

Expand health insurance coverage for young adults with cancer

Research shows that European countries with national health systems have better cancer survival rates than those with social (private) insurance models, partly because young adults often lack comprehensive health insurance, or might delay diagnoses.^{36,37} Implementing comprehensive, accessible healthcare policies in the EU is crucial to ensure timely diagnoses and effective treatment for CAYA cancer survivors, especially those aged 26 to 39, improving survival rates and outcomes.³⁷

Promote best practices in cancer care to overcome geographic disparities

Formulate strategies for access to care and treatment quality between rural and urban settings and income disparities across countries and neighbourhoods. This is crucial as cancer mortality is consistently higher in Central and Eastern European countries.³⁸ The data will inform interventions that integrate healthy behaviours into daily life and consider financial constraints (e.g., access to workout equipment, gym memberships, transportation, nutrition).³⁹⁻⁴²

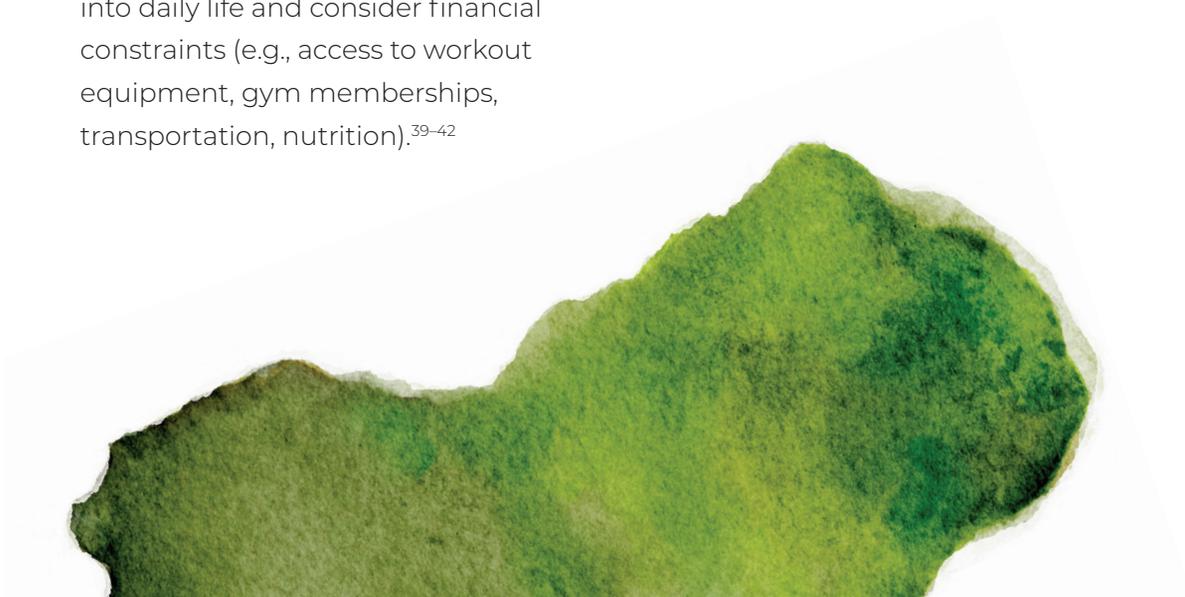
KNOWLEDGE AND EDUCATION

Educate patients and families about their employment rights and opportunities

The surveys revealed that employment concerns are frequently overlooked by healthcare professionals. Addressing this issue is essential for improving the long-term quality of life for cancer survivors. Establish targeted programmes to educate young adults with cancer about their employment rights and create career opportunities through educational grants, internships and professional development guidance.³²

Improve public health messaging in rural and low SES populations

The Patient Survey highlighted equal access to care as a major concern. Resources should be allocated to educate patients in low SES areas about healthcare accessibility, early diagnosis programs, and insurance literacy. Such measures can significantly enhance cancer survival rates, particularly in regions where increased health spending and resources have been demonstrated to improve outcomes.⁴³



Conclusions

- * The European Commission has been working on cancer since 1985 with EU countries and civil society, in close collaboration with the World Health Organisation, the Joint Research Centre and the International Agency for Research on Cancer. In 2021, announcing a €5.3 billion budget for the 2021-2027 EU4Health⁴⁴ programme paving the way to a European Health Union, the EU launched one of the most ambitious and comprehensive Cancer Plans yet: Europe's Beating Cancer Plan⁴⁵. Backed with unprecedented EU investment and unparalleled political momentum for action on cancer, the EU4Health programme and other EU instruments provide a substantial €4 billion budget earmarked for cancer.
- * We urge the Commission to prioritise the integration of equity, diversity, and inclusion (EDI) principles throughout all EU health initiatives with dedicated funding and resources for research, programs, and interventions aimed at addressing disparities in cancer prevention, diagnosis, treatment, and survivorship among marginalised and underserved populations, and look at social determinants beyond the currently captured data in the Inequalities Register.
- * Additionally, the Commission should promote the development and implementation of EDI-focused policies, guidelines, and best practices across EU member states to ensure equitable access to quality cancer care for all individuals, regardless of their socio-economic status, ethnicity, gender identity, sexual orientation, age, or other factors.

53% of young people with cancer think policymakers don't do enough to address issues of diversity and inclusion in their programmes

Closing remarks

The EU-CAYAS-NET project demonstrates how multi-stakeholder engagement can inform practical steps towards more equitable and inclusive cancer care. Building on the findings that informed our recommendations, the project EDI workstream also set out to develop an Equity, Diversity and Inclusion Toolkit and Training Programme.

The interactive curriculum featuring a train-the-trainer toolkit, in-person workshops and online content aims to equip three audiences - clinicians and healthcare providers; patient and community organisations; as well as researchers and educational institutions with greater awareness and skills to challenge prejudice and tailor cancer care to underserved groups.

The workshops will empower participants to take local action to support patients, the tailored case studies and interactive sessions will showcase tangible steps healthcare professionals can take to make clinics more welcoming, and the course will demonstrate how researchers can proactively make studies more inclusive. The Equity, Diversity and Inclusion Toolkit and Training Programme will be available on beatcancer.eu from the summer of 2024.

While confronting discrimination and disparities spanning various facets of cancer care, these recommendations have presented possibilities within reach for numerous institutions and sectors. Whether addressing inequities through strategic interventions among staff and structures or spotlighting overlooked voices via carefully framed health communication, research and lived experience have shown feasible recommendations worth pursuing in every setting.

With patient communities keeping systems accountable, researchers continuing to reveal where marginalisation manifests, and decision-makers calling for pivot points toward justice, a person-centred future in health seems increasingly achievable.

*** * * * ***

Acronyms & Abbreviations

AYA	Adolescents and young adults.
CAYA	Child, adolescent, and young adult.
EDI	Equality/equity, diversity, and inclusion.
EU-CAYAS-NET	EU Network of Youth Cancer Survivors.
HCP	Healthcare Professional
LGBTIQ+	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, and others.
SES	Socio-economic status.
PATIENT SURVEY	Online survey of participants from minority groups
HCP SURVEY	Survey of healthcare professionals



GLOSSARY

Term	Definition
Equality	Equal treatment of all people.
Equity	Fair treatment of all people.
Diversity	Including and representing people from a variety of backgrounds and perspectives without prejudice.
Intersectionality	Intersectionality describes the potential for unique forms of discrimination to arise from overlapping personal characteristics, e.g. a Black woman.
Cross-sectional (survey)	It is a type of study design in which researchers collect data from many individuals at a single point in time.
Gender	A social construct informed by the norms, roles and behaviours that we attribute to being male/masculine, female/feminine, or third gender.
Grey literature	A wide range of different information that is produced outside of traditional publishing and distribution channels, and which is often not well represented in indexing databases.
Inclusivity	Active inclusion or participation of marginalised people and those with lived experience of inequity.
LGBTIQ+	Used to refer to the sexual and gender minority community. It is also common to see LGBT used.
Minority	Any group of persons whose members share common characteristics of culture, religion or language, or a combination of any of these factors that are considered to make up a small part of the global or local culture.
Minoritised	A group who may not be a global minority, but is considered as such based on factors related to their immediate context or environment, e.g. people of colour within predominantly white countries.
Psychosocial	The context of the combined influence that psychological factors and the surrounding social environment have on physical and mental wellness and ability to function.
Scoping review	A scoping review is a type of knowledge synthesis that uses a systematic and iterative approach to identify and synthesise an existing or emerging body of literature on a given topic.
Sex	The underlying biological profile of a person. It influences a range of bodily responses that are important in tackling infection or disease.
Sexual orientation	A person's sexual feelings towards other people and certain genders e.g. bisexual.
Transgender	An umbrella term for a person whose gender identity differs from the sex they were registered as at birth.
Socio-economic status	The social standing or class of an individual or group. It is often measured as a combination of education, income, and occupation.
Migrant	A person who changes their country of habitual residence and who is not a citizen of their country of residence. ⁴⁵
Refugee	A person who has been granted international protection by a country of asylum because of feared persecution, armed conflict, violence, or serious public disorder in their origin country. ⁴⁶

Bibliography

1. European Union. Charter of Fundamental Rights of the European Union. Published October 26, 2012. Accessed February 21, 2024. <https://www.refworld.org/docid/3ae6b3b70.html>
2. European Commission. European Cancer Inequalities Registry. Published 2023. Accessed February 1, 2024. <https://cancer-inequalities.jrc.ec.europa.eu>
3. The European Network of Equality Bodies.
4. Eche IJ, Aronowitz T. A Literature Review of Racial Disparities in Overall Survival of Black Children With Acute Lymphoblastic Leukemia Compared With White Children With Acute Lymphoblastic Leukemia. *J Pediatr Oncol Nurs*. 2020;37(3):180-194. doi:<https://dx.doi.org/10.1177/1043454220907547>
5. World Health Organization. Childhood Cancer Inequalities in the WHO European Region.; 2022. <http://apps.who.int/bookorders>.
6. Bhatia AK, Fossi A, Goodspeed BL, et al. Abstract LB138: The conception of an Oncology Neurodiversity Work Group to address cancer disparity for individuals with autism and intellectual or developmental disability (IDD) at the Sidney Kimmel Cancer Center. *Cancer Res*. 2023;83(8_Supplement):LB138-LB138. doi:10.1158/1538-7445.AM2023-LB138
7. Abrahao R, Lichtensztajn DY, Ribeiro RC, et al. Racial/ethnic and socioeconomic disparities in survival among children with acute lymphoblastic leukemia in California, 1988-2011: A population-based observational study. *Pediatr Blood Cancer*. 2015;62(10):1819-1825. doi:<https://dx.doi.org/10.1002/pbc.25544>
8. Sullenger RD, Deal AM, Grilley Olson JE, et al. Health Insurance Payer Type and Ethnicity Are Associated with Cancer Clinical Trial Enrollment Among Adolescents and Young Adults. *J Adolesc Young Adult Oncol*. 2022;11(1):104-110. doi:<https://dx.doi.org/10.1089/jayao.2021.0008>
9. Butow PN, Bell ML, Aldridge LJ, et al. Unmet needs in immigrant cancer survivors: a cross-sectional population-based study. Meiser B Yates P LE, team POC operative RG (PoCoG) C, eds. *Support Care Cancer*. 2013;21(9):2509-2520. doi:<https://dx.doi.org/10.1007/s00520-013-1819-2>
10. Bava L, Freyer DR, Radbill LM, Johns AL. Association of language proficiency, sociodemographics, and neurocognitive functioning in dual-language Latino survivors of childhood acute lymphoblastic leukemia and lymphoma. *Pediatr Blood Cancer*. 2021;68(9):e29118. doi:<https://dx.doi.org/10.1002/pbc.29118>
11. Patel SK, Miranda L, Delgado N, et al. Adaptation of an Intervention to Reduce Disparities in School HRQOL for Latino Childhood Cancer Survivors. *J Pediatr Psychol*. 2020;45(8):921-932. doi:<https://dx.doi.org/10.1093/jpepsy/jsaa048>
12. Sleight AG, Ramirez CN, Miller KA, Milam JE. Hispanic Orientation and Cancer-Related Knowledge in Childhood Cancer Survivors. *J Adolesc Young Adult Oncol*. 2019;8(3):363-367. doi:<https://dx.doi.org/10.1089/jayao.2018.0099>
13. Ussher JM, Allison K, Perz J, Power R. LGBTQI cancer patients' quality of life and distress: A comparison by gender, sexuality, age, cancer type and geographical remoteness. Team O with CS, ed. *Front Oncol*. 2022;12:873642. doi:<https://dx.doi.org/10.3389/fonc.2022.873642>
14. Gannon T, Phillips B, Saunders D, Berner AM. Knowing to Ask and Feeling Safe to Tell - Understanding the Influences of HCP-Patient Interactions in Cancer Care for LGBTQ+ Children and Young People. *Front Oncol*. 2022;12. doi:10.3389/fonc.2022.891874

15. Cloyes KG, Guo JW, Tennant KE, et al. Exploring Social Support Networks and Interactions of Young Adult and LGBTQIA+ Cancer Survivors and Care Partners. *Front Oncol.* 2022;12:852267. doi:<https://dx.doi.org/10.3389/fonc.2022.852267>
16. Waters AR, Bybee S, Warner EL, Kaddas HK, Kent EE, Kirchhoff AC. Financial Burden and Mental Health Among LGBTQIA+ Adolescent and Young Adult Cancer Survivors During the COVID-19 Pandemic. *Front Oncol.* 2022;12:832635. doi:<https://dx.doi.org/10.3389/fonc.2022.832635>
17. Desai MJ, Gold RS, Jones CK, et al. Mental Health Outcomes in Adolescent and Young Adult Female Cancer Survivors of a Sexual Minority. *J Adolesc Young Adult Oncol.* 2021;10(2):148-155. doi:<https://dx.doi.org/10.1089/jayao.2020.0082>
18. Power R, Ussher JM, Perz J, Allison K, Hawkey AJ. Surviving Discrimination by Pulling Together: LGBTQI Cancer Patient and Carer Experiences of Minority Stress and Social Support. *Front Oncol.* 2022;12:918016. doi:<https://dx.doi.org/10.3389/fonc.2022.918016>
19. Maurice-Stam H, van Erp LME, Maas A, et al. Psychosocial developmental milestones of young adult survivors of childhood cancer. group DL study, ed. *Support Care Cancer.* 2022;30(8):6839-6849. doi:<https://dx.doi.org/10.1007/s00520-022-07113-3>
20. Tonorezos ES, Barnea D, Cohn RJ, et al. Models of Care for Survivors of Childhood Cancer From Across the Globe: Advancing Survivorship Care in the Next Decade. *J Clin Oncol.* 2018;36(21):2223-2230. doi:<https://dx.doi.org/10.1200/JCO.2017.76.5180>
21. Hauken MA, Holsen I, Fismen E, Larsen TMB. Working toward a good life as a cancer survivor: a longitudinal study on positive health outcomes of a rehabilitation program for young adult cancer survivors. *Cancer Nurs.* 2015;38(1):3-15. doi:<https://dx.doi.org/10.1097/NCC.0000000000000138>
22. Niedzwiedz CL, Knifton L, Robb KA, Katikireddi SV, Smith DJ. Depression and anxiety among people living with and beyond cancer: a growing clinical and research priority. *BMC Cancer.* 2019;19(1):943. doi:<https://dx.doi.org/10.1186/s12885-019-6181-4>
23. Boonman AJ, Cuypers M, Leusink GL, Naaldenberg J, Bloemendal HJ. Cancer treatment and decision making in individuals with intellectual disabilities: a scoping literature review. *Lancet Oncol.* 2022;23(4):e174-e183. doi:10.1016/S1470-2045(21)00694-X
24. National Cancer Institution. Neurodiversity. Published April 25, 2022. Accessed February 21, 2024. <https://dceg.cancer.gov/about/diversity-inclusion/inclusivity-minute/2022/neurodiversity>
25. Schmitz C, Baum J, Lax H, et al. Fertility preservation and fulfillment of parenthood after treatment of hematological malignancies: results from the "Aftercare in Blood Cancer Survivors" (ABC) study. *Int J Clin Oncol.* 2020;25(6):1187-1194. doi:<https://dx.doi.org/10.1007/s10147-020-01639-4>
26. Belpame N, Kars MC, Beeckman D, et al. The 3-Phase Process in the Cancer Experience of Adolescents and Young Adults. *Cancer Nurs.* 2018;41(3):E11-E20. doi:<https://dx.doi.org/10.1097/NCC.0000000000000501>
27. Janssen SHM, Vlooswijk C, Manten-Horst E, et al. Learning from long-term adolescent and young adult (AYA) cancer survivors regarding their age-specific care needs to improve current AYA care programs. *Cancer Med.* Published online 2023. doi:<https://dx.doi.org/10.1002/cam4.6001>

28. Kye SY, Lee HJ, Lee Y, Kim YA. Public Attitudes towards Cancer Survivors among Korean Adults. *Cancer Res Treat.* 2020;52(3):722-729. doi:<https://dx.doi.org/10.4143/crt.2019.265>
29. Greer M. Disability Disparities in Cancer Care. *ONS Voice.* <https://voice.ons.org/news-and-views/disability-disparities-in-cancer-care>. Published March 7, 2023. Accessed April 19, 2023.
30. Garmy P, Jakobsson L. Experiences of cancer rehabilitation: A cross-sectional study. *J Clin Nurs.* 2018;27(9-10):2014-2021. doi:<https://dx.doi.org/10.1111/jocn.14321>
31. Lo AC, Samuel V, Chen B, Savage KJ, Freeman C, Goddard K. Evaluation of the discussion of late effects and screening recommendations in survivors of adolescent and young adult (AYA) lymphoma. *J Cancer Surviv.* 2021;15(2):179-189. doi:<https://dx.doi.org/10.1007/s11764-020-00922-7>
32. Scardaville MC, Murphy KM, Liu F, et al. Knowledge of Legal Protections and Employment-Related Resources Among Young Adults with Cancer. *J Adolesc Young Adult Oncol.* 2019;8(3):312-319. doi:<https://dx.doi.org/10.1089/jayao.2018.0097>
33. Pousette A, Hofmarcher T. IHE-REPORT-2024_1_; 2024. Accessed February 19, 2024. https://ihe.se/app/uploads/2024/01/IHE-REPORT-2024_1_.pdf
34. Bava L, Johns A, Freyer DR, Ruccione K. Development of a Culturally Competent Service to Improve Academic Functioning for Latino Survivors of Acute Lymphoblastic Leukemia: Methodological Considerations. *J Pediatr Oncol Nurs.* 2017;34(3):222-229. doi:<https://dx.doi.org/10.1177/1043454216676837>
35. Bressoud A, Real del Sarte O, Stiefel S, et al. Impact of family structure on long-term survivors of osteosarcoma. *Support Care Cancer.* 2007;15(5):525-531. <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med6&NEWS=N&AN=17205278>
36. Bonneau J, Dugas K, Louis A, Morel L, Toughza J, Frappaz D. [Educational and social outcome after childhood cancer]. *Bull Cancer.* 2015;102(7-8):691-697. doi:<https://dx.doi.org/10.1016/j.bulcan.2015.03.010>
37. Abrahao R, Maguire FB, Morris CR, Parikh-Patel A, Parsons HM, Keegan THM. The influence of the Affordable Care Act-Dependent Care Expansion on insurance coverage among young cancer survivors in California: an updated analysis. *Cancer Causes Control.* 2021;32(1):95-101. doi:<https://dx.doi.org/10.1007/s10552-020-01360-7>
38. OECD. Beating Cancer Inequalities in the EU. OECD; 2024. doi:10.1787/14fdc89a-en
39. Howell CR, Wilson CL, Yasui Y, et al. Neighborhood effect and obesity in adult survivors of pediatric cancer: A report from the St. Jude lifetime cohort study. *Int J Cancer.* 2020;147(2):338-349. doi:<https://dx.doi.org/10.1002/ijc.32725>
40. Afshar N, English DR, Chamberlain JA, et al. Differences in cancer survival by remoteness of residence: an analysis of data from a population-based cancer registry. *Cancer Causes Control.* 2020;31(7):617-629. doi:<https://dx.doi.org/10.1007/s10552-020-01303-2>
41. Petridou ET, Dimitrova N, Eser S, et al. Childhood leukemia and lymphoma: time trends and factors affecting survival in five Southern and Eastern European Cancer Registries. *Cancer Causes Control.* 2013;24(6):1111-1118. doi:<https://dx.doi.org/10.1007/s10552-013-0188-y>
42. Friedrich P, Lam CG, Kaur G, Itriago E, Ribeiro RC, Arora RS. Determinants of Treatment Abandonment in Childhood Cancer: Results from a Global Survey. *PLoS One.* 2016;11(10):e0163090. doi:<https://dx.doi.org/10.1371/journal.pone.0163090>

43. Linendoll N, Murphy-Banks R, Sae-Hau M, et al. Evaluating the role of financial navigation in alleviating financial distress among young adults with a history of blood cancer: A hybrid type 2 randomized effectiveness-implementation design. *Contemp Clin Trials*. 2023;124:107019. doi:<https://dx.doi.org/10.1016/j.cct.2022.107019>
44. European Commission. EU4Health programme 2021-2027 – a vision for a healthier European Union. Published 2021. Accessed March 5, 2024. https://health.ec.europa.eu/funding/eu4health-programme-2021-2027-vision-healthier-european-union_en
45. European Commission. Europe's Beating Plan.; 2021. Accessed March 5, 2024. https://ec.europa.eu/commission/presscorner/detail/en/ip_21_342
46. Barwise K, Talkers A, Linklater E. INTEGRATING MIGRATION INTO HEALTH INTERVENTIONS European Union A TOOLKIT FOR INTERNATIONAL COOPERATION AND DEVELOPMENT ACTORS.; 2022. Accessed April 30, 2023. <https://eea.iom.int/sites/g/files/tmzbdl666/files/mmicd/toolkit-mmicd-health.pdf>

European Network of YOUTH CANCER SURVIVORS

- 9 Beneficiaries
- ▨ 28 Associated Partners



* For more information please see the event programme and other details on www.beatcancer.eu



Co-funded by
the European Union

Co-funded by the European Union. Views and opinions expressed are however those of the authors) only and do not necessarily reflect those of the European Union or the European Health and Digital Executive Agency (HaDEA). Neither the European Union nor the granting authority can be held responsible for them.