YOUTH CANCER EUROPE

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CANCER NETWORK

Guidelines for Inclusive Events for People Affected by Cancer

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If reading the text is difficult, you can scan the QR code below to listen to it in audio format.

The audio version follows the same structure as the booklet and was **generated using artificial intelligence** and reviewed by humans.

About this publication

This publication was developed by Youth Cancer Europe as part of Task 5.6 of the **YARN (European Youth Cancer Network)** project, co-funded by the European Union under the EU4Health Programme (Grant Agreement No. 101219053).

Coordination: Youth Cancer Europe

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For any questions, please contact
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Events for people affected by cancer

Throughout this booklet, the term **events for people affected by cancer** refers to any activity that brings people together around cancer, including conferences, workshops, support groups, training courses, community gatherings, advocacy events, and educational meetings.

These events bring together people with lived cancer experience[1], caregivers, patient advocates, healthcare professionals, researchers, policymakers, and the wider community to exchange knowledge, build connections, share experiences, and contribute to shaping cancer care, research, and advocacy.

Why inclusion and accessibility matter

People living with and beyond cancer[1] may have practical, physical, emotional, or social needs that influence how they take part in meetings and community activities. Their experiences can also be shaped by factors such as disability, neurodiversity, gender, ethnicity, socioeconomic circumstances, caring responsibilities, or other aspects of identity and life situation.

Participation is not equally accessible to everyone. Practical, financial, physical, communication, and social barriers can affect whether people are able to attend, feel welcome, safe, or can fully contribute. Designing events to be inclusive and accessible helps remove unnecessary barriers, creating environments where people feel respected, supported, and able to participate in ways that work for them.

Why these guidelines

These guidelines were developed to provide practical support for planning and delivering more inclusive and accessible events for people affected by cancer, particularly for people from underserved and underrepresented communities.

They are intended for event organisers, patient organisations, and anyone planning activities for people affected by cancer. They may also be useful for patient advocates, caregivers, healthcare professionals, policymakers, and other stakeholders interested in promoting good practice.

The aim is not to prescribe a single way of organising events, but to offer practical recommendations that help organisers identify and reduce barriers to participation. Not every recommendation will apply to every event, but even small changes can make activities more welcoming, accessible, and inclusive for a wider range of participants.

How these guidelines were developed

The development of this publication was led by a multidisciplinary working group bringing together people with different professional and personal backgrounds, the majority of whom are young people with lived cancer experience.

The work builds on the **Recommendations for Equitable, Diverse and Inclusive Cancer Care**[2] and the **EDI Train-the-Trainer Toolkit**[3], both developed by Youth Cancer Europe as part of an earlier EU4Health-funded project, EU-CAYAS-NET.

To inform the development of this booklet, the working group reviewed 15 existing guidelines and resources on inclusive event planning from organisations across Europe and beyond, identifying common principles and good practices relevant to people affected by cancer.

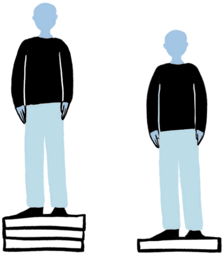
This work was complemented by an online community survey and a focus group held during the first meeting of the Youth Cancer Council (YCC), involving 25 young people with lived cancer experience. Participants were invited to comment on the draft recommendations, the usability of the document, and the factors they considered important for creating inclusive and accessible events.

The findings from the literature review and community consultation informed the final recommendations, resulting in a practical set of guidance for organisers of events for people affected by cancer, with additional considerations for supporting participation from underserved and underrepresented communities.

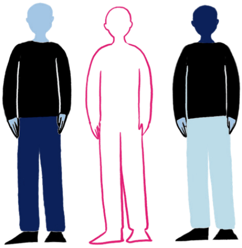
Understanding underserved and underrepresented groups

Throughout these guidelines, we use the term **underserved** and **underrepresented groups** to acknowledge that people may face different barriers to participation and inclusion. Using these broader terms helps avoid incomplete or selective lists and recognises that the experiences and needs of communities vary across different settings and contexts.

Underserved refers to people who may have reduced access to information, services, support, or opportunities to participate, due to barriers that are practical, cultural, social, economic, geographic, linguistic, digital, or systemic.



Underrepresented refers to people who are not adequately reflected in an organisation's membership, leadership, advisory structures, workforce, volunteers, programme design, decision making, communications, or monitoring activities, relative to the communities the organisation aims to serve.



These groups may include, but are not limited to, people who experience one or more of the following:

- **Race, ethnicity, culture, language, nationality, or migration related factors**, including refugees, migrants, displaced people, and minority ethnic communities
- **Gender identity or sexual orientation**, including lesbian, gay, bisexual, transgender, intersex, queer, and other sexual and gender minorities
- **Disability and accessibility needs**, including physical, sensory, intellectual, and learning disabilities, and long-term conditions affecting functioning

- **Neurodivergence**, such as autism, attention related differences, dyslexia, and other neurodevelopmental profiles

- **Mental health conditions or psychosocial support* needs**, including distress, anxiety, depression, trauma related needs, and other mental health experiences that may affect access, participation, or support needs

- **Socioeconomic disadvantage**, including financial insecurity, unstable housing, food insecurity, limited access to transport, and employment insecurity

- **Education and health literacy barriers**, including lower formal education, limited literacy, or difficulties navigating health systems and information

- **Geographic and infrastructural barriers**, including rural or remote settings, limited-service availability, and limited digital connectivity

- **Age and life stage factors**, including adolescents and young adults, older adults, and people whose needs are not well met by standard service models

- **Family and caring responsibilities**, including young parents, single parents, carers, and people with limited informal support networks

- **Legal or administrative barriers**, including lack of documentation, insecure residency status, or fear of discrimination that reduces engagement with services

- **Religious background or belief**, where it may influence participation, communication, scheduling, dietary needs, or access to culturally safe support

Many people belong to more than one underserved or underrepresented group. These experiences can overlap and compound barriers. **This is often referred to as intersectionality**, where different aspects of a person's identity or circumstances interact to shape their access to support, participation, and representation.

For event organisers, this means **recognising that barriers are rarely experienced in isolation**. People may face multiple, overlapping challenges that influence how they access information, services, and community support. For example, someone may be a young parent living with cancer while facing financial insecurity, live in a rural area while also having mobility limitations, or be a trans person who is also from an underrepresented ethnic background.

Context matters

Diversity and exclusion do not look the same across Europe. What constitutes an underserved or underrepresented group **can vary by country, region, or community and neighbourhoods**, depending on history, demographics, local health systems, and social context.

Organisations are encouraged to interpret the term **'underserved and underrepresented groups'** in a way that is **meaningful and accurate for their setting**, while remaining aligned with the principles of equity, inclusion, dignity, and non-discrimination.

How to use these guidelines

The general recommendations are intended to support the planning and delivery of all events for people affected by cancer whenever possible. In addition, the sections relating to underserved and underrepresented groups highlight considerations that may be particularly relevant depending on the audience and context of the event.

These guidelines are designed to be practical and adaptable rather than prescriptive. Not every recommendation will apply to every event, and organisers are encouraged to use them as a flexible resource to help identify opportunities to improve inclusion and accessibility.

It may also be helpful to review the recommendations before and after each event, reflecting on what worked well, what barriers may have remained, and what could be improved in the future.

General recommendations for inclusive events for people affected by cancer

1. Building a Team

- Form a multidisciplinary organising team and involve people with diverse lived experiences and perspectives in planning and venue selection
- Aim for diverse representation among speakers and panellists (e.g. different genders, ethnicities, ages, disabilities, and lived experiences)
- Assign contact persons to support participants with arrival, agenda changes, safety, and practical or accessibility needs
- Train staff and volunteers on emergency procedures, basic EDI principles, respectful communication, and how to respond to accessibility needs
- Designate a member of the organising team who is responsible for participant wellbeing and can signpost appropriate support services if needed

> “Having the event in the same hotel (as the event venue) makes such a difference, especially for people with chronic fatigue.
>
> - Survey respondent”

2. Choosing an accessible venue

- Choose a safe, comfortable, and accessible venue, accommodation, and networking spaces (see Disability and accessibility needs)
- Where possible, provide additional spaces for quiet reflection, prayer, breastfeeding, medical needs, or private conversations
- Ensure clear signage and unobstructed layouts that allow people to move around the venue easily
- Consider the needs of caregivers, children, and participants accompanied by assistance animals
- Consider environmental factors such as noise levels, lighting, temperature, and opportunities for quiet space, particularly for participants with sensory sensitivities, neurodivergence, or treatment-related side effects
- Ensure that the venue has accessible emergency procedures and evacuation arrangements that can accommodate participants with different accessibility needs

3. Designing an inclusive programme

- Plan an interactive agenda that allows time for participants to connect and, where appropriate, includes smaller group discussions or activities
- Collect relevant information in advance about attendees' dietary, mobility, communication, accessibility, and any other requirements that may affect participation, including any requirements related to emergency evacuation planning where appropriate
- Build in regular rest breaks and allow sufficient time between sessions and activities
- Encourage equitable participation by creating opportunities for different voices to contribute, for example through moderated discussions or anonymous questions

- Plan networking activities that take different communication styles, energy levels, and social interaction preferences into account

4. Participant wellbeing and emotional safety

- Set out shared expectations for inclusion and respectful behaviour in participant communications and event materials
- Make sure participants know who they can approach if they need support or assistance during the event
- Give participants the opportunity to indicate how they would like to be addressed, including their preferred name and pronouns, and respect these preferences throughout the event
- Where appropriate, offer optional buddy or volunteer support for participants who would benefit from additional practical assistance
- Allow participants to take breaks, leave sessions, or step away from activities when needed without requiring explanations
- Encourage sensitive or personal discussions to take place in appropriate private spaces
- Recognise that not everyone wishes to disclose personal information about themselves. Obtain consent before sharing names, photographs, contact details, or other identifying information
- Where appropriate, provide content warnings and signpost relevant support resources when sessions include potentially distressing topics

> “I would not feel comfortable if my cancer diagnosis was made public. I want to be able to choose when and with whom to share that information.
>
> - Survey respondent”

5. Inclusive communication

- Share key event information well in advance, including the agenda, venue, travel arrangements, accessibility information, and other practical details participants may need to plan their attendance
- Give participants opportunities to communicate accessibility requirements, questions, or concerns before the event
- Use clear and straightforward language, avoiding unnecessary jargon, acronyms, and technical terminology wherever possible
- Present information in accessible formats that are easy to read, navigate, and understand, taking into account different literacy levels, cognitive needs, and communication preferences
- Consider the language needs of participants and provide translated materials, interpretation, or language support where feasible
- Use communication channels that are familiar and accessible to the intended audience, recognising that participants may have different levels of digital access, confidence, or platform preferences

6. Food and catering

- Collect dietary information in advance and communicate clearly about the options that will be available
- Provide catering that accommodates dietary requirements, cultural preferences, religious needs, and medical restrictions where relevant

> “When there are participants who are still in treatment, it is important to avoid strong aromas, such as perfumes, smoke, or strongly scented food.
>
> - Survey respondent”

- Clearly label allergens, ingredients, and dietary options, and allow participants to bring their own food if they have specific medical, dietary, or cultural requirements

- Where possible, offer a choice of food options rather than a single menu, recognising that treatment-related side effects, medical conditions, and dietary restrictions may affect what people are able or willing to eat

7. Accessible travel

- Share clear travel information in advance, including transport options, accessibility information, expected travel times, and practical guidance for reaching the venue

- Recognise that travelling to an event may be stressful or unfamiliar for some participants, particularly those travelling internationally, travelling alone, navigating a new environment, or experiencing anxiety related to travel

- Ask participants in advance about any travel-related accessibility requirements or concerns so that reasonable accommodations or additional guidance can be considered where possible

- Consider how participants will travel between accommodation, event venues, meals, and social activities, and whether these arrangements are practical and accessible for people with different mobility levels, energy limitations, and levels of confidence travelling independently

- Allow sufficient time for rest after travel and between activities

8. Family and caregivers

- Recognise that caring responsibilities for children or other dependants may affect a person’s ability to attend or travel

- Where relevant, ask participants about caring responsibilities in advance so that any practical arrangements can be considered where possible

- Recognise that some participants may require a caregiver, support person, or personal assistant in order to participate fully in the event

- Where possible, accommodate participants who need to attend with a caregiver, support person, or personal assistant

9. Reducing financial barriers

- Where possible, minimise the need for participants to cover substantial costs in advance, recognising that upfront expenses and reimbursement processes may create barriers to participation

- Communicate reimbursement procedures, timelines, eligible expenses, and any costs that participants will be expected to cover themselves clearly in advance, including any reimbursement or currency exchange limitations that may affect participants travelling internationally

- Where participation fees apply, consider whether any fee waivers, bursaries, or reduced-rate places can be offered to participants who may otherwise be unable to attend

10. Facilitating inclusive participation

- Design presentations and event materials using clear language, readable fonts, good colour contrast, and simple layouts that are easy to follow

- Present information in ways that support different literacy levels, language backgrounds, communication preferences, and learning styles

- Recognise that some participants may experience cognitive difficulties, concentration challenges, fatigue, sensory sensitivities, or information overload, and consider how content, pacing, and presentation formats may affect participation

- Where possible, offer different ways to participate, such as speaking, using chat functions, submitting questions anonymously, contributing in writing, or participating in smaller group discussions

- Consider whether virtual or hybrid participation could help reduce barriers for people who are unable to attend in person due to health, caregiving responsibilities, financial constraints, travel difficulties, or accessibility needs

- Where appropriate, consider whether additional communication support, interpretation, captioning, or other accessibility services may be needed based on the audience and format of the event

- If presentations, recordings, or event materials are shared after the event, consider providing them in formats that are accessible and easy to use

Reflect and improve

After each event, invite participants to share feedback on accessibility, inclusion, participation, and any barriers they experienced. Use this feedback to understand what worked well, identify opportunities for improvement, and help make future events more inclusive and accessible. Where appropriate, communicate any changes made as a result of participant feedback.

Additional considerations for different identities, backgrounds, and accessibility needs

The recommendations in this section build on the general recommendations presented earlier in the booklet. They highlight additional considerations that may help remove barriers for participants with different identities, backgrounds, and accessibility needs. Not every recommendation will apply to every event, and organisers are encouraged to adapt them to the purpose, audience, and resources available.

1. Gender identity and sexual orientation

- Only collect information about gender where it is genuinely necessary for organising or delivering the event
- Give participants the opportunity to indicate how they would like to be addressed, including their preferred name and pronouns, and ensure organisers and speakers use these consistently throughout the event
- Use inclusive language in presentations, discussions, registration forms, and event materials, avoiding unnecessary assumptions about participants' identities, relationships, or family structures
- Where possible, ensure that participants have access to gender-neutral toilet facilities or other inclusive options appropriate to the venue
- Recognise that some participants may choose not to disclose aspects of their identity and respect their privacy throughout the event

2. Neurodiversity

- Provide practical information before the event, including the programme, venue layout, accessibility arrangements, contact details, and what participants can expect throughout the event to help reduce uncertainty
- Where possible, provide access to a quiet or low-stimulation space where participants can take breaks, rest, or regulate their sensory environment if needed
- Where possible, include opportunities for conversation in quieter settings alongside larger social or networking activities, recognising that not everyone is comfortable networking in busy or noisy environments
- Recognise that participants may engage, communicate, or regulate themselves in different ways, and avoid interpreting these behaviours as lack of interest or disengagement
- When planning the event environment, consider how noise levels, lighting, crowding, and other sensory factors may affect participation, and reduce unnecessary sensory overload where possible

> “I feel best when I also see people with different kinds of disabilities taking part. I feel included and that my voice is important.
>
> - Survey respondent”

3. Disability and accessibility needs

- Ask participants about any accessibility requirements in advance so that reasonable adjustments can be considered where possible

- Consider whether participants can access and use every part of the event independently and safely, including registration, meeting rooms, catering areas, networking activities, accommodation, and transport where relevant

- Consider whether seating arrangements support participants with different mobility needs, physical disabilities, fatigue, or other health-related limitations throughout the event

- Where appropriate and based on participants' needs, consider additional accessibility measures such as accessible formats, captioning, sign language interpretation, hearing support, accessible signage, or other communication support

- Where relevant to the audience, encourage speakers to ensure that important visual information is also communicated verbally

4. Culture, language, religion, nationality, and migration-related factors

- Recognise that not all participants will be equally confident communicating in the event language, and allow additional time for questions, discussion, and clarification where needed

> “It was difficult for me, as someone who does not speak English as a first language, to follow all the discussions.
>
> - Survey respondent”

- Encourage speakers and moderators to use clear language, explain unfamiliar terminology, and avoid unnecessary jargon, idioms, or culturally specific references where possible

- Where appropriate, consider whether interpretation, translated materials, or multilingual support would help reduce language barriers for participants
- Recognise that communication styles, social norms, and cultural expectations may differ, and encourage an environment where participants feel comfortable asking questions or seeking clarification
- Consider whether cultural or religious practices may influence participation, and where appropriate, take these into account when planning schedules, mealtimes, breaks, or catering arrangements

Every event is different, and not every recommendation will be relevant or achievable in every context. These guidelines are intended to support practical decision-making rather than prescribe a single approach to organising inclusive events.

Organisations are encouraged to use the recommendations in ways that best reflect the needs of their participants, the purpose of their event, and the resources available.

Glossary

Accessibility	The design of environments, communication, services, and activities so that people with different needs can access and participate in them as independently and fully as possible.
Accessibility requirements	Individual adjustments, services, or arrangements that help a person participate fully in an event, such as step-free access, captioning, accessible information, dietary adjustments, or additional communication support.
Caregiver	A person who provides practical, physical, or emotional support to someone affected by cancer. This may include family members, friends, or paid personal assistants who help a participant attend and take part in an event.
Equitable/Equity	Providing different levels or types of support based on individual needs, recognising that people affected by cancer do not start from the same position.
Equity, Diversity and Inclusion (EDI)	An approach that aims to ensure fair access, meaningful participation, and respectful support for all people, recognising and responding to differences in background, identity, and circumstances.
EU4Health Programme	The European Union’s health funding programme supporting actions to strengthen health systems and reduce health inequalities and inequities.
Event organiser	Any individual, organisation, or organising team responsible for planning or delivering an event for people affected by cancer.
Health literacy	A person’s ability to access, understand, and use health information and services to make informed decisions.
Inclusion/Inclusive	Creating environments and practices where people feel welcomed, respected, and able to participate fully.
Intersectionality	The way different characteristics or circumstances (such as socioeconomic status, disability, gender identity, or migration background) can overlap and compound barriers or disadvantages.
Lived experience	Knowledge gained through direct personal experience of cancer, including diagnosis, treatment, and life with and beyond cancer.

Living with and beyond cancer	A term describing the wide range of experiences of people affected by cancer, including those in treatment, post-treatment, living with chronic or metastatic disease, or experiencing long-term effects.
Neurodivergence	Natural differences in how people think, learn, and process information, such as autism, attention-related differences, or dyslexia.
Patient organisation	A group led by or working closely with people affected by cancer, providing peer support, information, advocacy, or services based on lived experience.
Peer support	Support provided by people with shared lived experience, offering understanding, practical advice, and emotional support.
Psychosocial support	Support addressing emotional, psychological, and social needs related to cancer, including wellbeing, coping, and participation.
Reasonable adjustments	Practical changes or accommodations made to reduce barriers and enable people with different needs to participate as fully as possible.
Socioeconomic barriers	Obstacles linked to income, employment, education, housing, or access to resources that can limit participation or access to support.
Underserved groups	People who have reduced access to information, services, or support due to practical, social, economic, cultural, geographic, or systemic barriers.
Underrepresented groups	People who are not adequately reflected in an organisation's membership, leadership, decision making, or activities relative to the communities it aims to serve.
YARN – European Youth Cancer Network	An EU4Health-funded project (Grant Agreement No. 101219053) focused on strengthening equitable, patient-centred approaches to cancer care, peer support, advocacy, and policy across Europe.
Youth Cancer Council (YCC)	A pan-European advisory body of young people with lived cancer experience within the YARN project, established to ensure youth perspectives inform and shape project design and outputs.
Youth Cancer Europe (YCE)	A pan-European patient advocacy network representing young people affected by cancer, and coordinator of the YARN project.

References

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3 | **Youth Cancer Europe, Inclusive Employers.** Equity, Diversity and Inclusion Principles in Cancer Care: Train-the-Trainer Toolkit. 2024. Developed within the EU-CAYAS-NET project, co-funded by the European Union under the EU4Health Programme (Grant Agreement No. 101056918).

About YARN

YARN (European Youth Cancer Network) is the largest youth cancer network established within an EU-funded project to date. Bringing together organisations across 28 European countries, the project works to strengthen equitable, patient-centred approaches to cancer care, peer support, advocacy, and policy, with a strong emphasis on equity, diversity and inclusion.

A core pillar of YARN is the Youth Cancer Council (YCC), a 100-member advisory body of young people with lived cancer experience, aiming for representation from all EU Member States. The Council plays an active role in shaping project activities and outputs, helping ensure they remain grounded in real needs and diverse lived experiences across Europe.

YARN is coordinated by Youth Cancer Europe (YCE), a pan-European patient advocacy network representing young people affected by cancer from more than 40 countries. YCE has a long-standing track record of translating lived experience into European policy, research, education, and practical resources that improve the lives of young people living with and beyond cancer.

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