YOUTH CANCER EUROPE

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EUROPEAN YOUTH CANCER NETWORK

Equity, Diversity and Inclusion

Self-Assessment Checklist for Patient Organisations

Co-funded by the European Union

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.**

It was developed within **YARN – the European Youth Cancer Network**, a project co-funded by the **European Union under the EU4Health Programme.**

For any questions, please contact **youthcancereurope.org**

About this publication

This publication was developed as part of **Task 5.3, “EDI Self-Assessment Tool for Patient Organisations”**, of the **YARN (European Youth Cancer Network)** project, funded by the European Union under the EU4Health Programme (Grant Agreement No. 101219053).

The checklist was created through an evidence-informed, co-creation process involving literature review, analysis of existing equity, diversity and inclusion frameworks and tools, and building on resources developed within the EU-CAYAS-NET project. Its development brought together contributions from YARN Beneficiaries and Associated Partners, as well as direct input from members of the Youth Cancer Council. The methodology and development process are described in detail in **Deliverable D5.1**.

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Why equity* matters in patient organisations

People affected by cancer do not experience diagnosis, treatment, and life beyond cancer in the same way. Differences in background, identity, resources, health literacy*, geography, and social support can shape who accesses information, who feels welcome, who is heard, and who is left out. Without intention, patient organisations* can unintentionally reproduce these inequities, even when inclusion* is a shared value.

Focusing on equity helps patient organisations move from good intentions to fairer access, meaningful participation, and responsive support for the full diversity of people they aim to serve.

Equity, diversity and inclusion in the European context

Equity, diversity and inclusion (EDI)* are increasingly recognised as essential components of high-quality cancer care across Europe. European cancer policy, including the EU Cancer Plan[1] , highlights the need to reduce inequalities in access, outcomes, and lived experience, particularly for groups who face structural or social barriers.

For patient organisations, this means not only advocating for equitable systems, but also examining internal practices, cultures, and decision-making processes to ensure they do not unintentionally exclude or disadvantage certain groups.

This checklist supports that reflection at organisational level, in a way that is practical, proportionate, and adaptable across different national and community contexts.

Why this checklist

While equity, diversity and inclusion are increasingly recognised as priorities in cancer care, patient organisations often lack practical tools to assess how these principles are reflected in their own structures, activities, and ways of working. **Good intentions alone are not enough** to identify where barriers exist, who may be missing, or where change is most needed.

This checklist was developed within **YARN – the European Youth Cancer Network**, a project co-funded by the European Union under the EU4Health Programme (Grant Agreement No. 101219053), to support patient organisations in translating equity commitments into **concrete reflection and action**. It builds on earlier work on equity, diversity and inclusion in cancer care and responds to needs consistently raised by patient communities through ongoing engagement and project activities.

The checklist is designed to be **practical, proportionate, and adaptable**. It does not aim to rank organisations or impose a single model of inclusion, but to help patient organisations identify strengths, recognise gaps, and prioritise next steps that are realistic for their context and capacity.

The co-creation* process

This checklist was developed through a structured and collaborative approach that combined evidence-based resources, expert input, and lived experience*. Its content and framing draw on the **Recommendations for Equitable, Diverse and Inclusive Cancer Care**[2] and the **EDI Train-the-Trainer Toolkit**[3], which together provide a conceptual and practical foundation for advancing equity, diversity and inclusion within patient organisations.

The checklist is also aligned with the **Recommendations and Implementation Roadmap for Minimum Standards of Specialist Adolescent and Young Adult Cancer Care Units**[4,5], ensuring coherence with broader standards for equitable, person-centred cancer care.

The development process further included a targeted **literature review** synthesising current evidence on inclusive patient support, health equity, and organisational best practices.

Working group discussions with project partners contributed insights grounded in diverse national and organisational contexts.

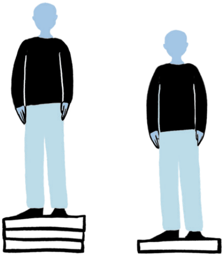
A dedicated **focus group with the Youth Cancer Council*** ensured that the perspectives and lived experiences of young people living with and beyond cancer* directly informed the checklist, strengthening its relevance and practical applicability.

Translation and localisation work carried out by project partners **across multiple countries** and languages ensured cultural appropriateness, accessibility*, and relevance across diverse European settings.

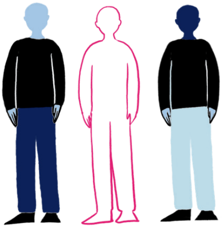
Across these inputs, a consistent theme emerged: patient organisations often intend to be inclusive, but may unintentionally overlook groups who face additional barriers to participation, representation, and access to support.

To avoid incomplete or selective lists within each checklist item, we use the term **underserved and underrepresented** groups throughout.

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 influences care experiences, stigma, 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 patient organisations, 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 being a young parent with cancer and facing financial insecurity, living in a rural area while also having mobility limitations, or 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 this checklist

This checklist is intended for **patient organisations**, meaning communities of people with lived cancer experience. Throughout this booklet, when we refer to patient organisations, it is assumed that these communities are made up of young people with lived cancer experience.

This self-assessment checklist is a practical reflection tool to help organisations understand how equity, diversity and inclusion are currently reflected in their work and where further action may be needed. It is not designed as an audit or compliance exercise, but as a starting point for internal discussion and improvement.

The checklist includes 10 questions covering areas such as representation and leadership, policies and accountability, accessibility, outreach, support, and organisational culture.

Complete the checklist collaboratively.

Ideally several people within the organisation should review the questions together and agree on the answers. Base responses on **current practice**, not intention.

Organisations may also find it useful to **repeat the checklist periodically (for example once a year)** to review progress and track changes over time.

Response options and scoring

Each question includes three response options:

Yes – this practice is in place and working well

Could do better – some elements are in place, but gaps or inconsistencies remain

No – this practice is not currently in place

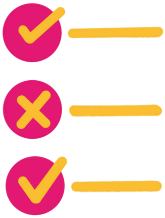
Only answer "**Yes**" if you can clearly identify the policy, practice, or procedure that supports that response.

For organisations that wish to use a numerical score to support reflection or track progress over time, the following scoring can be applied:

Yes = 2 points

Could do better = 1 point

No = 0 points



The scores across all 10 questions can be added together to provide an overall score ranging from 0 to 20. This score should be used as an **indicative guide**, not a judgement, and is most useful when combined with discussion about why certain areas scored higher or lower and what actions could follow.

Organisations are encouraged **to repeat the checklist periodically (for example, annually)** to monitor progress and assess the impact of changes over time.

EDI Self-Assessment Checklist for Patient Organisations

1. Representation and leadership

Do we have meaningful representation of underserved and underrepresented groups within our organisation, including in leadership and decision-making?

Representation should go beyond tokenism*. Including diverse perspectives in leadership strengthens trust and relevance in how services and priorities are shaped.

☐ Yes
☐ Could do better
☐ No

2. Policies and accountability

Do we have clear organisational policies and procedures on equity, diversity and inclusion, including accountability for how they are implemented?

Policies translate intent into practice. Accountability mechanisms* help ensure EDI commitments are consistently applied across activities, partnerships, and internal culture.

☐ Yes
☐ Could do better
☐ No

3. Training and capacity

Do we provide regular training and support for staff and volunteers to build cultural humility*, inclusive communication skills, and confidence in supporting diverse communities?

Ongoing learning helps teams recognise barriers, avoid unintended harm, and deliver respectful, responsive support.

☐ Yes
☐ Could do better
☐ No

4. Safe and respectful participation

Do we have mechanisms to ensure people from underserved and underrepresented groups feel safe, respected, and able to raise concerns without negative consequences?

Clear routes for feedback, safeguarding*, and complaints help people engage with the organisation safely and reduce the risk of discrimination being overlooked.

☐ Yes
☐ Could do better
☐ No

5. Feedback and co-design

Do we routinely seek feedback from underserved and underrepresented groups, and use it to improve our services, programmes, and communications?

Feedback is most useful when it leads to visible change. Inclusive co-design improves relevance and reduces gaps between intention and real experience.

☐ Yes
☐ Could do better
☐ No

6. Accessibility of communications and activities

Are our communications, events, services, and educational materials accessible and inclusive, including for people with disabilities, learning differences, and different language or literacy needs?

Accessibility includes format, language, venue access, digital access, sensory considerations, and practical adjustments that allow equitable participation.

☐ Yes
☐ Could do better
☐ No

7. Socioeconomic barriers

Do we identify and actively reduce socioeconomic barriers* that can prevent people from accessing our support, such as costs, transport, time off work, childcare, or digital exclusion?

Removing practical barriers is a core equity action. It helps ensure support is available based on need rather than ability to pay or capacity to travel.

☐ Yes
☐ Could do better
☐ No

8. Outreach and trust building

Do we carry out outreach and partnership work that intentionally reaches underserved and underrepresented communities, including those who may not typically engage with patient organisations?

Targeted outreach helps address invisibility gaps, builds trust, and improves awareness of support among people who are often missed.

☐ Yes
☐ Could do better
☐ No

9. Tailored support and referral pathways

Do we offer, or can we reliably signpost to, tailored support that meets the needs of different underserved and underrepresented groups?

Some needs require adapted approaches, such as language-appropriate materials, culturally safe spaces, disability informed formats, or specific psychosocial support pathways.

☐ Yes
☐ Could do better
☐ No

10. Continuous improvement

Do we regularly assess our progress on equity, diversity and inclusion and adjust our policies, practices, and programmes based on what we learn?

EDI is not a one-off task. Regular review helps organisations stay responsive as communities, contexts, and needs evolve.

☐ Yes
☐ Could do better
☐ No

Interpreting your score

Use your score as a starting point for action, not a judgement. The ranges below suggest where to focus next.

0–4

Starting point

EDI is not yet consistently embedded in how your organisation works.

What to prioritise:

- Agree internally that EDI is a shared responsibility, not an add-on
- Identify 1–2 immediate gaps (for example representation, accessibility, or feedback mechanisms)
- Assign clear ownership for next steps

5–9

Building foundations

Some inclusive practices are in place, but they are uneven or informal.

What to prioritise:

- Formalise what already works into clear policies or routines
- Strengthen accountability (who does what, and how progress is checked)
- Involve underserved and underrepresented groups more systematically in feedback or co-design

10–14

Established practice

EDI is visible across several areas of your organisation, though some gaps remain.

What to prioritise:

- Review practices through an equity lens (who still struggles to access or participate)
- Improve consistency across teams, activities, or regions
- Use data or feedback to refine programmes and outreach

15–20

Embedded and responsive

EDI is well integrated into how your organisation plans, delivers, and evaluates its work.

What to prioritise:

- Regularly review impact, not just activity
- Share learning and good practice with partners or peer organisations
- Stay responsive as community needs and contexts change

If you’re not sure where to start

Equity, diversity and inclusion work in patient organisations is often most effective when it starts **small, practical, and close to the community.**

If your score highlights gaps, consider beginning with one or two of the following:

- **Listen first:** create a simple, safe way for people from underserved and underrepresented groups to share their experiences with your organisation
- **Remove one barrier:** identify a practical obstacle (costs, language, access, timing, format) and address it in a concrete way
- **Clarify responsibility:** agree who in your organisation is responsible for following up on EDI-related actions
- **Set a start date:** agree when the first change, policy, or action will begin. A clear date helps turn ideas into action
- **Use what already exists:** adapt current activities, events, or peer support* rather than creating something new
- **Involve people with lived experience early:** not only as participants, but in shaping decisions and priorities

Progress does not require doing everything at once. Small, visible changes can build trust, improve access, and create momentum for longer-term improvements.

We recognise that time, funding, and organisational capacity may be limited, especially in patient communities that rely on volunteers. However, this should not prevent organisations from **starting with an honest internal discussion** and identifying one small step they can take.

Language and inclusion

Language matters. The words used by patient organisations shape who feels recognised, respected, and safe to engage. Inclusive language does not require perfection, but it does require awareness, reflection, and willingness to adapt.

Throughout this checklist, language is used intentionally to **avoid assumptions** about identity, background, or experience and **reflect diversity without relying on fixed or exhaustive labels.**

Organisations are encouraged to reflect on their own language practices, including how people are invited to self-identify, how pronouns are respected where relevant, and how communications are adapted for different audiences and contexts.

Research and lived experience show[6] that there is no single term that works for everyone. Commonly used terms such as “patient” and “survivor” are meaningful and empowering for some, while feeling limiting, inaccurate, or uncomfortable for others, particularly for people living with chronic or metastatic cancer, those living post-treatment, or those who do not identify with struggle-based narratives.

Pronouns in practice

Pronouns are the words used when speaking about a person, such as she, he, or they. Patient organisations can create a safer, more inclusive environment by making pronouns visible in optional ways, for example by including them on **name badges** or offering **pronoun pins** at meetings and events. Sharing pronouns **should always be optional**, and no one should be required to disclose, explain, or justify them.

However, making pronouns visible as an **organisational practice** signals a trans-inclusive environment and creates **opportunities for connection, understanding, and allyship.**

Combat-style language and heroic framing (such as “fighting cancer”, “winning the battle”, or “being strong”) can unintentionally reinforce stigma, blame, or feelings of failure, particularly when illness progresses or recurs, and may exclude or silence people whose experiences do not align with these narratives.

Emerging terms such as “**living with and beyond cancer**” and “**lived experience**” are increasingly used in Europe and beyond, as they can better reflect a wider range of cancer experiences and support autonomy and self-identification. At the same time, these terms may not translate easily across all languages or cultural contexts.

We encourage patient organisations to:

- respect how individuals choose to describe themselves
- invite self-identification rather than making assumptions
- remain attentive to age, culture, language, cancer stage, and personal context
- regularly review and adapt language used in communications, programmes, and advocacy

Inclusive language is not static. It evolves alongside communities, evidence, and lived experience. Patient organisations play an important role in supporting this evolution by **listening, learning, and remaining responsive to the people they represent.**

EDI training and learning resources

This checklist is designed as a practical self-assessment tool. It does not aim to provide a comprehensive overview of all available EDI training opportunities. Instead, patient organisations who wish to deepen their learning or support implementation may find the following resources helpful:

Equity, Diversity and Inclusion Principles in Cancer Care – Train-the-Trainer Toolkit

A practical toolkit developed by Youth Cancer Europe to support patient organisations and trainers in understanding and applying EDI principles in cancer care.

Equity, Diversity and Inclusion in Cancer Care | Video Playlist

A curated YouTube playlist by Youth Cancer Europe featuring over 30 videos, including testimonials, webinars, and discussions on EDI in cancer care.

ACE Academy (forthcoming)

An upcoming training and capacity-building initiative within the YARN project, designed to support patient advocates and organisations with structured learning opportunities, including equity, diversity and inclusion.

References

1 | European Commission. (2022) Europe’s Beating Cancer Plan.

2 | 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.

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

4 | Katie Rizvi, Urska Kosir, Ana Totovina (2024) Recommendations and Implementation Roadmap for Minimum Standards of Specialist Adolescent and Young Adult (AYA) Cancer Care Units, Youth Cancer Europe; European Commission co-funded project: EU-CAYAS-NET EU4H-2021-PJ-04:101056918.

5 | U. Košir, F. Lysen, N. Unterecker, T. Deželak, E. Sturesson, I. Shakhnenko, D. Stark, K. Rizvi, A.-S. Darlington, L. Wee et al. (2024). Recommendation & Implementation Roadmap: Minimum Standards of Specialist Adolescent and Young Adults (AYA) Cancer Care Units. Youth Cancer Europe; European Commission co-funded project: EU-CAYAS-NET EU4H-2021-P3-04-101056918.

6 | O’Callaghan, S., Monge-Montero, C. and Rizvi, K., 2025. “Living with and beyond” the terms “patient” and “survivor”: A lived experience discussion of terms used by young adults with cancer. Seminars in Oncology Nursing, 41(3), p.151890.

Glossary

Accessibility	The design of communication, services, environments, and activities so that people with different needs can use them equally, without barriers.
Accountability mechanisms	Clear ways of assigning responsibility, monitoring actions, and following up to ensure commitments are implemented in practice.
Co-creation	A collaborative approach where people with lived experience actively contribute to the design, development, and improvement of activities, tools, or services.
Cultural humility	An ongoing practice of self-reflection and learning that recognises cultural differences, power imbalances, and the limits of one's own knowledge.
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.
EU Cancer Plan	The European Beating Cancer Plan. A European Union initiative aimed at improving cancer prevention, diagnosis, treatment, quality of life, and reducing inequalities across Member States.
EU4Health Programme	The European Union's health funding programme supporting actions to strengthen health systems and reduce health inequalities.
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 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.
Safeguarding	Policies and practices designed to protect individuals from harm, abuse, or exploitation within organisational activities.
Self-assessment	A structured process in which an organisation reflects on its own practices to identify strengths, gaps, and areas for improvement.
Socioeconomic barriers	Obstacles linked to income, employment, education, housing, or access to resources that can limit participation or access to support.
Tokenism	The superficial inclusion of individuals from underrepresented groups without giving them meaningful influence or participation.
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.
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 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.
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.

This checklist was developed within YARN – the European Youth Cancer Network, a project co-funded by the European Union under the EU4Health Programme (Grant Agreement No. 101219053).

YARN is the largest youth cancer network established within an EU-funded project to date, bringing together 19 Beneficiaries, one Affiliated Entity, and 39 Associated Partners across 28 European countries. The project focuses on strengthening equitable, patient-centred approaches across cancer care, peer support, advocacy, and policy, with a strong emphasis on equity, diversity and inclusion.

Youth Cancer Europe, the project coordinator, is a pan-European patient advocacy network representing young people affected by cancer from over 40 countries. YCE has a long-standing track record in shaping European policy and practice on adolescent and young adult cancer care, equity, diversity and inclusion, mental health, and patient engagement.

A core pillar of YARN is the **Youth Cancer Council**, 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 outputs, ensuring they remain grounded in real needs and diverse lived experiences across Europe.

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Notes

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PanCare Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer

european cancer ORGANISATION

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