Patient Advisory Committee on Equal Representation

Inclusive Voices in Patient Organisations

This report was made possible through the support of Astellas. We thank all contributors, patient organisations, and advocacy groups whose insights and experiences informed this work. The authors retain all editorial control.

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This report was developed by the Patient Advisory Committee on Equal Representation.

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Welcome

The Inclusive Voices in Patient Organisations report, developed by the Patient Advisory Committee on Equal Representation initiative, examines diversity, inclusion, and equity within patient organisations across Belgium, The Netherlands, the United Kingdom, Germany, Spain, Australia, the United States, and Canada. It highlights gaps, shares insights, and provides recommendations to empower underrepresented groups, strengthen participation, and build a more inclusive and representative healthcare landscape.

CONCEPT

This report examines diversity, inclusion, and equity in patient organisations, highlighting challenges and recommending strategies to improve representation and participation.

Executive Summary

The “Inclusive Voices in Patient Organisations” report, developed by the Patient Advisory Committee on Equal Representation, explores diversity, inclusion, and equity within patient organisations across Belgium, the Netherlands, the United Kingdom, Germany, Spain, Australia, the United States, and Canada.

It highlights significant representation gaps, shares insights from various regions, and provides recommendations to foster inclusivity in patient organisations and healthcare advocacy.

> There is an urgent need for patient organisations to enhance inclusivity

Results

Data on internal diversity in patient organisations is scarce. Looking more widely at diversity within non-profit organisations, while women are well-represented in the workforce and hold many leadership roles, they remain underrepresented as board chairs.

Racial and ethnic minorities, disabled individuals, and LGBTQ+ leaders are also underrepresented in decision-making, reducing diverse input in policy and advocacy. Immigrants and younger professionals face barriers like limited networks, unconscious bias, and a lack of leadership development.

These challenges are often compounded for those who belong to more than one marginalised group, particularly where low income, education access, or regional disadvantage intersect.

Promising practices

Many patient organisations have adopted strategies to improve diversity and inclusion, including

- Collecting demographic data
- Setting representation targets
- Establishment of advisory groups
- Board skills matrices
- Career development initiatives
- Paid internship programmes

Patient organisations using these strategies report improved representation, clearer accountability, and more responsive governance.

Short term recommendations

- Expand outreach to diverse communities
- Ensure inclusive recruitment practices
- Create diverse patient advisory groups

Medium term recommendations

- Launch leadership training for diversity
- Implement Diversity, Equity, and Inclusion policies
- Set diversity targets in governance

Long term recommendations

- Embed Diversity, Equity, and Inclusion in mission
- Build long-term community partnerships
- Hold leadership accountable for Diversity, Equity, and Inclusion

Inclusion strategies should account for how overlapping identities shape lived experience and access to leadership. Patient organisations should be mindful that power structures, if left unexamined, tend to sustain themselves. By questioning established norms, leaders can help build governance that genuinely reflects the diversity of the communities they represent.

Patient organisations thrive when they invite scrutiny, engage in self-reflection, and adapt to changing demographics and needs. This means investing in mentorship, challenging unconscious biases, and ensuring diverse perspectives shape governance at every level.

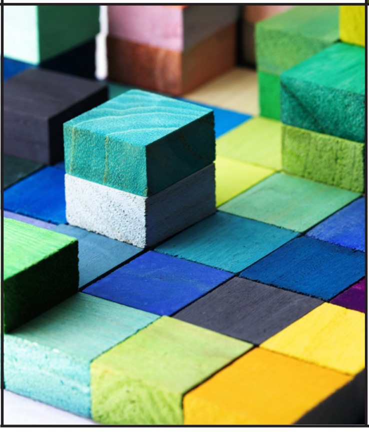
When organisations do not push for change, they allow unfair systems to stay in place

14%
of board chairs in charities for people with physical health conditions are disabled in the UK, compared to 18% of the general population

6%
of non-profit chairs identify as LGBTQ+ in the USA, compared to 8% of the general population

13 %
of board members of health non-profits are immigrants in Canada, compared to 23% of the general population

26%
of board members of the top 40 companies are women in Germany, compared to 50% of the general population



7%
of board members of the top 50 companies are from ethically diverse backgrounds in the Netherlands, compared to 25% of the general population

Introduction

Opportunities

Diverse leadership within patient organisations improves advocacy, decision-making, and access to care. When these organisations reflect the communities they serve, they build trust, increase relevance, and deliver better outcomes.

Leaders with lived experience of marginalisation are better equipped to understand and address the barriers faced by underrepresented groups. For example, ethnically diverse boards are more likely to invest in outreach to underserved communities. Inclusive leadership also helps shape research that responds to real-world needs, influencing policy, education, and service design in more equitable ways.

Patients are more likely to engage with organisations that reflect their identities. This trust increases participation in clinical trials, treatment programmes, and support services. It also improves the quality of governance and service delivery, helping to reduce disparities in areas such as cancer screening or mental health support for LGBTQ+, disabled, and minority populations.

Boards that include a range of perspectives are more likely to challenge assumptions and identify innovative solutions. High-level involvement, such as co-leadership and co-design, leads to deeper, more lasting structural change than symbolic inclusion alone. Peer support, culturally reflective leadership, and inclusive environments sustain participation over time.

However, meaningful progress remains constrained by persistent barriers. These include underrepresentation, a lack of training in inclusive methods, and limited funding to support long-term change. Addressing these challenges requires an inter-sectional approach that recognises how overlapping identities shape experience and influence leadership access.

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Inclusion is the foundation of lasting legitimacy and impact.

Challenges

Despite the clear benefits of Equity, Diversity, and Inclusion initiatives, patient organisations face significant obstacles in their implementation. Recent political shifts have reinforced resistance to inclusion efforts. As Equity, Diversity, and Inclusion policies become increasingly politicised, patient organisations should remain committed to fostering inclusive leadership and representation, even amid external challenges.

Change is often met with fear. Some leadership teams hesitate to prioritise diversity, seeing it as a challenge to long-standing power structures.

Many patient organisations operate with limited and unstable funding, making it difficult to move beyond aspirational commitments to diversity and inclusion. Without consistent resources, efforts to embed inclusive governance, equitable engagement, and representative leadership often lack sustainability. Long-term investment is essential to support lasting change and enable patient organisations to prioritise these goals as core parts of their mission.

Even well-intentioned organisations may struggle with unconscious biases that affect hiring, board selection, and leadership development. Without intentional efforts to recognise and counteract these biases, patient organisations risk replicating the same exclusionary patterns that exist in broader society.

Without reliable data, accountability is impossible. Many organisations lack formal processes to track diversity metrics, and in some regions, demographic data collection is restricted by law.

Equity, Diversity, and Inclusion efforts often lose momentum after initial enthusiasm fades. Without embedding inclusion into long-term strategies, organisations risk treating diversity as an optional initiative rather than a fundamental necessity. External pressures - whether political, financial, or cultural - may tempt patient organisations to deprioritise Equity, Diversity, and Inclusion, but patient leaders should not abandon their principles under pressure. Building a truly inclusive patient organisation demands sustained commitment beyond short-term goals.

Many individuals face overlapping forms of discrimination. For example, someone who is disabled and from an ethnic minority may also face barriers linked to socioeconomic status. Without recognising intersectionality, inclusion efforts risk oversimplifying complex lived experiences.

Patient organisations should recognise that Equity, Diversity, and Inclusion is not a passive goal but an active stance against exclusion and inequity.

By embedding Equity, Diversity, and Inclusion into governance, leadership, advocacy, and healthcare accessibility, patient organisations can drive meaningful and lasting change. This approach reflects a clear commitment to fairness, representation, and the needs of all communities they serve.

> Leaders should take a deliberate stand, refusing to retreat in the face of external pressures.

Methodology

This report examines diversity, inclusion, and equity within patient organisations using a mixed-methods approach, combining quantitative data analysis with qualitative insights to provide a comprehensive view of representation in the sector. Research focused on patient organisations across Belgium, the Netherlands, the United Kingdom, Germany, Spain, Australia, the United States, and Canada.

Data collection

To gather meaningful insights, the study relied on two primary sources of data: crowd-sourced data and case studies of best practices.

Crowd-sourced data was drawn from existing surveys, which provided valuable benchmarking data on leadership diversity, board composition, workforce demographics, and inclusion policies. These surveys captured diversity trends across multiple countries and healthcare sectors, offering a broad overview of the current landscape.

Case studies and promising practices were analysed to supplement the quantitative findings. By studying patient organisations known for their successful diversity initiatives, the research identified effective strategies to improve inclusion and representation. These real-world examples showcase practical approaches to fostering inclusive leadership in patient organisations.

Data analysis

The collected data were examined using descriptive statistics to uncover key patterns and trends.

Descriptive statistics were used to assess the composition of boards, gender balance, and workforce diversity within patient organisations. This analysis identified key representation gaps among demographic groups, particularly in leadership roles. The data revealed how well women, racial and ethnic minorities, LGBTQ+ people, and disabled individuals are represented in leadership.

However, the lack of comprehensive and standardised data made comparative analysis across countries and organisations highly challenging. Most patient organisations do not systematically collect or report demographic data on leadership and workforce composition, leading to significant gaps in understanding representation trends.

National data protection laws, differences in Equity, Diversity, and Inclusion reporting practices, and cultural variations in how diversity is measured further complicated direct comparisons.

Limitations

While this report provides valuable insights, several limitations should be acknowledged.

In many countries, data was unavailable for patient organisations. As a result, we referenced related sectors such as health NGOs and corporate governance to explore diversity trends.

The lack of standardised data makes it difficult to compare diversity across countries and organisations. Many patient groups do not report leadership demographics, limiting understanding of how overlapping inequalities interact. An intersectional approach is needed to reflect the full complexity of exclusion in governance.

Voluntary participation bias may have influenced the results, as organisations already engaged in Equity, Diversity, and Inclusion efforts were more likely to participate. This self-selection may have skewed the findings, meaning that organisations with limited or no Equity, Diversity, and Inclusion initiatives may be underrepresented.

Much of the data relied on self-reported information, which can introduce inconsistencies and incomplete responses. Variations in reporting standards and transparency further impacted the completeness of the dataset.

Cross-country comparability issues constrained the scope of analysis. National data collection laws, cultural sensitivities, and legal restrictions on demographic reporting made direct comparisons difficult. In some cases, definitions of key demographic categories such as race, ethnicity, or disability differed significantly between countries, making standardised analysis complex.

These limitations affect the scope and comparability of the findings. Inconsistent data, limited participation from less active organisations, and reliance on adjacent sectors may lead the report to over-represent progress and under-represent ongoing challenges. Cross-country comparisons are constrained, and gaps in demographic reporting reduce the accuracy of representation analysis. As a result, while the report highlights key trends and promising practices, it does not present a complete or standardised global picture.

Key milestones in the evolution of civil society and patient organisations

1945

Article 71 of the United Nations Charter established provisions for consulting non-governmental organizations, creating a framework for civil society engagement in UN activities.

1975

The United Nations adopted the Declaration on the Rights of Disabled Persons, promoting global efforts to protect rights, dignity, and inclusion while improving equity and access to opportunities and services.

1990

The World Health Organization's Global Strategy for Cancer Control emphasised the importance of inclusion and equity in cancer care globally, inspiring patient organisations to advocate for improved healthcare access for all.

1996

The United Nations Economic and Social Council Resolution 1996/31 improved consultative arrangements for non-governmental organisations, expanding their role in UN discussions and enhancing civil society's influence on global policies.

2015

The United Nations 2030 Agenda recognises civil society as essential partners in achieving and monitoring Sustainable Development Goals, including Good Health, Gender Equality, and Reduced Inequalities.

2016

The World Health Organization adopted the Framework of Engagement with Non-State Actors which established guidelines for patient organisations and other non-state actors to collaborate without undue influence.

2018

The first edition of the "Handbook for Non-State Actors on Engagement with the World Health Organization" was published.

2023

The World Health Organization launched its Civil Commission which enables patient organisations to contribute to global health policymaking.

2024

World Health Organization member states unanimously adopted a landmark resolution emphasising the importance of social participation in health systems.

AUSTRALIA

In 2020, the Institute of Community Directors Australia released the report “Rethink What You Know About Not-for-Profit Governance”, drawn from a survey conducted with 1,878 senior leaders in the not-for-profit sector. Of the participating organisations, 11% were health-related non-profits.

Boards tend to have strong representation of women, but they are less diverse in terms of age, cultural backgrounds, and inclusion of disabled people.

The survey found that a majority of board members, 66%, were women, and 43% reported having at least one member from a culturally and linguistically diverse background.

A significant portion of board members, 68%, were over 50, with 27% being over 65. Senior citizen/retiree members were present on 74% of boards.

Most boards, 78%, included at least 40% women. Approximately 68% of boards had a consumer or patient representative. A smaller proportion, 28%, included members with disabilities, while 15% had Aboriginal or Torres Strait Islander representation. Additionally, 17% of boards featured at least one person under 25, and 17% included at least one member who identified as LGBTQI.

In the non-profit health sector, 68% of respondents highlighted the importance of board diversity.

28%

of non-profit boards have at least one disabled person

78%

of non-profit boards have at least 40% women

17%

of non-profit boards have at least one person who is LGBTQ+

43%

of non-profit boards have at least one person from a culturally and linguistically diverse background

Promising practice examples from Australia

Canteen	established a Diversity & Inclusion Advisory group so that the lived experience of their workforce is represented in their work to support young people with cancer, which enhances service relevance and satisfaction
National Breast Cancer Foundation	created a Board skills matrix to evaluate expertise, experience, and diversity, guiding recruitment and governance
Victorian Comprehensive Cancer Centre Alliance	transitioned to a more diverse Board structure incorporating new expertise and broader representation that included consumer, patient, and regional perspectives

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BELGIUM

The 2024 Belgium Spencer Stuart Board Index analysed the board composition of 47 companies, 8% of which were healthcare companies. The 2022 SD Worx diversity survey analysed 312 Belgian companies on their diversity, equity, and inclusion practices.

There is limited data on internal diversity within patient organisations, including aspects like gender, ethnicity, disability, and LGBTQ+ representation.

Due to limited publicly available data on patient organisations, this section draws on diversity trends in the broader non-profit and corporate sectors.

The EU Directive on Gender Balance in Corporate Boards requires that by June 2026, listed companies must ensure either 40% of non-executive directors or 33% of all board directors are women. Currently, women make up more than half of the Belgian workforce but hold only 6.4% of CEO roles and 39% of board positions. Non- Belgian foreigners hold 39% of board positions. 40% of top Belgian companies have no directors under the age of 50.

In Belgium, 69% of companies have committed to neutral recruitment policies, while 72% are committed equal pay and conditions across gender, age, and religion. Additionally, 71% ensure equal access to training. However, only 36% actively involve managers in diversity initiatives through internal training. Clear reporting systems and tracking goals are limited, with just 29% evaluating managers' contributions to diversity objectives.

No available data exists on the internal diversity of patient organisations in Belgium.

39%

of board members of the top 47 companies are women

99%

of Belgian listed companies adhere to at least 90% of the provisions of the Belgian Code on Corporate Governance

59%

of Belgian listed companies link board member bonuses to Environmental, Social, and Governance targets

14%

of the Belgian population is employed by companies and institutions that have signed the national Diversity Charter

Promising practice examples from Belgium

Luminus SA	conducts regular anonymous diversity surveys to evaluate workforce diversity, inclusion, and equity, guiding the development of targeted action plans.
AXA Belgium	launched a mentoring programme tailored for colleagues of non-EU descent, aiming to eliminate advancement barriers, identify development areas, address challenges, and explore potential career pathways
World Federation of Advertisers	surveys and reports on its workforce diversity, highlighting the experiences of women, ethnic minorities, disabled people, and LGBTQ+ people.

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NETHERLANDS

The 2022 Netherlands Spencer Stuart Board Index reviewed the board composition of 50 of the largest public companies on the Dutch segment of the NYSE Euronext.

There’s little data on the diversity of people leading patient organisations, including gender, ethnicity, disability, and LGBTQ+ representation

Due to limited publicly available data on patient organisations, this section draws on diversity trends in the broader non-profit and corporate sectors.

The EU Directive on Gender Balance in Corporate Boards mandates that by June 2026, listed companies must have at least 40% female non-executive directors or 33% female board members. The Dutch Diversity Act (2022) requires one-third female and one-third male representation on supervisory boards.

In the Netherlands, women hold 39% of non-executive director roles in the top 50 companies, up from 18% a decade ago, yet executive leadership remains male-dominated. Women occupy just 17% of executive board positions, and ethnic diversity is even more limited, as only 7% of executive board directors are from ethnically diverse backgrounds.

A slightly higher proportion, 19%, hold executive committee roles, which oversee key business functions but may not include board membership. In 2022, 28% of top companies still had all-male executive committees. Women hold just 10% of chair positions.

Data on disabled and LGBTQ+ individuals in boardrooms is lacking, and patient organisations have little diversity data, as research focuses on corporate boards.

17%

of executive board members of the top 50 companies are women

7%

of board members of the top 50 companies are from ethically diverse backgrounds

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82%

of the top 50 companies link board member bonuses to Environmental, Social, and Governance targets

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19%

of the Dutch population is employed by companies and institutions that have signed the Dutch Diversity Charter

Promising practice examples from the Netherlands

Nederlandse Spoorwegen (Dutch Railways)	mandates that high-level job vacancies must be submitted to a diversity committee, ensuring that women and multicultural candidates are included in the selection process.
Aquent talent agency	introduced bias-free CV templates to ensure fair hiring by focusing on skills and removing biased details like name, gender, and nationality
ABN AMRO bank	launched a training programme to support ethnically and culturally diverse employees in overcoming barriers and developing soft skills, with 70% promoted within six months.

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CANADA

In 2021, Statistics Canada released the report "Diversity of Charity and Non-Profit Boards of Directors: Overview of the Canadian Non-Profit Sector", based on a crowd-sourced questionnaire targeting non-profits and charities. Of the participating organisations, 9% were health-related organisations.

Boards with a written policy regarding diversity were more likely to have members from diverse population groups

Regarding diversity in health non-profit organisations, when asked whether they had a written policy to promote diversity within their board of directors, the responses were as follows: 38.2% answered Yes, 36.2% answered No, and 25.5% did not know.

The sociodemographic characteristics of board members from participating organisations revealed that 32.9% were aged 65 or older, 60.5% were female, 8.5% were persons with a disability, 3.7% identified as First Nations, Métis, or Inuit, 8.9% were from visible minority groups, 13% were immigrants, and 6.5% identified as LGBTQ2+.

Although these results come from a crowd-sourcing initiative and cannot be considered fully representative of the broader non-profit sector, they offer valuable insights into the composition of boards within charities and non-profits.

38%

of health non-profits have a written policy to promote diversity within their board of directors

61%

of board members of health non-profits are women

33%

of board members of health non-profits are aged 65 or older

13%

of board members of health non-profits are immigrants

Promising practice examples from Canada

Canadian Cancer Society	The Canadian Cancer Society has committed to collecting demographic data and diversifying its workforce by supporting Black, Indigenous, and people of colour in leadership.
Canadian Partnership Against Cancer	aims for gender parity (50% women/non-binary) and 30% representation of equity-deserving groups on boards/senior management.
Leukemia & Lymphoma Society of Canada	The board of the Leukemia & Lymphoma Society of Canada pledged to develop and evaluate strategic inclusion and diversity plans, ensuring accountability and prioritisation.

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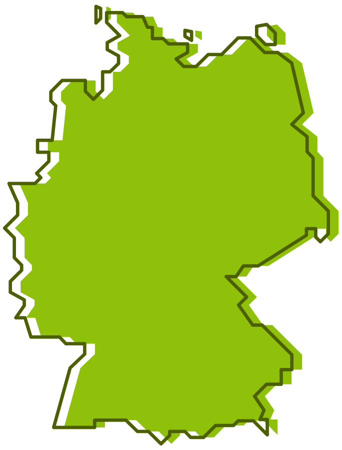

GERMANY

Due to limited publicly available data on patient organisations, this section draws on diversity trends in the broader non-profit and corporate sectors.

Women hold 28.7% of executive positions within companies, below the Western European average of 34.8%. Around 11% of the population identifies as LGBTQ+, but data on their representation in leadership is limited. Additionally, 9.4% people in Germany live with disabilities, yet there is scarce data on their presence in leadership roles.

Approximately 29.9% of the German population has a migrant background. Ethnic minorities represent 12.7% of the federal administration workforce. Data on ethnic minority participation in charity leadership is limited.

Approximately 17.7% of the German population is employed by companies and institutions that have signed Germany's Diversity Charter.

Of the top DAX 40 companies, 55% of companies link board member bonuses to diversity targets, and 50% of the companies report having a formal diversity strategy.

No available data exists on the internal diversity of patient organisations in Germany.

Key sources on diversity in German workforces include McKinsey's "Diversity Wins: How Inclusion Matters", the Federal Statistical Office's labour market data, Charta der Vielfalt's "Diversity Factbook", and the German Diversity Index.

There is a gap in data collection regarding gender, ethnicity, disability, LGBTQ+, and other dimensions of diversity within patient organisations.

26%

of executive board members of DAX 40 companies are women

50%

of DAX 40 companies have a formal diversity strategy

55%

of DAX 40 companies link Board member bonuses to diversity targets

18%

of the German population is employed by companies and institutions that have signed Germany's Diversity Charter

Promising practice examples from Germany

Stiftung für junge Erwachsene mit Krebs (Foundation for Young Adults with Cancer)	established a Patient Advisory Board to advise the Board and executive team on strategic issues
Deutsches Krebsforschungszentrum (German Cancer Research Center)	signed the Charter of Diversity and appointed a Diversity, Equity, and Inclusion Manager to develop and implement a comprehensive diversity, equity, and inclusion strategy
Deutsche Krebsgesellschaft (German Cancer Society)	endorsed the DivINe (Diversity in Neuro-Oncology) initiative to advance career development opportunities for women in the field

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SPAIN

Due to limited publicly available data on patient organisations, this section draws on diversity trends in the broader non-profit and corporate sectors.

The EU Directive on Gender Balance in Corporate Boards requires that by June 2026, listed companies must ensure either 40% of non-executive directors or 33% of all board directors are women. Currently, women make up more than half of the Spanish workforce but hold only 7.7% of CEO roles and 32% of board positions

All health sector companies surveyed in the "Innodiversity in the Spanish Business Fabric" report expressed a commitment to fostering female talent, 82% implemented measures to actively adopt and report on practices that promote diversity and inclusion within LGBTQ+ individuals, and 82% ensured the inclusion of disabled people.

No available data exists on the internal diversity of patient organisations in Spain.

The XI Report on Women Directors 2023 study by Institute of Higher Business Studies analysed the top 35 companies from Spain. The 2022 report, "Innodiversity in the Spanish Business Fabric," published by Fundación para la Diversidad and Instituto de Empresa University, analysed 786 companies, with the health sector comprising 8.91%.

Patient organisations have a shortage of data on their internal diversity, including gender, ethnicity, disability, and LGBTQ+ representation

32%

of board members of the top 35 companies are women

53%

of listed companies adhere to at least 90% of the Good Governance Code's recommendations.

69%

of the top 35 companies link Board member bonuses to Environmental, Social, and Governance targets

13%

of the Spanish population is employed by companies and institutions that have signed Spain's Diversity Charter

Promising practice examples from Spain

Cepsa Energy	established a Equal Employee Network to promote the inclusion of the LGTBI+ collective and raise awareness about gender identity and sexual orientation
Ilunion Hotels	is a socially focused business group, employing over 1,700 people, 41% of whom have a disability
Medicina Intensiva Scientific Journal	committed to achieve at least 30% women within the journal's editorial committee and council

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United Kingdom

In 2020, Third Sector Trends released the report "Third sector trends 2020 briefing: Diversity and inclusion in third sector leadership", drawn from a survey conducted with 3,158 Third Sector organisations in the United Kingdom.

Black, Asian, and Minority Ethnic individuals face systemic underrepresentation and barriers to entry in the charity sector

Black, Asian, and Minority Ethnic individuals make up 14.0% of the United Kingdom population, yet in non-profit organisations focused on people with physical health conditions, they account for only 8.5% of charity chairs and 9.6% of chief executive officers. Black, Asian, and Minority Ethnic people are also more likely to face discrimination during recruitment processes.

Disabled people hold 14.0% of chair positions and 11.4% of chief executive officer roles in non-profit organisations focused on people with physical health conditions.

Women make up 44.4% of chairs and 67.0% of chief executive officers in non-profit organisations focused on people with physical health conditions.

People from low socioeconomic backgrounds also face barriers to entering the charity sector, particularly due to the reliance on unpaid internships. These internships, particularly in expensive cities like London, create barriers for individuals who cannot afford to work without pay, limiting opportunities for underrepresented groups in the charity sector.

14%

of board chairs in non-profit organisations for people with physical health conditions are disabled

44%

of board chairs in non-profit organisations for people with physical health conditions are women

15%

of small non-profit organisations have an LGBTQIA+ or person aged under 30 on their board

9%

of board chairs in non-profit organisations for people with physical health conditions are from Black, Asian, and Minority Ethnic backgrounds

Promising practice examples from the United Kingdom

Cancer Research UK	became the first major UK charity to offer paid internships, leading to 30% of its interns coming from Black, Asian, and Minority Ethnic backgrounds
Young Lives vs Cancer	recruited a trustee specifically to provide leadership in cultivating an inclusive culture and champion diversity and inclusion at the Board level
Blood Cancer UK	put in place new recruitment processes including name blind shortlisting, involving people affected by cancer, and sharing questions before panel interviews

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UNITED STATES

In 2021, the Urban Institute released the report "Non-Profit Trends and Impact", based on a crowd-sourced questionnaire targeting non-profits and charities in the United States of America. Of the participating organisations, 8% were health-related organisations.

The results highlight significant disparities in racial, gender, and disability representation on non-profit boards

The 2021 survey analysed the demographics of non-profit organizations across urban, suburban, and rural areas. The findings reveal significant variations in racial and ethnic representation. In urban core areas, 67.1% of board chairs identified as white, while 32.9% were non-white. In rural areas, 39.7% of board chairs were non-white, with 24.3% identifying as Black or African American.

Regarding gender, 51.3% of board chairs were male, 46.4% were female, and 1.3% were transgender, non-binary, or other. In terms of disability, 6% of board chairs across all areas reported having a disability, with rural areas showing a higher percentage at 8%.

The most common age range for board chairs was 55-64 years old.

6%

of non-profit board chairs are disabled

47%

of non-profit chairs are women

6%

of non-profit chairs identify as LGBTQ+

21%

of non-profit chairs are non-white

Promising practice examples from the USA

American Cancer Society	Launched a Diversity, Equity, and Inclusion Action Plan that includes specific goals such as increasing the percentage of employees from diverse racial and ethnic backgrounds
Leukemia & Lymphoma Society	Established an inclusive excellence action plan that includes diversifying the board of directors and senior leadership
Greenpeace	reports the percentages of Black, Indigenous, and People of Colour, women, people over 40, and trans and non-binary people within its leadership, management, and overall staff

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Threats to diversity, equity, and inclusion are threats to us all

When diversity, equity, and inclusion practices are eliminated, democracy is undermined. Power becomes concentrated in the hands of a select few, while the broader population is left unrepresented and underserved.

Without meaningful diversity, equity, and inclusion actions, we risk silencing the perspectives of younger people, older adults, women, pregnant people and new parents, disabled people, LGBTQ+ communities, ethnic and racial minorities, and people of minority faiths or no religious belief.

Diverse workplaces and leadership drive innovation.

Use online platforms to mobilise supporters and raise awareness through campaigns and coordinated actions.

Form alliances with other organisations that share similar goals to amplify impact and create a united front against discrimination or exclusion.

Partner with global human rights organisations to create pressure and accountability for governments and institutions failing to protect marginalised groups.

Empower marginalised voices by training individuals to share their experiences in media, public forums, and legislative settings

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Change takes time. Movements like women's suffrage required over 20 years of sustained organising, coordinated action, and public pressure. The decisions we make now will shape whether exclusion persists or more representative systems emerge.

Patient organisations that prioritise inclusion are better equipped to meet community needs. Research shows those with inclusive practices are 1.7 times more likely to lead in innovation. Advocacy begins by listening to a broad range of voices and distributing power. When leadership and resources remain in the hands of a few, trust erodes and participation declines.

Neglecting equity has consequences. About 69 percent of organisations report leadership that does not reflect their communities. Without clear inclusion strategies, many face high staff turnover, weak community ties, and reduced effectiveness.

Organisations that invest in equity see results. Recruitment and mentorship raised board diversity by 15 percent. Cultural competence training improved minority patient satisfaction by 20 percent. Inclusive leadership workshops reduced staff turnover by 25 percent. Community advisory councils increased health programme participation by 30 percent. Diverse leadership teams achieved 10 percent stronger revenue growth than their peers.

Recommendations

To advance diversity, inclusion, and equal representation in patient organisations, stakeholders should take concrete steps across short-, medium-, and long-term time-frames. Sustainable change requires ongoing commitment, not just initial efforts.

Patient organisations

Short Term (12 months)

- Engage with underrepresented communities to increase participation at all levels
- Collect and publish the results of anonymous demographic surveys to identify gaps in representation

Medium Term (1-3 years)

- Offer training and mentorship for people from diverse backgrounds
- Establish diverse patient-led groups with real decision-making power

Long Term (1-3 years)

- Ensure diversity policies are integrated into bylaws and leadership selection processes
- Provide financial and accessibility support to ensure inclusive engagement

Policymakers and government agencies

Short Term (12 months)

- Ensure patient organisations can collect and analyse diversity data without mandatory public disclosure
- Implement guidelines that promote diverse representation in advisory boards and councils

Medium Term (1-3 years)

- Pass and uphold legislation preventing discrimination
- Introduce recognition programs for organisations that demonstrate strong Equity, Diversity, and Inclusion commitments

Long Term (1-3 years)

- Partner with international human rights and health organisations to create binding agreements that protect patient organisations and Equity, Diversity, and Inclusion policies
- Require diverse patient voices, including LGBTQ+, disabled, and minority populations, to have permanent seats in health advisory councils, legislative processes, and public policy decision-making

Funders and granting organisations

Short Term (12 months)

- Dedicate specific funding streams to organisations advancing representation
- Ensure organisations report on inclusion efforts as part of funding eligibility for grant applications

Medium Term (1-3 years)

- Provide resources for training, governance reforms, and leadership development
- Develop clear benchmarks for measuring progress in funded diversity initiatives

Long Term (1-3 years)

- Shift from short-term projects to long-term funding for structural change to invest in sustainable support for patient organisations that demonstrate a true commitment to excellence and internal diversity
- Provide sustained, multi-year funding to help patient organisations move beyond aspirational commitments and embed inclusive practices into their core operations, including leadership development, inclusive governance, and equitable engagement

Healthcare institutions and professionals

Short Term (12 months)

- Offer training to underrepresented people within patient organisations
- Prioritise engagement with patient organisations that actively include diverse voices in their work

Medium Term (1-3 years)

- Partner with patient organisations that demonstrate inclusive leadership
- Offer Equity, Diversity, and Inclusion training to help patient organisations implement inclusive governance

Long Term (1-3 years)

- Create long-term collaborations between healthcare institutions and patient organisations to continuously support inclusive leadership and governance structures
- Advocate for diverse patient organisations to be formally included in national and international healthcare policy discussions

Diversity is the foundation of resilient patient organisations, requiring bold action to build truly inclusive advocacy.

Conclusion

Achieving diversity, equity, and inclusion within patient organisations leads to more relevant and responsive services, increased trust from the communities they serve, and improved engagement in programmes, research, and policy work. It enables organisations to identify and address health disparities, amplify underrepresented voices, and ensure that governance and decision-making reflect the full spectrum of patient experiences.

This report highlights the persistent gaps in data on diversity in leadership, decision-making, and governance structures, underscoring the need for deliberate and sustained action. While some progress has been made, underrepresented communities remain excluded from key leadership roles, limiting their ability to influence policies and improve healthcare outcomes.

Patient organisations should resist complacency and take proactive steps to embed diversity, equity, and inclusion principles into their structures. This includes diversifying leadership, fostering inclusive decision-making, and removing barriers to participation. Policymakers, funders, and healthcare institutions also play a crucial role in advancing these efforts by ensuring long-term support, legal protections, and sustained investment in inclusive governance.

True progress requires institutional commitments, accountability, and the courage to challenge existing power structures. By implementing the recommendations outlined in this report, patient organisations can build a more representative, resilient, and impactful movement that serves all communities, ensuring that no voice is left unheard.

Without data, diversity remains an aspiration, not a reality. Patient organisations should track representation while protecting their people from discrimination and harm.

Patient Advisory Committee on Equal Representation