CASE STUDIES

Tackling health inequalities in rare and less common cancers

January 2026

cancer52
the common voice for
rare & less common cancers

Introduction

Everyone should have a fair chance of beating cancer, but for people with rare and less common cancers, getting a timely diagnosis and the right care can be much more difficult.

Rare and less common cancers include all cancers other than the four most common: breast, bowel, lung and prostate. These cancers make up almost half of all cancer diagnoses in the UK, yet more than half of all cancer deaths. Progress in survival has not kept pace with the four most common cancers.

These challenges are felt most acutely in communities already facing health inequalities. People living in more deprived areas, people from Black and minority ethnic communities, disabled people, people with diverse gender identities and sexualities, children and young adults, are all at greater risk of poorer outcomes.

Cancer52's members are working to address these inequalities in a range of ways. By working alongside people with lived experience to shape services, providing flexible, patient-centred support, and amplifying patient voices, our member charities are changing lives while contributing to national policy objectives to tackle health inequalities.

The following case studies provide examples of how Cancer52's members are helping to ensure everyone gets the care and support they deserve, and that no one has to navigate diagnosis, treatment or support alone.

Inequalities in rare and less common cancers

People affected by rare and less common cancers:

- Are more likely to have to return to their GP many times before a diagnosis.
- Often wait longer for treatment and struggle to access specialist support that meets their needs.
- Frequently experience practical, cultural, financial and communication barriers not always recognised by the health system.
- May face further systematic, unfair and avoidable differences in their health, and the care they receive, due to factors such as age, deprivation, disability, ethnicity, geography, sex and sexual orientation.

Breaking down barriers through community theatre

Oracle Head and Neck Cancer UK

Oracle Head and Neck Cancer UK worked with University Hospitals of Leicester NHS Trust and African-Caribbean community leaders to increase awareness of head and neck cancer, reduce stigma, and encourage people to seek help earlier.

Head and neck cancers are a group of cancers that develop in the tissues and organs of the head and neck, including the mouth, throat, voice box, nasal cavity, sinuses, and salivary glands. While relatively uncommon, but they can be aggressive if not detected early.

The project was sparked when clinicians noticed that African-Caribbean patients were presenting with more advanced symptoms of head and neck cancers than other groups. To understand this properly, the partnership spent several months engaging with seven African-Caribbean community groups across Leicester.

People described a deep sense of not being taken seriously by professionals, concerns about discrimination, and longstanding taboos around talking about cancer.

During these conversations, community leaders proposed using storytelling as a way to open up conversations. Oracle responded by partnering with Theatre Sans Frontiers and Newcastle University to co-design Community Conversations, a theatre-based awareness programme. They combined community-written sketches based on real stories, forum theatre scenes where audience members could step into the action, and spaces to ask questions directly to clinicians.

Workshops with youth theatre groups helped build confidence among younger community members, ensuring the work was intergenerational and sustainable beyond the project. The project has been successful in building trust, challenging stigma, and creating culturally meaningful ways to talk about symptoms and early diagnosis.

Find out more about Oracle Head and Neck Cancer.

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ORACLE
Head & Neck Cancer UK

Tackling gender health inequalities with The Health Collective

Wellbeing of Women

The Health Collective was founded in 2023 by Wellbeing of Women to address the UK's persistent gender health gap.

This gap is even more pronounced for women and people assigned female at birth from marginalised communities, who often face overlapping barriers linked to racism, homophobia, transphobia, disability, or cultural stigma. For example, women from marginalised communities are less likely to participate in screening programmes and are at higher risk of late-stage cancer diagnoses, poorer outcomes, and lower survival rates.

The Collective brings together over 50 grassroots women's health organisations representing a wide range of lived experiences, as well as over 25 healthcare professionals working with women from marginalised backgrounds. Members include groups supporting Black and Asian communities, LGBTIQ+ people, visually and hearing-impaired women, neurodiverse women, faith-based organisations, and culturally specific women's groups.

By bringing together these organisations, the Health Collective ensures that the voices of marginalised communities are heard in shaping policy, research, and healthcare provision.

The Health Collective meets regularly to share insights, identify common challenges, and shape coordinated policy recommendations. Together, they advocate for mandatory cultural competency training for healthcare professionals, accessible and culturally appropriate health information, and increased representation of marginalised groups in research, clinical trials, and data collection. In the cancer context, this includes campaigns to improve awareness and uptake of screening programmes, ensure diagnostic pathways are inclusive, and reduce disparities in access to specialist care.

The Health Collective has become a powerful voice influencing national women's health policy, helping ensure that new strategies, services, and research priorities reflect the realities of women from all backgrounds, demonstrating the impact of uniting diverse grassroots organisations to drive lasting systemic change.

Find out more about The Health Collective.

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WELLBEING OF WOMEN

Tackling racial inequalities in blood cancer diagnosis and care

Myeloma UK

Myeloma UK partnered with the Race Equality Foundation to understand and reduce inequalities in diagnosis and care for Black communities, who are disproportionately affected by myeloma but often less well served by traditional awareness and information approaches.

Myeloma is two to three times more common among Black African and Black Caribbean people. Yet people from these communities are often diagnosed later, sometimes after multiple GP visits or emergency admissions. Myeloma UK recognised the need to understand lived experience more deeply and to design communication approaches that resonated culturally.

The partnership held focus groups and interviews across the UK, conducting both in person and online conversations with people affected by myeloma.

Participants described the challenges of recognising symptoms that can be vague, such as back pain or fatigue; mistrust in health services; a lack of representation in patient information; and the importance of faith and community support systems.

Drawing on these insights, the team co-developed new awareness resources shaped by Black patients' voices and produced with community members. They centred on real stories, showcased people living with myeloma, and used clearer language to explain symptoms and when to seek help. The resources, launched during Blood Cancer Awareness Month 2025, form the basis of a longer-term commitment to culturally tailored communication and better partnerships between clinicians and communities. The work aims not only to improve early recognition of symptoms but to strengthen trust, responsiveness, and equity across the myeloma care pathway.

Find out more about Myeloma UK.

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MyelomaUK

Improving cervical screening for LGBTIQ+ people

OUTpatients

OUTpatients, the UK's LGBTIQ+ cancer charity, partnered with the West Yorkshire and Harrogate Cancer Alliance and creative agency Mobas to address lower cervical screening uptake among LGBTIQ+ people. Many people in this community face stigma, previous negative experiences, and misinformation, which can prevent them from attending potentially life-saving screening appointments.

Over 12 months, the partnership carried out extensive research to understand barriers to screening. This included desk research and co-creation focus groups with LGBTIQ+ individuals aged 25–64, the age range targeted by the national cervical screening programme. Participants shared concerns, myths, and experiences, highlighting anxieties about clinician interactions, terminology, appointment comfort, and inclusivity.

Using these insights, the team co-designed the Remove the Doubt campaign. It featured authentic images of community members, practical tips for attending a cervical screening appointment, and clear guidance on rights and options. For example, this may include calling ahead, requesting a double appointment, and adjustments for people taking testosterone. The campaign ran across digital channels, out-of-home advertising, and at community events such as Happy Valley Pride, where team members engaged directly with local LGBTIQ+ communities.

The campaign reached 4.84 million people and won a Patient Experience Network National Award (PENNA) in 2024 for its person-centred approach. Campaign materials continue to be used nationally, amplifying its long-term impact.

Most importantly, the initiative empowered LGBTIQ+ individuals to feel informed and confident about attending cervical screening. Community members reported greater understanding of the process and reassurance that their needs and preferences would be respected.

The campaign demonstrates the value of community-led, inclusive health communication, highlighting how co-design and authentic representation can reduce barriers, increase uptake, and save lives.

Find out more about OUTpatients.

क्या आप या आपका कोई रिश्तेदार या दोस्त

मूत्राशय के कैंसर से प्रभावित है?

Reaching patients facing language and cultural barriers

Fight Bladder Cancer

Fight Bladder Cancer is taking a proactive approach to tackling inequalities in access to information and support, particularly among people who face barriers related to language, digital exclusion and cultural perceptions of cancer.

Fight Bladder Cancer's research shows that some of the languages most commonly spoken by people with bladder cancer, such as Hindi, Portuguese and Urdu, are not among the commonly translated languages nationally. This meant that valuable resources were unavailable in the languages people actually needed, creating hidden barriers to understanding symptoms, treatment options and follow-up care.

To address this, Fight Bladder Cancer worked directly with hospitals, local community groups and patient organisations to understand real communication needs more accurately. They also explored cultural attitudes to bladder cancer, including stigma around urological symptoms and fears about seeking help. These insights informed a more inclusive approach to both translation and outreach.

By strengthening cultural awareness among healthcare staff, improving the relevance of translated materials, and building relationships with community partners, the charity has strengthened trust, improved engagement, and ensured better support for underrepresented communities affected by bladder cancer. Their work demonstrates how listening to patients, challenging assumptions and designing communication with communities can reduce inequalities in cancer pathways.

Find out more about Fight Bladder Cancer.

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fight bladder CANCER

Improving early diagnosis of ovarian cancer

Target Ovarian Cancer

The This Van Can roadshow was created to improve early diagnosis of ovarian cancer across Greater Manchester, where rates of late-stage diagnosis remain higher than the national average. This award-winning initiative was a partnership between Target Ovarian Cancer, the Dianne Oxberry Trust, and the Greater Manchester Cancer Alliance, and ran from February to April 2025.

Using local data, the team identified neighbourhoods with high rates of late-stage ovarian cancer and deployed a mobile outreach van to meet people where they are: in supermarkets, shopping centres, and other high-footfall locations across all ten Greater Manchester boroughs. The van offered a wide range of interactive and educational resources, including symptom diaries, information leaflets, quizzes, true-or-false games, model ovaries, and videos. Visitors could also have one-to-one conversations with friendly staff to better understand the symptoms of ovarian cancer and discuss when to contact their GP.

The project reached 8,296 people, including 1,888 high-level interactions where participants engaged in in-depth discussions or completed detailed surveys. Social media activity extended the project's reach to over 1.1 million impressions, and local media coverage amplified awareness further.

Local partners praised the initiative as one of their most effective collaborations, noting its innovative combination of data-driven targeting, community engagement, and charity-clinician partnerships. Understanding of ovarian cancer symptoms among participants rose dramatically, from an average score of 2.6/10 before engagement to 9.8/10 afterwards. The van also provided guidance on risk factors, such as family history and age, helping participants understand their personal risk.

The project demonstrated the value of meeting people where they are, using evidence to focus efforts, and combining expertise across sectors. Initiatives like This Van Can empowers communities with knowledge that can save lives through earlier diagnosis.

Find out more about Target Ovarian Cancer.

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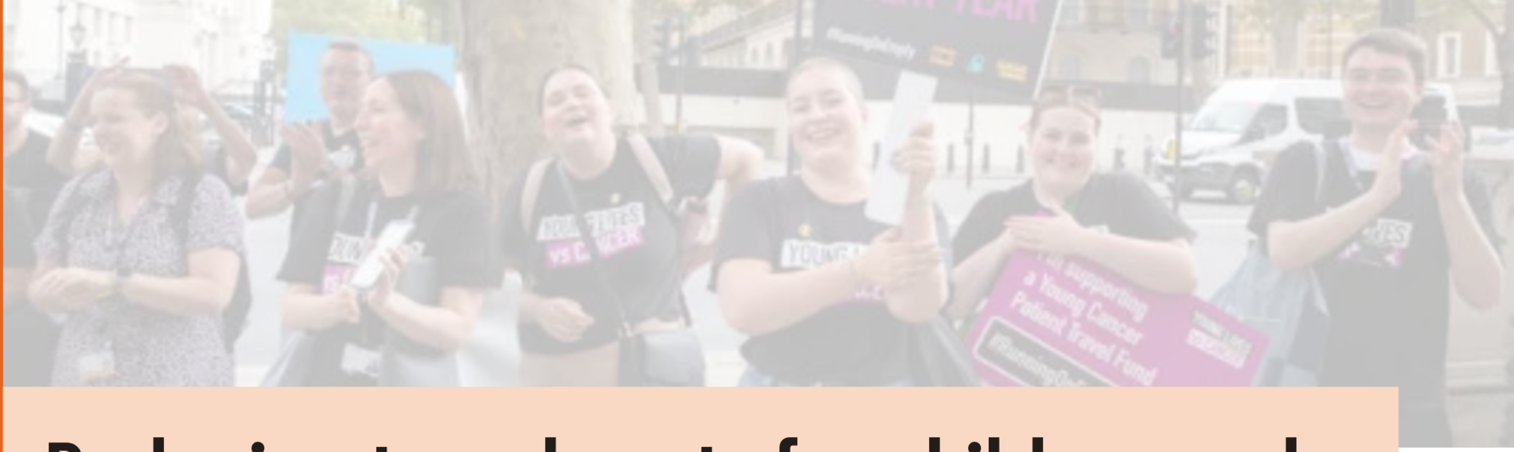
Target Ovarian Cancer



Reducing travel costs for children and young people's cancer treatment

Young Lives vs Cancer

For many children and young people with cancer, specialist treatment is only available far from home, often requiring families to travel hundreds of miles each month. These journeys bring significant costs for transport, parking, accommodation, and food, which can push households into financial strain. Young Lives vs Cancer's research shows that children and young people face, on average, double the travel burden experienced by adults with cancer, with one in ten missing or delaying treatment due to travel costs.

To understand the impact, the charity spoke directly with hundreds of young people and their families. They heard stories of missed appointments, mounting debt, emotional strain, and the feeling that cancer had taken over every aspect of life. Vic, a 21-year-old lymphoma patient from the Isle of Wight, described spending up to £80 per day traveling to Southampton for treatment, leaving little money for food or daily essentials.

Through these conversations, the charity highlighted not just the financial costs, but the emotional and practical impact on young patients.

Young people were actively involved in shaping Young Lives vs Cancer's #RunningOnEmpty campaign, sharing their experiences publicly, and participating in petitions and events, including delivering over 11,500 signatures to 10 Downing Street. Their voices made clear that travel burdens affect wellbeing, education, social life, and family stability.

The #RunningOnEmpty campaign illustrates the power of directly centring young people's experiences. By listening to their voices, Young Lives vs Cancer has been able to advocate for a Young Cancer Patient Travel Fund, designed to ensure that no child or young person has to miss treatment due to travel costs. The project demonstrates the importance of embedding lived experience at the heart of healthcare advocacy and the transformative impact of youth-led engagement in driving change.

Find out more about Young Lives vs Cancer.