ECONOMIST IMPACT

Beyond survival

Shifting the focus to living well with cancer and beyond

Supported by Pfizer

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Contents

About this report

Recognising the need for a holistic, patient-centred approach to cancer, Economist Impact examined the state of cancer care in Europe, with a particular focus on France, Germany and the UK, and sought to redefine how success in cancer care is measured.

From survival to survivorship: shifting the focus to living well with cancer and beyond discusses opportunities for improving cancer care in Europe by shifting the focus from survival to survivorship. The report focuses on Economist Impact's North Star Framework (Appendix A), a new tool for measuring success in cancer care, highlighting six key aspects of the Framework that are often overlooked in national cancer control plans.

This analysis brings together findings from a series of research components including an in-depth literature review and desk research, expert interviews, and a series of surveys and country workshops. Alongside the report is a methodology note (Appendix B) that describes the research approach and North Star Framework in greater detail.

The Economist Impact team would like to thank the following individuals (listed alphabetically) for generously contributing their time and insights, which have been critical to the creation of this report:

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Executive summary

The overall incidence of cancer is increasing in Europe, but advances in cancer care mean that more people are surviving and living longer. Over two-thirds of cancer patients live more than five years beyond their diagnosis, and Europe has over 23.7m cancer survivors.[1] Yet already, the continent's cancer control efforts are falling short, with delays and unmet needs reported from diagnosis through to post-treatment follow up.[2] At the same time, our research suggests that non-medical aspects of cancer care and support, such as economic security and mental health, remain under-supported.

Countries' national cancer control plans (NCCPs) need to evolve to tackle the growing and changing disease burden. Although existing plans rightly emphasise service provision from detection through treatment, they do not always consider the full spectrum of patient needs. Expanding NCCPs to fully encompass survivorship—the mental, physical, social and emotional health of individuals from the time of cancer diagnosis through the balance of their lives—is key to improving the patient experience and enabling individuals to live well with and beyond cancer.

This Economist Impact report presents the outcomes of a programme of research focused on uncovering the key components of a survivorship-centric approach to cancer care, focusing on Europe. The research included a literature review, expert workshops and interviews, and surveys of patients, healthcare professionals (HCPs) and the general public from France, Germany, Spain and the UK.

The findings informed the development of a North Star Framework of metrics that redefines how we measure success in cancer care—shifting the focus from solely survival to survivorship—while keeping patients at the centre. Together, the framework and this report provide key metrics and concepts that can be embedded in NCCPs to strengthen their focus on survivorship and improve patient experience and ability to live well with cancer and beyond.

Key areas of opportunity identified in the North Star Framework include:

Tailoring information to individual needs
Information is a crucial weapon in the fight against cancer, but provision is often limited or unevenly available. Timely action from the public and patients is critical to preventing and overcoming cancer, but this action depends on having the right information available

when a person needs it and in a format that is easy to interpret. In our survey, only 62% of respondents from the general public reported that they have access to useful and trustworthy information about risk factors for cancer and screenings, while 55% reported having access to useful and trustworthy information about cancer care. Understanding cancer risk factors and knowing which symptoms to watch out for and what services are available are critical to reducing cancer risk and early cancer detection.

Ensuring robust provision of psychosocial support

Psychosocial support is a critical part of cancer survivorship but provision is uneven, and not all healthcare professionals receive adequate training in this area. In our survey, four in ten people living with cancer reported their mental health as "poor" or "very poor", yet one-third of HCPs reported receiving no training in mental health. Experts also caution that psychosocial service provision is falling short—which may be due to the lack of clear and standardised guidelines around psychosocial care for cancer patients at the EU level, including the need to ensure that specialised mental health professionals are part of multidisciplinary teams. Enshrining robust psychosocial support in NCCPs and regional guidance documents can help to ensure that patients receive the support they need.

Providing financial and economic support

Financial and economic worries related to cancer are also significant, with 25% of the general public from our survey reporting concerns that their current health coverage would not be sufficient to cover their costs in the event of a cancer diagnosis.[i] Health systems can support patients with these and other psychosocial concerns by ensuring that patients are connected with relevant resources, patient advocacy groups (PAGs) and charities. More broadly, governments need to ensure non-discrimination for cancer survivors in relevant financial and labour market regulations using legislation such as the "right to be forgotten" at the end of a specified period after the conclusion of treatment.

Focusing on healthcare workforce training to improve patient-centred care

The majority of HCPs in our survey reported that they had adequate survivorship-related training in critical areas like pain management, but training in other areas was less common. Less than half (41%) had training in sexual and reproductive care considerations, and around the same proportion (38%) have received training in the use of shared decision-making frameworks. Only 14% had training in using patient decision aids that can help patients to better understand their options and participate actively in healthcare choices. The healthcare workforce needs greater training in topics and tools such as these that can facilitate shared decision-making and holistic patient-centred care.

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[i] In response to Economist Impact survey question, "How confident are you that your health coverage would sufficiently support you (ie, cover costs) if you develop cancer?"

Prioritising equity

Socioeconomic factors, including race, ethnicity, gender and rural versus urban residence can all cause measurable disparities in cancer care, treatment provision and access to survivorship care. Lifestyle risk factors such as smoking, poor diet, alcohol consumption and lack of physical activity are more prevalent in those from lower socioeconomic backgrounds. After a cancer diagnosis, marginalised communities are more likely to face obstacles such as a lack of access to specialist treatment facilities. Similarly, stigma and discrimination mean that some patient groups, including older adults and those with learning disabilities, are less likely to be considered for certain treatments. Inequities in access to diagnostic technology and treatment options also contribute to disparities in outcomes. NCCPs must account for the profound impact of socioeconomic background to meaningfully reduce cancer risk and improve the care experience and outcomes for all people living with cancer.

Improving data collection, monitoring and evaluation

Robust data is essential for identifying gaps and discontinuities in cancer care. Improving survivorship is an ambitious but necessary task that requires consistent monitoring and evaluation. To identify where existing services fall short, health systems and governments need to capture, analyse and act on robust data. Improving data collection requires dedicated funding and provisions for monitoring and evaluation in NCCPs, as well as inter-operability across different data collection platforms. Better tracking and understanding of patient experiences and outcomes throughout the cancer journey and across disciplinary silos will be critical to continuing to improve cancer care across Europe.

Introduction

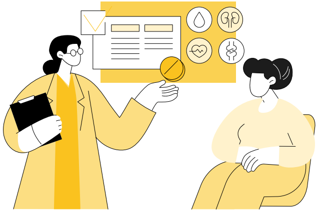
The incidence of cancer is increasing, and Europe is disproportionately affected by the growing burden.[3,7] Europe, although home to just under 10% of the world's population, accounted for 22% of global cancer cases and 20% of deaths in 2022.[4] Concerning trends are emerging: more than one in four people in many European countries will face a cancer diagnosis by the age of 75,[5] and the incidence of some cancers, including colorectal cancer, is rising among younger adults.[6]

However, thanks to earlier detection and better treatments, cancer death rates are decreasing in most European nations.[5,7] By 2020, an estimated 14.9m people in Europe had been living more than five years after a cancer diagnosis, with a total of 23.7m cancer survivors across the continent (approximately 5% of the population).[1] With more people living longer with cancer, there is a growing need to support people to live the best possible lives from the point of diagnosis onwards—that is, focusing on survivorship rather than solely survival.

> **"Cancer represents the top expenditure for the French National Health Insurance, amounting to €22.6bn [US$26.4bn], well ahead of cardiovascular diseases (€19.4bn), mental health (€17.5bn) and diabetes (€9.6bn). The exponentially rising costs of cancer care compel us to rethink our current models, especially in the context of escalating therapeutic costs."**
>
> **Benjamin Gandouet**, Director General, Prevention and Screening, Nouvelle Aquitaine

DEFINING SURVIVORSHIP

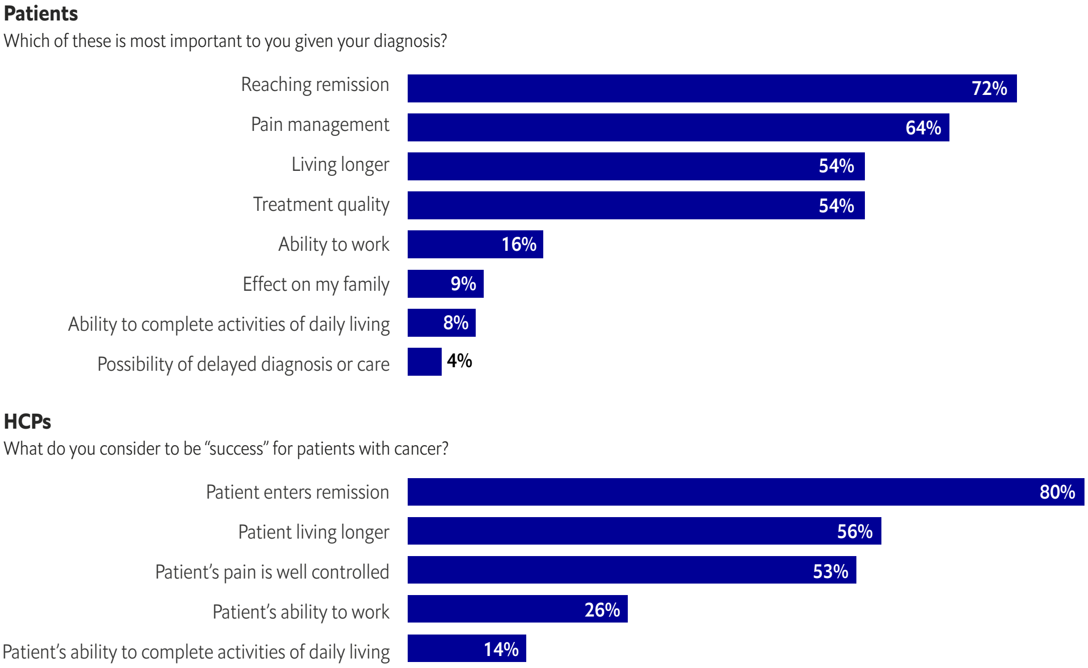
Different definitions of survivorship exist, with some using the term to refer to the period after diagnosis and others using it to refer to the period after a person has survived a specific amount of time without active disease.[8] In order to take a holistic perspective, in this report, we define survivorship as the mental, physical, social and emotional health of individuals from the time of cancer diagnosis through the balance of their lives. Similarly broad definitions have also been adopted by other organisations.[9,10] Looking at cancer care through a survivorship lens entails taking a more comprehensive view of how effectively health systems and society support patients at every stage in their journey.



> **"Survivorship means different things to different people. It is important to ask the kind of support that people need going forward."**
>
> **Sonali Johnson**, Head of Knowledge, Advocacy and Policy, Union for International Cancer Control (UICC)

Surviving cancer is widely considered the primary goal in cancer care. This is understandable given the historical perception of cancer as a "death sentence". "Too many people still are totally terrified of the word cancer and we need to change that conversation," says Geoffrey Bellingan, Medical Director of Surgery and Cancer at University College London Hospitals. Findings from our surveys reflect this[ii]: when asked about markers of success during cancer treatment, both remission and survival were among patients' and healthcare professionals' (HCPs) top three measures (Figure 1). Yet, a patient's ability to live well with and beyond cancer is also important. Other factors, such as pain management and treatment quality, are also priorities for patients and HCPs—and these are key to both survival and living well.

Figure 1: Priorities in cancer care



Source: Economist Impact analysis

[ii] For more information, see *Survey methodology* on pg 11

> **“Cancer survivorship is often overlooked in policy and research.”**
>
> **Mark Lawler**, Chair, International Cancer Benchmarking Partnership; Professor of Digital Health, Queen’s University Belfast

SURVEY METHODOLOGY

To better understand the current state of cancer care in Europe, we conducted a series of surveys in four European countries (France, Germany, Spain and the UK). In total, the survey populations included:

- 2,201 people from the general population
- 400 people living with cancer
- 410 healthcare professionals (HCPs) who reported working with cancer patients at least 50% of the time.

The surveys were conducted between November and December 2024 and completed anonymously online and via computer-assisted telephone interviewing. Survey participants were selected to reflect the demographics of the countries they represented (for example, age groups, education level, urban versus rural residency).

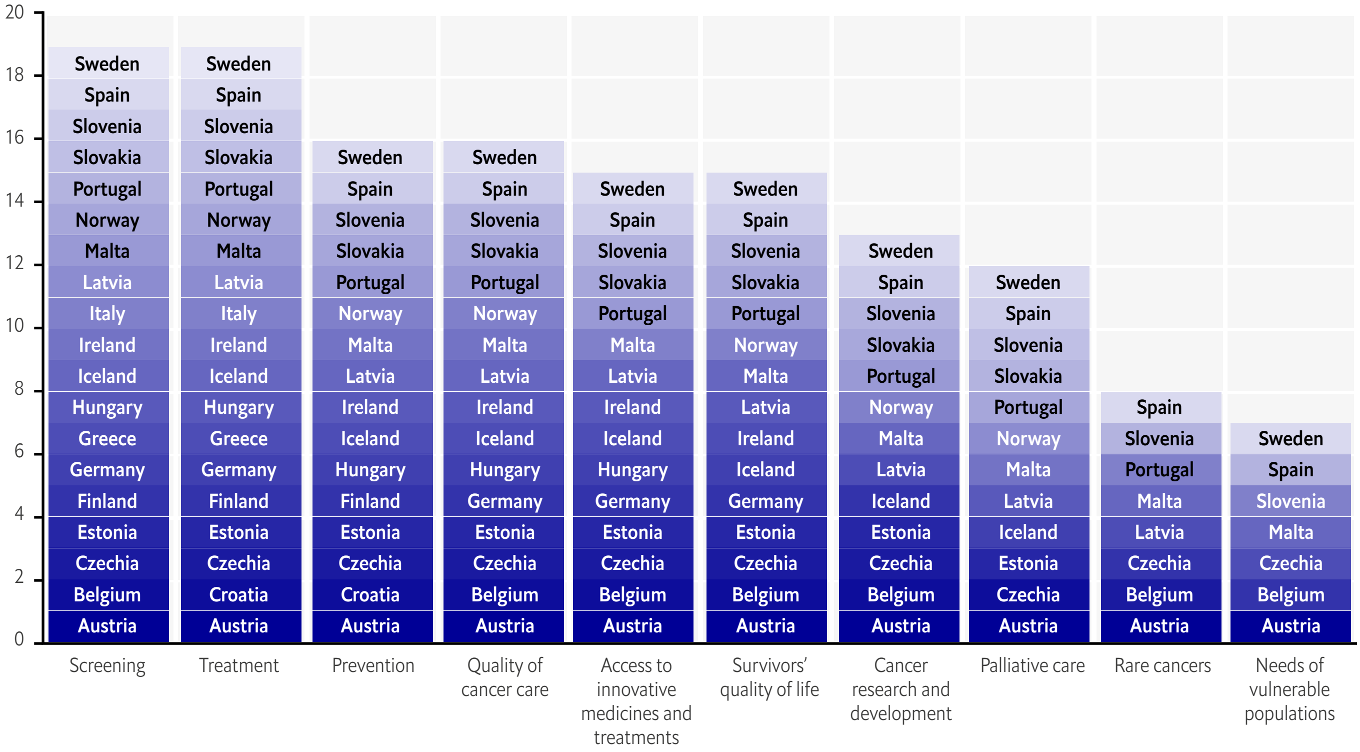
While efforts to reduce cancer cases and deaths through risk factor reduction, early detection and innovative treatments continue, more work is needed to elevate survivorship as a key objective for cancer care. “If we change the discussion to look at survivorship, people are better able to engage more sensibly in things like seeking help for symptoms,” says Gordon Wishart, Chief Medical Officer of Check4Cancer, a private provider of cancer screening, tests and diagnostics. “Survivorship is something we have to think much more widely about and improve.”

The role of national cancer control plans

National cancer control plans (NCCPs) lay out how health systems will tackle cancer, with the aim of reducing cases and deaths and improving patients’ quality of life.[11,12] However, not all countries have an NCCP; where NCCPs exist they do not often highlight the importance of survivorship, and many under-emphasise the importance of holistic, supportive care and patient-centricity.[7,13,14] For example, although NCCPs are in place in 25 of the 29 ‘EU+2’ (Norway and Iceland) countries, quality of life among survivors and the needs of vulnerable groups are less commonly covered than areas such as screening, treatment, prevention and quality of care (Figure 2).[7] An analysis of global cancer plans similarly identified that only around half of the plans include strategies for survivorship care and rehabilitation after treatment completion.[14]

Figure 2: Cancer care pathways included in NCCPs (selected countries)[7]

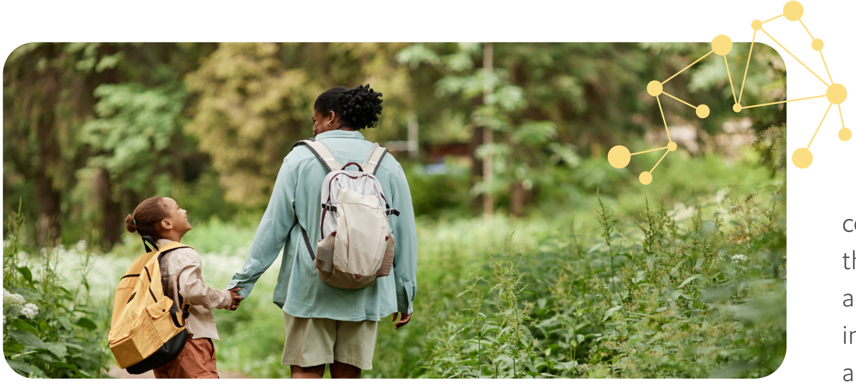
Number of countries



Source: OECD. Beating cancer inequalities in the EU: spotlight on cancer prevention and early detection 2024. Paris: Organisation for Economic Co-operation and Development. Available from: https://www.oecd.org/en/publications/beating-cancer-inequalities-in-the-eu_14fdc89a-en.html.

It is important that NCCPs take a survivorship-based, holistic approach to supporting cancer patients, as challenges such as financial discrimination, difficulty re-entering the labour market or reduction in earning capacity, and the psychological toll of cancer can have a significant impact, even for patients who recover successfully.[15,16,17,18,19] Health systems need robust metrics to understand not only clinical outcomes but also how patients are faring throughout the cancer journey across the multiple dimensions of their lives that are impacted by the disease. Despite growing awareness of these wider patient needs, Sonali Johnson, Head of Knowledge, Advocacy and Policy at the Union for International Cancer Control (UICC), flags that "cancer is still being treated predominantly as a medical issue".

However, addressing survivorship in NCCPs is just the starting point. Sufficient political will and support to successfully implement and maintain these plans is critical. The plans must be adequately funded and accompanied by sufficient guidance and support for healthcare providers and other stakeholders, as well as provision for monitoring and evaluation. Provisions for the latter, in particular, are integral to the success of NCCPs because they ensure that strategies are effectively implemented, goals are being met and resources are used effectively. Global leaders in cancer control, such as the UICC and the European Cancer Organisation, have highlighted the value of monitoring and evaluation in strengthening the overall impact of cancer control efforts by promoting continuous improvement and informed decision-making.[20,21] Through systematic data collection and analysis, monitoring and evaluation enables health systems to track progress and identify gaps or disparities in service delivery.[22,23] When tracking progress, understanding what success looks like is critical.



> **“Patients need balance. Health is not just the absence of disease. We need to look at psychological, emotional, social, sexual, environmental and cultural health too.”**
>
> **Alain Toledano**, Oncologist; President, Institut Rafaël

The North Star Framework

Survival measures, including overall survival, disease-free survival and progression-free survival, have long been key measures of success in cancer care.[24,25] Yet, as survival rates increase, there is a growing recognition of the need for more holistic and patient-centred metrics that reflect longevity, wellbeing, mental health, social and emotional support, and more.[26]

Our North Star Framework aims to transform how we think about and measure success in cancer care—shifting the focus from solely survival to survivorship—while keeping patients at the centre. The framework is not intended to reimagine or replace NCCPs, but rather redefine what success looks like in cancer care by providing key metrics and concepts that can be embedded in NCCPs to improve implementation and support for individuals with cancer and their families.

By integrating real-world insights and diverse stakeholder perspectives, the North Star Framework highlights key indicators for progress across the entire cancer journey, from prevention to end of life. Most importantly, the North Star Framework keeps patients at the centre by reimagining success in cancer care through the lens of survivorship. It’s not just about treating disease—it’s about empowering individuals to live well. This patient-first approach drives the framework’s vision for holistic, person-centred and equitable care across Europe.

Figure 3 provides a high-level summary of the framework, which includes two primary components:

1. **The cancer continuum**

   The North Star Framework assesses progress across the entire cancer care continuum—from prevention to end-of-life care. This portion of the framework includes seven domains that are key to holistic cancer care, from access to care through to financial support and more, providing a blueprint for comprehensively measuring success.

   We begin with prevention, acknowledging that the lead up to and timeliness of diagnosis may have an impact on outcomes and, therefore, survivorship.[27,28] The framework then follows the cancer journey through diagnosis, treatment and follow-up, the period beyond cancer (that is, after active treatment and initial follow-up are completed), and end-of-life care for those who need it.

2. **Enabling features**

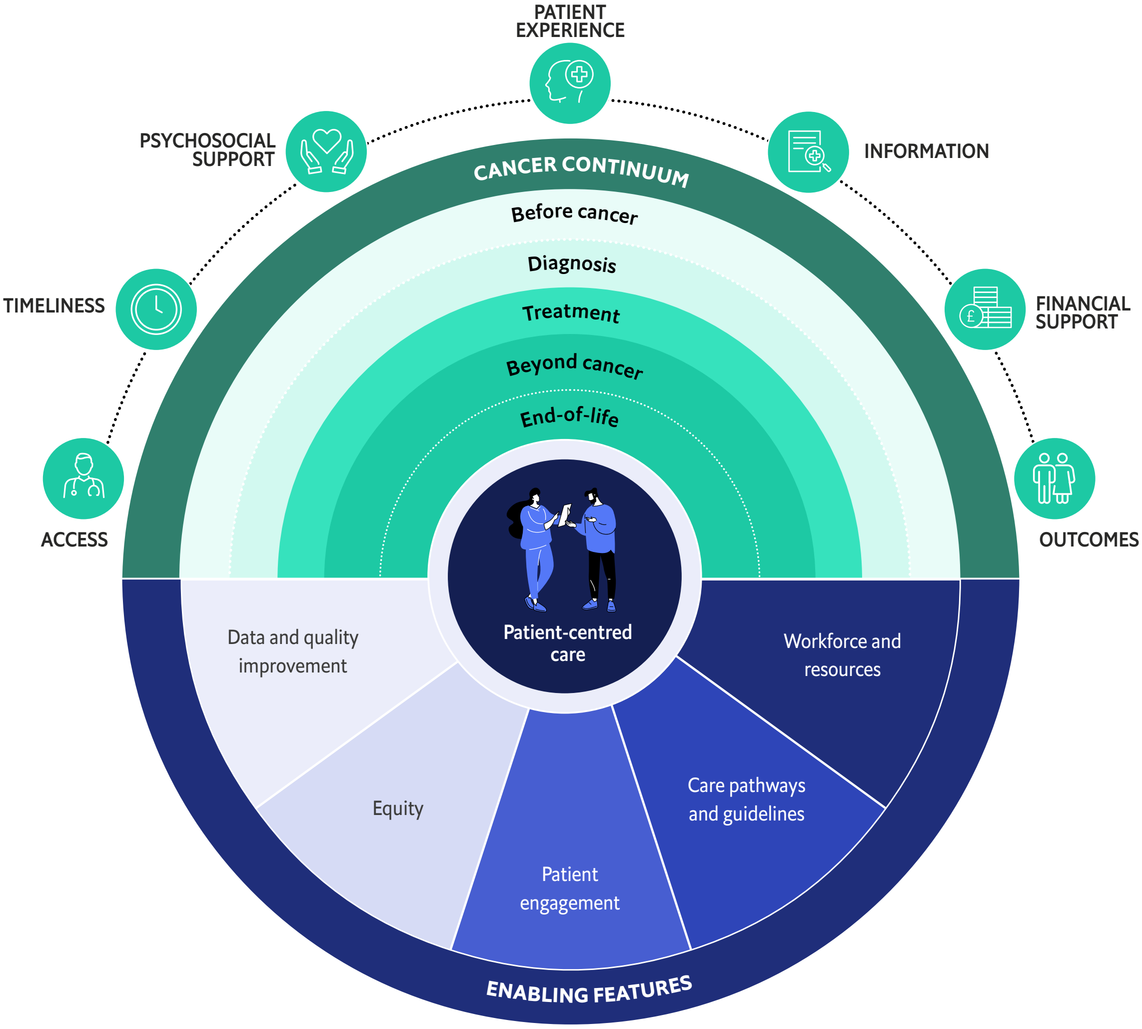
   We refer to the framework’s cross-cutting themes as **enabling features**—these characteristics are important throughout the cancer continuum and underpin the delivery of successful cancer care.

For full information about the metrics that make up the North Star Framework across the cancer continuum and enabling features, please see Appendix A. Details about the creation of the North Star Framework are contained in Appendix B.

Persistent gaps remain in delivering truly holistic, equitable and patient-centred cancer care. While some of the North Star Framework domains, such as ***access*** and ***timeliness***, have garnered considerable research and policy attention, other critical aspects of holistic care remain under-explored and under-emphasised.[14] This report shines a light on three domains that are central to how individuals experience the cancer journey but are often overlooked: ***information*** provision, ***psychosocial support***, and ***financial support***.

We also focus on three notable enabling features: ***workforce and resources***, ***equity,*** and ***data for quality improvement***. Although these components of The North Star Framework are not necessarily more important than the others, they are areas where guidance is fragmented and the potential for impact is high. By focusing on these specific components in our report, we seek to encourage more comprehensive and patient-centric support for individuals living with cancer.

Figure 3: Summary of the North Star Framework

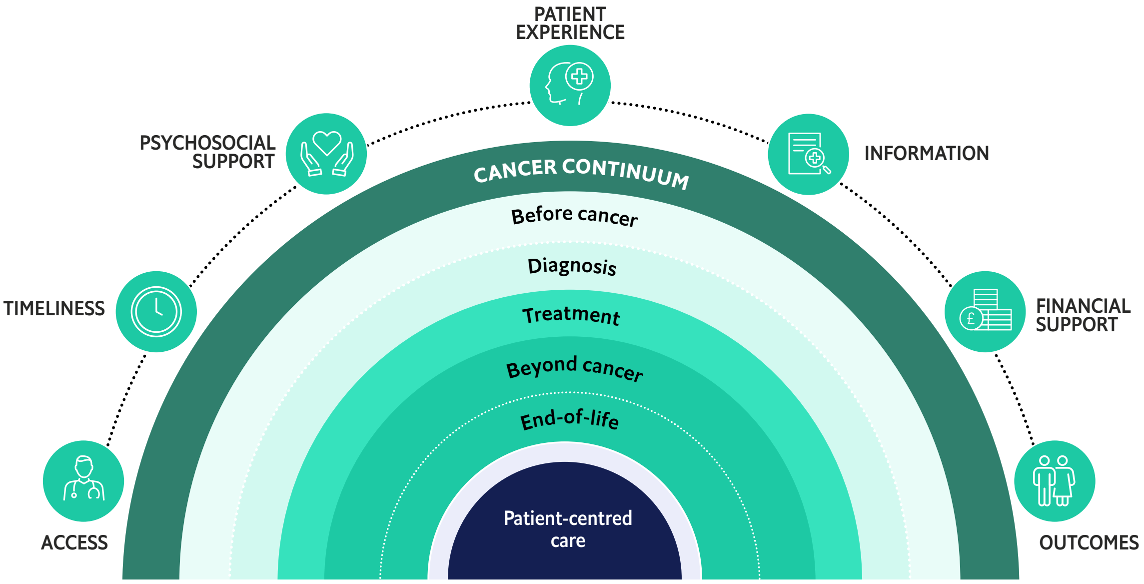


Source: Economist Impact analysis

Across the cancer continuum

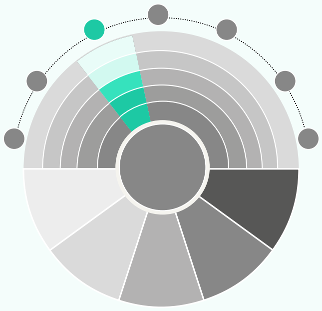
Addressing patient needs across the cancer care continuum—from before cancer[iii] to end-of-life care—demands a comprehensive, patient-centred approach that extends beyond clinical treatment. Key metrics are contained within the seven domains that surround the cancer continuum (Figure 4). While all seven domains of metrics are key to success in cancer, three domains focus on wider dimensions that are often overlooked in NCCPs: ***information***, ***psychosocial support*** and ***financial support***. Collectively, these domains move beyond traditional medical care and outcomes to promote a more holistic, patient-centred view of care across the cancer continuum that prioritises not only survival but also broader wellbeing.

North Star Framework: Cancer Continuum



[iii] "Before cancer" includes prevention, screening and provision of information about cancer risk. See Appendix B: Methodology for more information

Psychosocial support



Providing support that addresses the mental, emotional, social and spiritual needs of individuals with cancer and their families, such as counselling, support groups or education

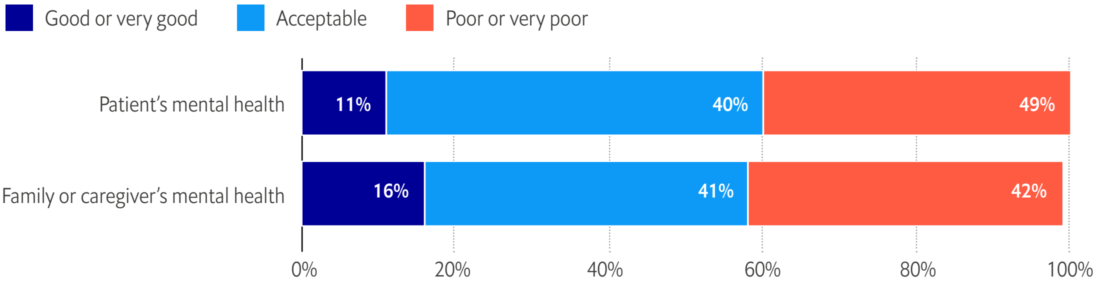
The North Star Framework's ***psychosocial support*** domain addresses the often-overlooked emotional and social dimensions of cancer care. Mental health and familial or social support structures profoundly impact how patients cope with a diagnosis, manage their treatment, and transition to survivorship.[29] This domain highlights the need for structured interventions, such as counselling, peer support groups, educational workshops and caregiver assistance. Psychosocial support can help to mitigate feelings of anxiety and depression, encourage treatment adherence, and positively impact quality of life.[30] When embedded in cancer care systems, it ensures that patients are treated not just for their disease but as whole individuals whose psychological and social wellbeing is integral to survivorship.

To be truly comprehensive, cancer care must go beyond treating the disease to encompass broader factors that enable patients to thrive. In the workshops and interviews with experts that were part of this research programme, psychosocial care was among the survivorship domains identified as both critical and under-supported. The framework emphasises the need for timely access to appropriate psychosocial resources and support at every juncture, from the point of receiving screening results or referral for diagnostic investigation, through the diagnostic process, during and after treatment, and into longer-term survivorship or end-of-life care. "Effective cancer care must go beyond tumour-targeted treatments," says Nina Fuller-Shavel, a physician and CEO of the National Centre for Integrative Oncology, a charity that aims to improve equitable access to integrative oncology support in the UK. "It should address the overall wellbeing of patients including quality of life, symptom management, nutrition, physical rehabilitation and psychological support."

A cancer diagnosis can be a stressful experience, evoking fear, shock, anxiety, cognitive problems and coping challenges, and interfering with social relationships, disrupting all dimensions of their life.[31,32] Four out of ten cancer patients in our survey rated their own mental health as poor or very poor, while a similar proportion (42%) reported that a family member or caregiver's mental health was poor or very poor (Figure 4).

Figure 4: Patient and caregiver mental health

How would you rate your mental health during your cancer treatment? How would you rate your family or caregiver's mental health during your treatment?



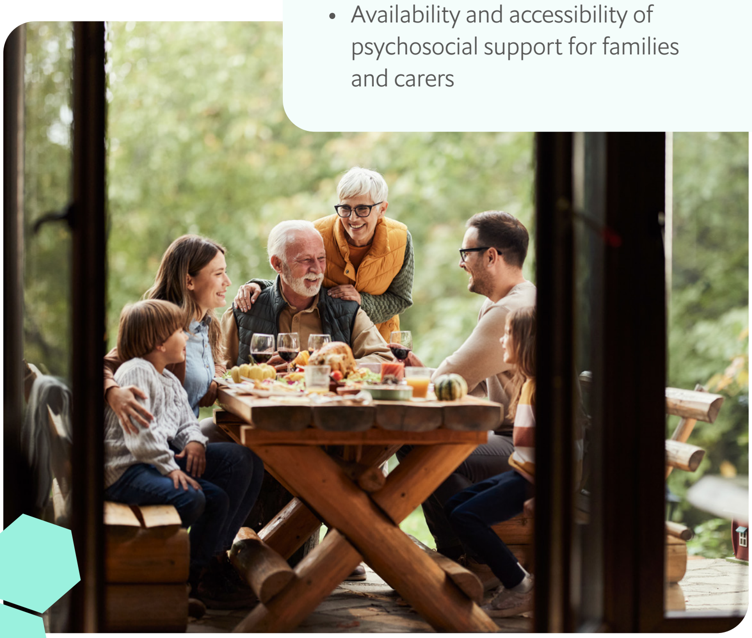
Source: Economist Impact survey

Having cancer heightens the risk of developing mental health disorders such as depression and anxiety in people with no history of mental ill health, while those with previous psychiatric history may be at greater risk of mortality.[33,34] The reasons why poor mental health may negatively affect cancer outcomes vary; they include both biological impacts such as hampered immune responses as well as negative impacts on lifestyle or health-seeking behaviours, including the ability to engage with available care and support.

Key metrics within the *psychosocial support* domain

- Assessment of psychosocial needs (eg, mental, emotional, social and spiritual)
- Availability and accessibility of psychosocial care and support for the patient
- Waiting times for psychosocial care and support
- Availability and accessibility of networks of support and community groups
- Availability and accessibility of psychosocial support for families and carers

> **"If you leave a patient in fear, you have not treated them. You have to enable them to be mentally, physically and socially well."**
>
> **Alberto Costa**, Scientific Adviser of the Former Commissioner, European Union Commission for Health and Food Safety



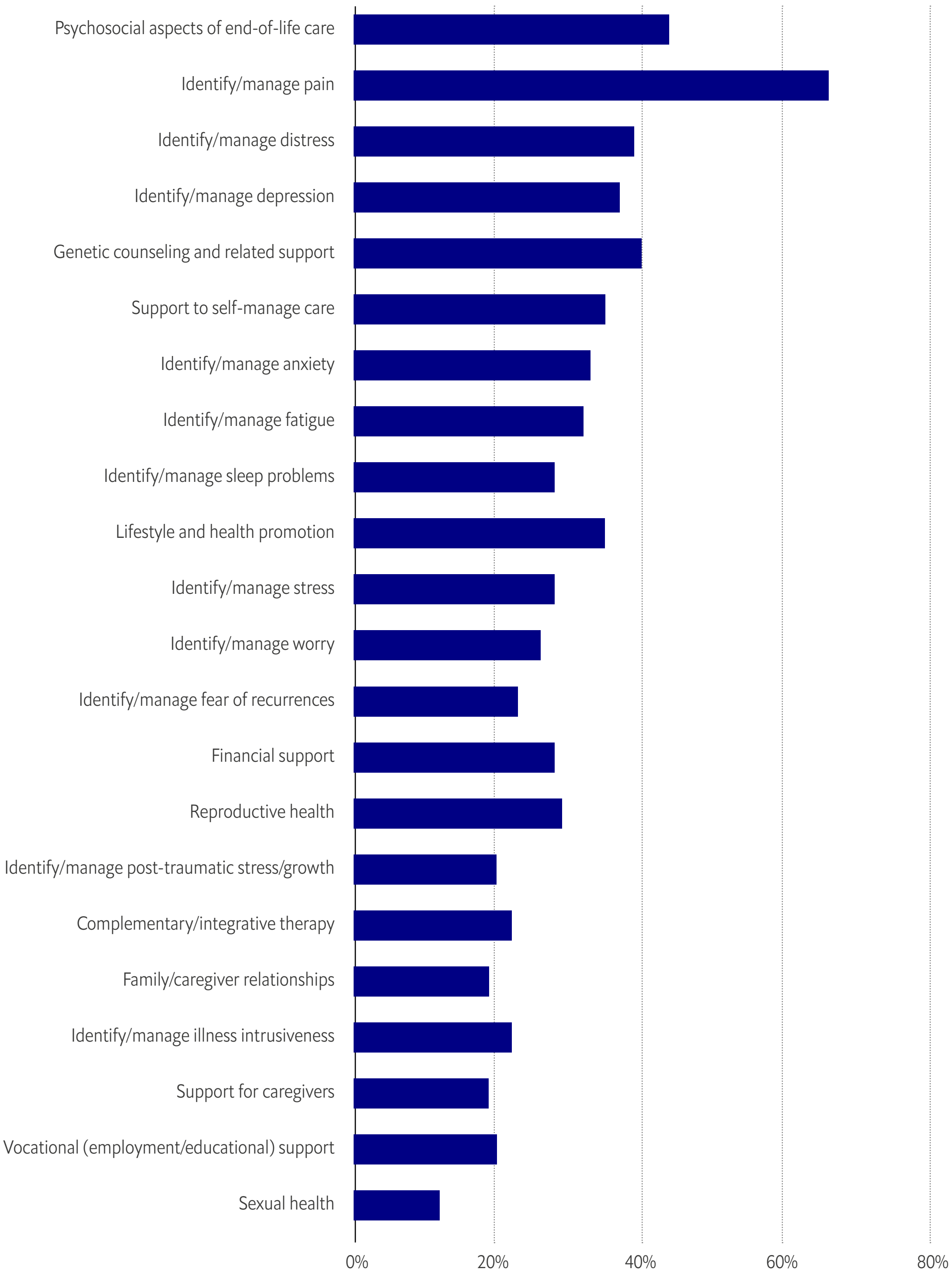
Psychological responses tend to be overlooked during cancer care planning, despite their importance for survivorship. "No one ever talks about a perfectly normal side effect, which is you're going to be feeling pretty low emotionally and psychologically as a result of what you're going through," says Barbara Wilson, the founder and director of Working with Cancer, a social enterprise focused on driving knowledge around cancer in the workplace. "Fearing for your life as a result of a cancer diagnosis is a perfectly rational response." Psychosocial consequences may also differ across cancer types. Patients with breast cancer, for instance, may have additional needs related to interpersonal relationships and intimacy.[35] People who fully physically recover may continue to experience psychological impacts, such as survivor's guilt from outliving fellow patients and anxiety about recurrence.

Psychosocial care in oncology aims to reduce distress caused by a cancer diagnosis and treatment while providing patients the skills to cope with the demands and uncertainties of the disease. Despite the prevalence of mental health challenges, it remains under-provisioned in training: 31% of HCPs in our survey reported not receiving any training in mental health.

An international, 37-country survey of HCPs and researchers in psycho-oncology across high-, middle- and low-income countries (HICs and LMICs) found that less than 40% reported routine inclusion of psychosocial or supportive care in post-treatment follow-up in their country, a figure that was similar across country income groupings. The most common post-treatment psychosocial services available were for psychosocial aspects of end-of-life care and the identification/assessment and management of pain. The least commonly available services reported were vocational (ie, employment and educational) support and sexual health (Figure 5).[36]

Figure 5: International provision of post-treatment psychosocial services in HICs[36]

Percentage of respondents from HICs reporting availability of psychosocial and supportive care services



"The psychological impact of cancer is largely either not understood or most people don't even know it exists," says Ms Wilson. "Most people still see cancer as a physical illness." According to Dr Fuller-Shavel, patients may receive only generic leaflets rather than individualised support, and there is a lack of timely psychological and supportive care. Psycho-oncology services can have wait times of up to six months or more, which is inadequate for patients facing immediate challenges, particularly those with metastatic cancer, she adds.

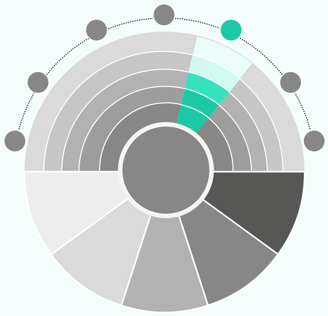
Patients' psychosocial needs do not only arise post-treatment. "I've spoken to a lot of patients who will say to me that they need [psychological care] at the beginning," says Dany Bell, Strategic Adviser for Cancer Care at Macmillan Cancer Support. "It's not something that should come afterwards. It should be there at the beginning and you should be able to access it when you need it."

> **"There is more and more evidence about the importance of psychosocial help for cancer patients, yet there are no clear and standardised guidelines at the European level and within countries. It is left to the goodwill of individual hospitals or clinics."**
>
> **Antonella Cardone**, CEO, Cancer Patients Europe

Among providers, lack of awareness, education and training, as well as time constraints during consultations, are among the causes of the shortfall in psychosocial support. At an institutional level, lack of funding, infrastructure, scientific conferences, education and training activities can limit psychosocial oncology care.[37] Experts also argue for more standardised approaches across the European region. "There is more and more evidence about the importance of psychosocial help for cancer patients, yet there are no clear and standardised guidelines at the European level and within countries," says Antonella Cardone, CEO of Cancer Patients Europe, a pan-European cancer patient association. "It is left to the goodwill of individual hospitals or clinics."

Although standards and guidelines are key, psychosocial support must be individualised; the desire for engagement with psychosocial care, the level of need and preferred format for such support varies widely among survivors. Some patients prefer to 'move on' without continuous reminders of their diagnosis, while others benefit from structured follow-up and peer support networks, according to Dr Johnson from the UICC. What matters is the provision of support for patients and their families, which suits their needs and preferences. "Patients living with cancer need a package of care. This includes active treatment for cancer as well as palliative care services and programmes to address the psychological, social, occupational and economic reintegration of cancer survivors." Caroline Berchet (PhD), Health Economist at the OECD, tells us. Not all of this support has to be provisioned by health systems, and people can be signposted to local support networks and support offered by charities.

Information



Ensuring that clear, comprehensive, accessible and personalised information is provided to empower the public, patients and their families to understand their risks, condition and their management options, participate in decision-making, manage care and navigate services effectively

In the North Star Framework, the ***information*** domain emphasises empowering individuals with clear, comprehensive and contextual knowledge about key cancer topics. Information provision is a critical component of patient-centred care, ensuring that individuals and families have the knowledge that they need to understand risks, navigate the healthcare system and actively participate in their care. Clear, accurate and accessible information is vital to the success of cancer prevention and care across the cancer continuum. However, the type of information individuals need and how it is shared varies by stage of the cancer journey.

Information before cancer

Key metrics within the *information* domain before cancer

Provision of clear, accurate and accessible information about:

- cancer risk
- screening availability and access
- screening tests including possible outcomes
- risk-reduction interventions (eg, HPV vaccinations, quit-smoking interventions) and their impact
- cancer symptoms and what to do if you are experiencing them

Improved health literacy and awareness, facilitated by provision of clear, accurate and accessible information, can help to increase the effectiveness of screening programmes and early detection.[38] The World Health Organization (WHO) considers “empowering and engaging people and communities” and “improving health literacy and reducing cancer stigma” to be the first steps in improving early diagnosis.[38]

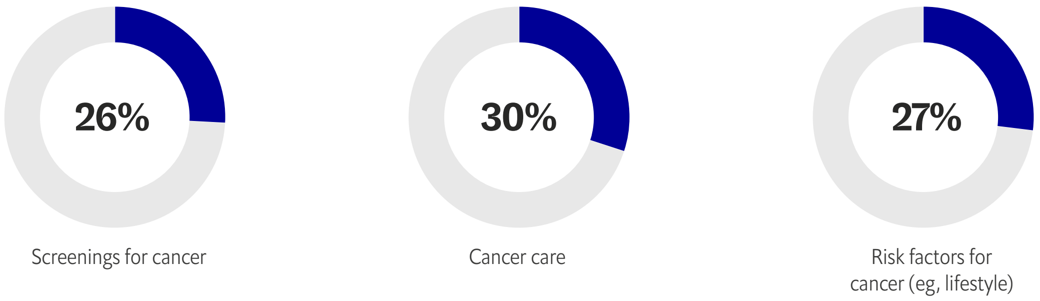
Findings from our survey indicate that many people in Europe do not feel that they have access to useful and trustworthy information about key cancer topics. A substantial proportion of the general public expressed a lack of access to useful and trustworthy information on cancer screening (26%), risk factors for cancer (27%) and cancer care (30%) (Figure 6). In addition, nearly one in five respondents (17%) said that they were unsure whether screening for breast and reproductive cancers (such as cervical cancer) was available in their local communities. For colorectal cancer this figure was higher at 21%, and 31% of respondents were not sure whether lung cancer screening was available in their local communities. The findings for lung cancer screening are perhaps not surprising, given that this type of screening is not yet fully rolled out in most of our survey countries, with most countries only in the piloting stages.[39] Of our countries of focus, only the UK has established a national lung cancer screening programme, with rollout currently underway in England.[39] However, even for established screening programmes such as colorectal, breast and cervical cancer screening a substantial minority were unsure if these programmes were being offered in their area. Overall findings illustrate the need for better promotion of available services and for creation and dissemination of useful and trustworthy information on cancer-related topics.

Dr Wishart explains that some public awareness campaigns—like those for breast cancer—have already been effective in raising the level of awareness in the general population. Other cancers where there is less awareness of what symptoms to look out for, or where there are less definitive symptoms, may be more likely to go undiagnosed for longer as members of the public delay seeking advice until symptoms worsen. Educating the general population through widespread campaigns can effectively support prevention and early diagnosis for cancer generally. Such initiatives raise public awareness about key signs and symptoms of cancer, encourage timely medical consultations, and inform communities about the availability of local screening services.

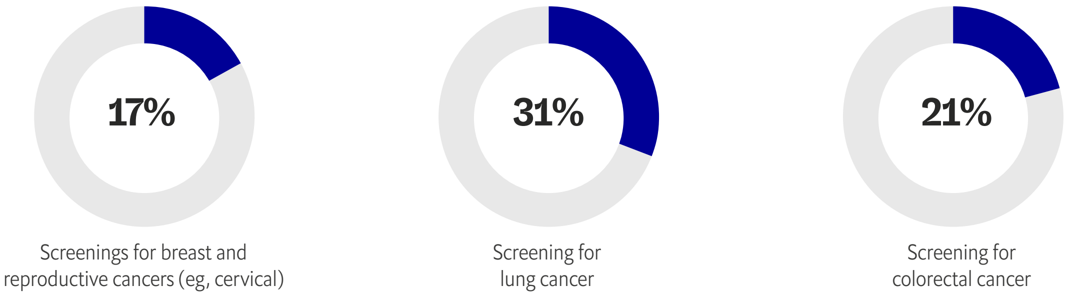
HCPs also play an important role in educating people about cancer, especially people's individual risks. Yet, 60% of European respondents from our general population survey reported that they have never been provided with information about cancer risks tailored to their personal background (such as their family history) by a HCP. Greater awareness of personal risks, the availability and potential benefits of screening for eligible groups, and key symptoms encourage individuals to seek care when needed. This, in turn, boosts the probability of early diagnosis and enhances patient outcomes.[38]

Figure 6: Access to information

Percentage of general public respondents that reports lacking access to useful and trustworthy information regarding:



Percentage of general public respondents who are unsure of the services available in their local community



Source: Economist Impact survey

> **“What might work in one population categorically won’t work in another. But we need to recognise that and tweak the actual approach so as to be culturally aware and ensure culturally-appropriate delivery.”**
>
> **Mark Lawler**, Chair, International Cancer Benchmarking Partnership; Professor of Digital Health, Queen’s University Belfast

Information for care and beyond

Key metrics within the *information* domain during care and beyond

Provision of clear, accurate and accessible information to patients about:

- prognosis
- treatment options and side effects (including the availability of innovative treatments)
- symptoms and symptom management
- self-management
- healthy lifestyle during treatment and follow-up
- routine follow-up processes
- comorbidities

Delivering personalised and easily accessible information emerges as a crucial factor in supporting patients through their care journey—during treatment and beyond. Relevant and accessible information must be available to those who want it. Information can help to empower patients and their families to understand diagnoses and evaluate treatment options. Well-informed patients are better equipped to engage in shared decision-making, which may improve cancer outcomes and quality of life.[40]

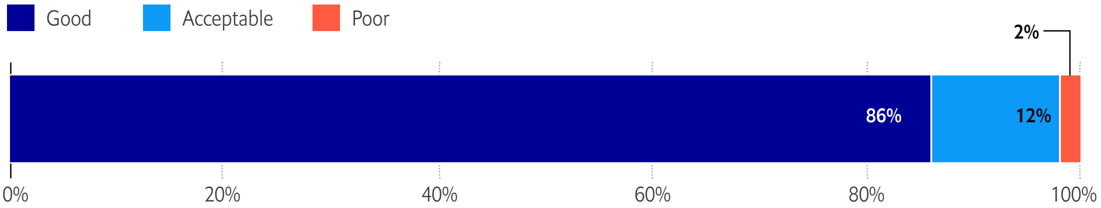
To maximise utility, information for patients must be:

- Easy to understand—using clear, plain language that is tailored to the patient’s literacy and health literacy level, as well as their preferred language.[38]
- Relevant—personalised based on disease stage, patient values and cultural context.[38]
- Available—easily accessible in various formats to suit patient preferences (eg, written, digital, audio).
- Collaborative—patients must be provided with opportunities to ask questions and receive clarifications.[41]

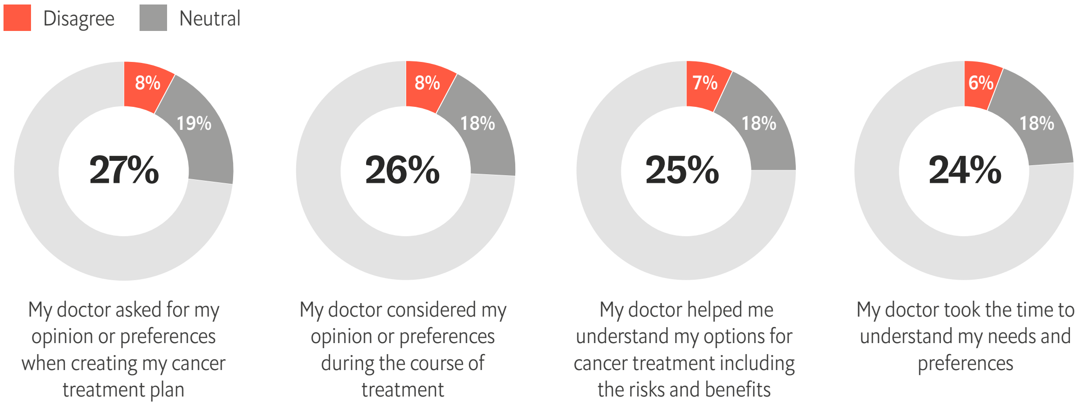
Good communication with HCPs is key to the success of shared-decision making efforts.[42] Although patients in our survey generally reported good relationships with their HCPs, some felt that HCPs could take more time to listen to their needs and preferences, consider their opinions, and help them to understand their treatment options (Figure 7). Ultimately, fostering a more patient-centred communication environment will lead to enhanced trust, improved treatment outcomes and a more positive healthcare experience overall.

Figure 7: Patient-provider relationships

Patient ratings on their HCP-patient relationship

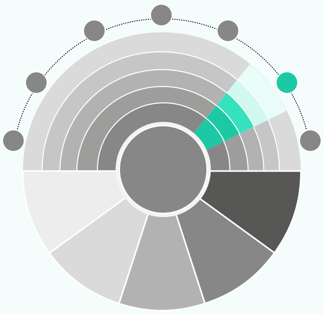


Percentage of patients who did not agree with the following statements or were neutral



Source: Economist Impact survey

Financial support



Providing the resources, services and support necessary to help patients and their families manage the direct and indirect costs of cancer care, to ensure that all individuals can access the care that they need without incurring financial hardship

Cancer care often imposes significant financial burdens on individuals and families, including direct and indirect costs associated with diagnosis, treatment and living with and beyond cancer. The North Star Framework's ***financial support*** domain calls attention to the need for systemic safeguards that prevent financial toxicity. This domain encourages the implementation of financial support programmes to support patients throughout their cancer journey. Alleviating economic stress enables better access to continuous, high-quality care and can help to prevent patients from choosing between affording care and meeting basic life needs.

Financial toxicity

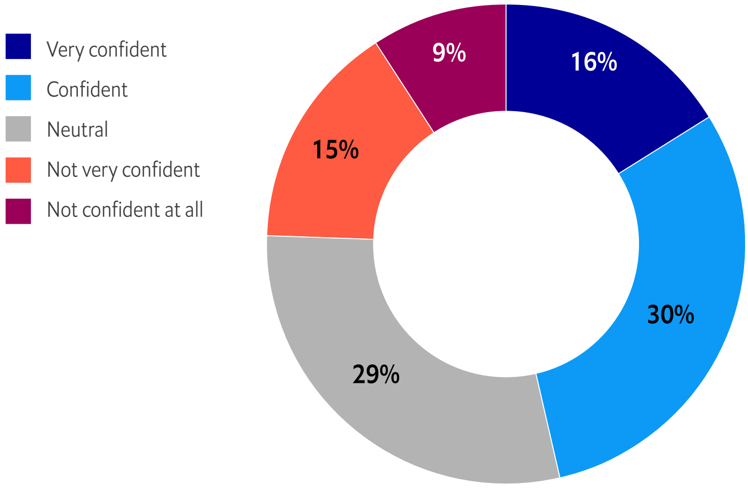
Financial toxicity can be defined as the objective burden and subjective financial distress derived from a cancer diagnosis and treatment.[43] It includes the direct and indirect costs of care to the patient, lack of access to financial support, inability to work or retain work, and exclusion or discrimination from accessing services like insurance or mortgages. All are burdens for patients, caregivers, families and households affected by cancer.

Financial toxicity can affect those who are undergoing treatment as well as those who have been in full remission for an extended period but still face ongoing barriers in accessing financial products and services such as insurance and credit facilities. It can also result from the impact of residual chronic health challenges on a patient's ability to work, and from new costs and uncertainties caused by disease recurrence.[43]

Although cancer is a major concern among the general population and cancer care may be covered by public healthcare systems, our survey found that many Europeans feel that their health coverage would be insufficient to support them if they were to be diagnosed with cancer. A quarter (25%) of the general population respondents in our survey were not very confident or not confident at all that their existing health coverage would sufficiently cover their costs in the event of a cancer diagnosis (Figure 8). In addition, 39% of respondents stated that they definitely or probably would consider purchasing supplemental health insurance to help cover costs of their care.

Figure 8: Cost concerns

How confident are you that your health coverage would sufficiently support you (ie, cover costs) if you develop cancer?



Source: Economist Impact survey

A study of patients in Germany identified that patients with cancer experienced a decrease in job incomes of 26-28% within a year of cancer diagnosis.[44] In another German study, of patients with advanced cancers, 81% reported paying for some care costs out-of-pocket. While monthly out-of-pocket costs were €200 (US$234) or less in 77% of affected patients, income loss was more impactful: of the patients reporting income loss, 24% experienced losses of more than €1,200 (US$1,401) per month.[45]

The Irish Cancer Society found that the average additional spending of a household with cancer is €756 (US$883) per month, which included bills for fuel, parking and meals during hospital visits.[46] A similar study in England reported that 83% of patients face additional costs of £569 (US$769) per month.[47] Although European countries offer universal health coverage, some patients choose to augment state-offered support with private medical coverage.[48,49]

Key metrics within the *financial support* domain

- Costs of treatment and care
- Ability to apply for loans, and other financial services
- Access to financial support (eg, to cover for direct medical costs or indirect costs, including leave from work, transportation, childcare, and so on)
- Insurability
- Ability and right to work as a disabled person without discrimination

Data from 16 trials across Italy, where care is free at the point of use, noted that 23% of participants faced financial toxicity associated with their cancer, and those who declared bankruptcy faced a significantly higher risk of death during follow-up.[50] Financial pressures impact not only individuals but also households. For example, Lung Cancer Europe found that 63% of patients surveyed reported reduced household income since diagnosis, with half of these experiencing a decrease of more than 30%.[51] The Lancet Commission on Women and Cancer also highlights the unpaid and unrecognised labour of women as caregivers for people with cancer.[52]

Return-to-work challenges include the impact of any physical, mental and cognitive symptoms; lack of coordination between health professionals, managers and the person returning to work; unsupportive coworkers and supervisors; family problems; and other psychosocial challenges.[53] In contrast, measures that can support return-to-work include receiving legal advice and personalised attention, as well as interdisciplinary collaboration between the person returning to work, healthcare professionals and company managers.[53] Experts also highlighted the need for encouraging healthier lifestyle factors at work. "You want to have healthy environments for people to return to once they've gone through care treatment," says Kate Oldridge-Turner, Head of Policy and Public Affairs at World Cancer Research Fund International. "You don't want to send them back to the environment that could have made them sick in the first place. So [for example] this is about access to healthy, affordable food."

Policy can help to tackle discrimination or stigma in the labour market. "In some countries like France or the Netherlands, cancer survivors are pragmatically treated as temporarily disabled, ensuring they aren't penalised long after recovery," explains Christof von Kalle, Chair for Clinical Translational Sciences at the Berlin Institute of Health at Charité. "But in places like Germany, people who have had cancer can still face discrimination when applying for insurance or bank loans, despite being fully functional and contributing members of society." Such inequalities suggest the need for harmonised policies that protect cancer survivors from long-term economic disadvantage. According to Christoph Kowalski, Director of the German Cancer Society's Department Health of Services Research, Germany has yet to implement the European Parliament's proposals on the right to be forgotten (see the box on Labour markets and economic rights for more detail).[54]

Experts identified many economic and labour challenges facing patients after treatment. "The hospitals and clinics that people attend during and after treatment are great at giving you advice on nutrition and exercise, but they rarely cover preparing for a return to work," says Ms Wilson. Responses must also recognise the individual needs of each patient, as some may not be able to return to their original employment, in which case appropriate social supports need to be in place, including support to find alternative employment if appropriate.

Labour markets and economic rights

As well as the immediate financial impact of cancer, survivors face discrimination in areas like insurance and mortgage applications, explains Prof Lawler. A law called le droit à l'oubli' (the right to be forgotten) was first adopted in France in 2016, stating that cancer survivors do not have to disclose their past history of cancer once a fixed number of years have passed after the end of their treatment, depending on the age of diagnosis, the histological type and the stage of cancer.[55] This law is not EU-wide but some member states have implemented the policy, with the number of years that must pass varying.[56] "This has led to inequality in survivor rights across countries," says Ms Cardone.

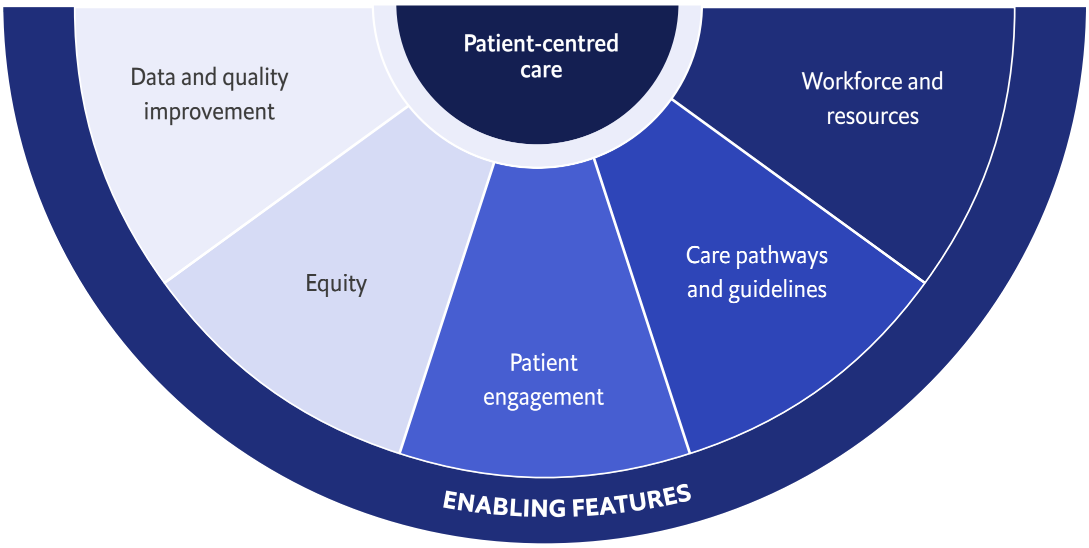
There is also an urgent need for flexible labour policies that allow survivors to remain in the workforce with job accommodations, says Fatima Cardoso, President of Advanced Breast Cancer (ABC) Global Alliance. Although cancer removes a large number of productive employees from the workforce, an estimated 1.8m survivors in the UK contribute £6.9bn (US$9.3bn) to the economy annually, alongside social contributions valued at £15.2bn (US$20.5bn) per year. If employment rates for cancer survivors were the same as for the general population, the former would contribute an additional £4bn (US$5.4bn) to the UK economy annually.[57] "Investing in supporting survivorship yields benefits for both patients and the economy by enabling more survivors to return to work," says Dr Lawler.

Alexandra von Korff, communication manager and patient representative at patients today and founder of Kick Cancer Chick, a breast cancer awareness organisation, describes many physical and mental challenges when returning to work, including misperceptions among colleagues. "A big issue when you talk about life after treatment is that everyone assumes everything is alright and back to normal. You're back at work, but you are not the same and you don't just continue where you stopped, because I am no longer the same person. My mindset and my priorities have changed, and I have long-term side effects like fatigue and concentration lags. It is sometimes exhausting when everybody is suggesting you're fine."

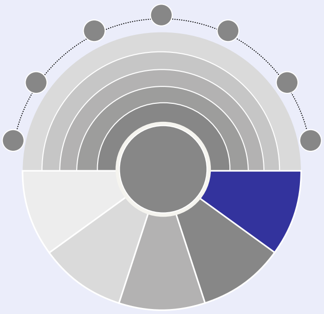
Creating an enabling environment

In the creation of our North Star Framework, it was evident that success across the cancer continuum relied on a strong health-system foundation. Through research and expert consultation, we identified five underpinning factors that are key to enabling successful national cancer control. These "**enabling features**" support the delivery of high-quality, evidenced-based care, as well as ensuring equitable access to care and considering the patient's perspective in decisions around care. The overarching enabling features within our framework include workforce and resources, care pathways and guidelines, patient-centred care, equity, and data and quality improvement (see box). Despite ambitious cancer funding

North Star Framework: Enabling Features



Workforce and resources



This enabler outlines the need for sufficient numbers of a well-trained, multidisciplinary workforce equipped with up-to-date, evidence-based knowledge, which is fundamental for meeting demand and providing quality care. Chronic under-funding and under-staffing can severely impact healthcare delivery, especially considering the rising need for patient-centred care and rapid treatments.[58] Adequate resource allocation to areas of need and strong communication between multidisciplinary teams ensures holistic support for patients.

plans, including the €4bn (US$4.7bn) earmarked for Europe's Beating Cancer Plan, there are resource shortages as countries battle against general funding cuts.[59] As well as having to deal with these tough conditions, the healthcare workforce's training also leaves HCPs underprepared to holistically cater for all aspects of survivorship. Our framework highlights workforce and resources as important enablers of success across the cancer pathway.

Key metrics within *workforce and resources*

- Sufficient healthcare workforce capacity to provide person-centred cancer prevention and care services
- Multidisciplinary cancer teams to enable holistic needs assessment and care
- Training and education of healthcare professionals to support delivery of holistic patient-centred cancer care
- Sufficient funding and resource allocation (eg, for research, social support programmes and health systems)

> **"Given the growing cancer burden and its increasing share in health insurance spending, a collective challenge emerges: preserving the economic sustainability of a health system that allows equitable, universal access to quality care."**
>
> **Benjamin Gandouet**, Director General, Prevention and Screening, Nouvelle Aquitaine

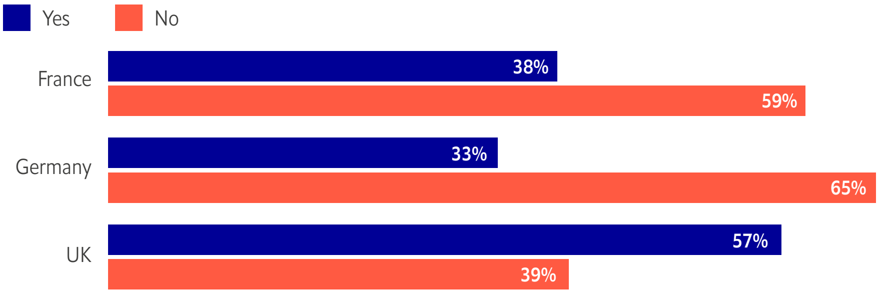
A key element of this enabler is sufficient workforce training. According to our survey, while most HCPs have received training in standard topics such as pain management, other areas identified in the framework are less common, and there is variability across countries.

For example, only 41% of HCPs say they have received training on sexual and reproductive care considerations in the context of patient-centred cancer care, with major disparities between surveyed countries (Figure 9). HCPs in the UK are much more likely to report receiving this training—57% told us that they have, compared with 38% in France and 33% in Germany. This will impact patients' experience. For instance, patients with breast cancer may express additional needs related to interpersonal relationships and intimacy.[35] Cancer treatments can take a toll on sexual desire/ability, beginning from the point of diagnosis. Therefore, such effects need to be considered at the beginning of management and throughout the process, factoring sexual wellbeing as a key part of overall health.[60] For patients of reproductive age, other considerations are required. "Fertility preservation discussions should occur at the time of diagnosis, especially for patients of reproductive age, rather than being deferred to the survivorship phase," says Dr Fuller-Shavel.

Psychosocial support is one of the core domains of the framework, as explored earlier, and there is significant variation in the level of training across European countries. According to our survey, more HCPs reported receiving training in mental health in the UK (81%), than in Germany (68%) and France (63%) (Figure 10).

Figure 9: HCP training in sexual and reproductive care considerations

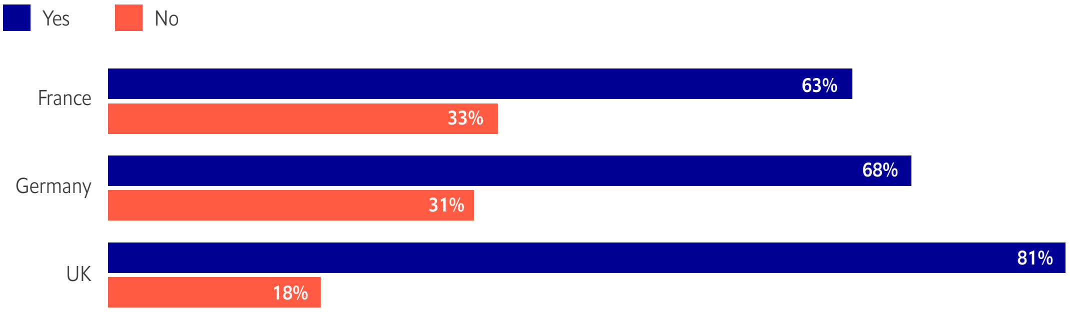
Have you received training in sexual and reproductive care considerations within the context of cancer care?



Source: Economist Impact survey

Figure 10: HCP training in mental health

Have you received training in mental health within the context of cancer care?



Source: Economist Impact survey

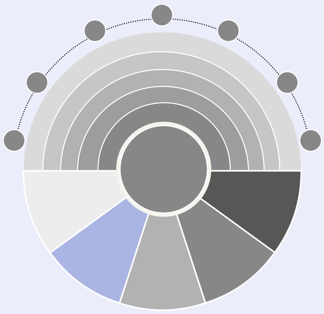
Oncologists should receive formal training in psychosocial care, communication skills and knowledge of when to refer patients for specialist psychological support. These are now described as mandatory by the Global Oncology Curriculum, a collaboration between the European Society for Medical Oncology (ESMO), the American Society of Clinical Oncology (ASCO) and the International Psycho-Oncology Society, and is being implemented by universities. In 2023, ESMO and ASCO guidelines were updated with a standalone chapter on psychosocial aspects of cancer.[61] Regarding access to psychosocial care for cancer patients, Prof von Kalle states: "In principle, if you're treated at a good centre, there's usually psychosocial help and psychological support and it can be fairly good. Is it the rule? Maybe not. Is it available whenever it's needed? Certainly not."

Researchers have called for the further evolution and improvement of training, such as understanding how psychosocial challenges differ across demographic groups like the LGBTQ+ community.[62,63] Not everything pertaining to psychosocial care and mental health can be taught academically—some aspects require experience. For example, HCPs need to be sensitive and empathetic towards their patients, picking up on emotional cues. "This is not easily taught in medical school," says Peter Fasching, Associate Professor of Gynaecology and Obstetrics Translational Medicine at the University of Erlangen in Germany.

A further training-related shortcoming relates to shared decision-making and patient-centricity. Training in the use of shared decision-making frameworks during cancer treatment is limited, with only 38% of HCPs surveyed reporting that they have received such training. Even fewer (14%) reported training in the use of patient decision aids—tools that are designed to help patients understand their options during treatment and to facilitate active patient participation during healthcare decisions. "It is crucial for doctors to have time to discuss treatments with the patient and to create an atmosphere where patients can ask important questions. Then, they can hear what the wishes of the patients really are," says Frank Griesinger, Director of Haematology and Oncology at Pius-Hospital Oldenburg.

> **"It's tremendously important to have patients engaged in decisions with their cancer management."**
>
> **Benjamin Anderson**, Former Lead, WHO Global Breast Cancer Initiative

Equity



This enabler emphasises the need for equitable distribution and consistent provision of high-quality, evidence-based services to all patients. This includes specific measures to support vulnerable populations who often face systemic and socioeconomic barriers to accessing care, such as the elderly, disabled, marginalised communities and those of lower socioeconomic status.[64] Disparities in cancer outcomes can be rooted in social and economic inequities, meaning that achieving universal and equitable access is a priority for bettering patient outcomes.[65]

Socioeconomic factors can cause measurable disparities in cancer care, treatment provision and the depth of survivorship care.[66] The framework identifies equitable and accessible care pathways and support for vulnerable populations to access to care as key for ensuring equity in a survivorship-oriented care pathway.

On the preventive side, lifestyle-related factors, such as smoking, diet, alcohol consumption and lack of physical activity, all contribute towards cancer rates, with 40% of all incidences of cancer in people aged 30 and older associated with these modifiable risk factors.[67,68] It is well established that risk factors for cancer are more common in people from socioeconomically deprived backgrounds, which can mean that those of lower socioeconomic status are at higher risk of developing cancer.[69]

Vulnerable and marginalised communities face inequitable access to care, says Dr Johnson. “Where you live and your socioeconomic background can impact outcomes,” she says. Ms Bell also calls for greater attention to people in deprived areas, ethnic minority groups and people with additional needs. “I remember speaking to an oncologist who lives in a very deprived area where health literacy is poor. She said she doesn’t try to explain genomic testing and precision medicine to them because it’s difficult for them to understand. So how is that choice in person-centred care really? Oncologists need to adapt and find a way to communicate with patients using simple language and help to enable those people to understand.”

Ms Bell adds that learning disabilities also give rise to further inequities. “Professionals don’t really understand or even recognise when someone has a learning disability,” she says.

Key metrics within *equity*

- Support for vulnerable populations to access care
- Equitable availability and accessibility of information and care (including digital information and services) for all population groups, including consideration of different sociodemographic groups and different cancer types

"They often present late with symptoms. They are often diagnosed at a later stage, and the reasonable adjustments that could be made are not necessarily made to make person-centred care easier for them." In addition, age-related bias can also influence treatment decisions, leading to under-treatment or fewer aggressive treatment options for older individuals.[70]

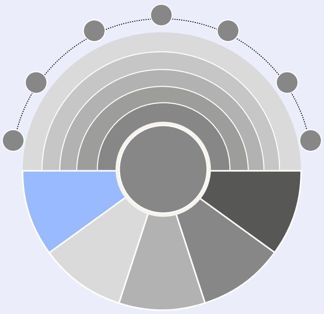
People with lower incomes or more insecure employment are more likely to face obstacles to being able to access cancer care, argues Ms Bell. "There are also people who can't afford to take time off work because they won't get paid," she adds. Specialised treatment facilities are often concentrated in urban, affluent areas, and treatments, like radiotherapy, that require multiple visits are especially affected by transport difficulties, potentially limiting adherence.[71] This again disproportionately affects people from more deprived areas who might face difficulties with transportation access or expense.

"There are some studies based on cancer registry data ... that relate cancer outcomes like survival to the area deprivation index", says Dr Kowalski. "These show an association between wealthier localities and better survival of the population." Once again, people with cancer in socioeconomically deprived areas bear the brunt of these disparities, especially when a lack of transport infrastructure and prohibitive travel costs can limit timely access to vital treatments.

There are disturbing treatment inequalities across Europe, such as differences in drug availability, surgical and radiotherapy capacity and access to targeted therapy, all of which affect survival rates. For example, Prof Lawler says, "Critically, not all countries have an appropriately resourced national cancer plan and a cancer research strategy, which negatively impacts survival. Working without a dedicated research-enabled, patient-centred cancer plan is akin to tackling one of the greatest challenges in human health with one hand tied behind your back." Medical systems in Eastern Europe have significantly lower access to targeted treatments than those in Western Europe, mainly owing to national reimbursement policies and issues with healthcare infrastructure and capacity.[72]

Countries are already targeting equity in their strategies for improving cancer care. For example, Europe's Beating Cancer Plan aims to reduce disparities by improving cross-border collaboration across treatment pathways; focusing on prevention, early detection, diagnosis, and treatment; and enhancing the quality of life for cancer patients and survivors.[73]

Data and quality improvement



Data and quality improvement is a key enabler for success in cancer care. Interoperable clinical information systems are vital for data sharing across the cancer care continuum. Together with robust data collection and surveillance, these systems and data can support ongoing research in cancer care and aid in identifying areas for improvement. Utilising data in this way drives enhancements at both clinical and national levels, ultimately leading to optimised care and a more efficient healthcare system.[74]

When shifting the focus to survivorship, understanding patient experiences and outcomes is paramount. There is an overarching need for better data-tracking and monitoring of patients' routes to diagnosis, treatments, outcomes and experiences. Leveraging these data for quality improvement and evidence-based action is key to driving meaningful change. The North Star Framework emphasises that robust data is essential for understanding which parts of the cancer journey are successful and which are most in need of support, enabling quality improvement initiatives.

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> **"We need a cultural change that considers the measurement of quality of life and psychological outcomes as part of the cure."**
>
> **Alberto Costa**, Scientific Adviser of the Former Commissioner, European Union Commission for Health and Food Safety

Understanding patient experiences

PROMs and PREMs capture patient symptoms, perspectives and experiences during their cancer treatment journey. Integration of PROMs into clinical care can improve patient-centricity of care, symptom control, health-related quality of care and patient outcomes.[75,76] "When effectively integrated, correlated and periodically reviewed, PROMs can empower clinicians to make more informed, patient-centred decisions across the care pathway," explains Matt Hickey, CEO of the Health Value Alliance.

See *patient experience* in the North Star Framework for more information on key metrics relating to this domain.

Patient-reported outcome and experience measures (PROMs and PREMs) provide insights directly from patients, offering a more nuanced picture of survivorship than possible from a sole reliance on traditional clinical endpoints such as disease progression or five-year survival rates. Embedding data collection on these patient-centred metrics across the cancer continuum can help to uncover critical gaps in care delivery. Poorly coordinated services, delays in treatment or lack of psychosocial support may be invisible in traditional data but become glaringly apparent through patient feedback. In this way, PROMs and PREMs can act as early-warning systems, allowing for real-time course correction and quality improvement.

While regional guidance, including the European Code of Cancer Practice and some NCCPs increasingly incorporate patient-reported outcomes (PROs), there are barriers to their collection and use for system-level quality improvement.[77] For example, PROs often rely on relatively lengthy patient questionnaires, which can be challenging to integrate into routine clinical practice. "We simply do not have the human resources to apply the questionnaires and analyse the data," says Ms Cardone. "There is also a technological barrier: the link between the questionnaires and the electronic patient records."

Dr Wishart also emphasises the importance of regular check-ins and electronic records to derive maximum value from patient data. "You can pick up when people are deteriorating—physically or mentally—and that kind of monitoring can make a big impact, especially when it triggers access to timely support," he says. Key challenges for the inclusion of PROs in routine care include the lack of technologies for patient data entry that synchronise with electronic health records, difficulties in providing real-time clinical responses to urgent patient-reported issues, the need for greater patient involvement in designing PROM questionnaires, and physician reluctance to use PROMs owing to trust or logistical and time barriers.[78,79]

Importantly, PROs do not replace survival data—but they should be used in combination with it. Whereas survival rates tell us if patients survive, PROs help to understand how patients are living. By collecting and analysing PROs alongside population-level data, health systems can ensure that care is not just life-prolonging but focused on survivorship.

> **"It's about understanding the patient, their history, their future and what their expectations are."**
>
> **Franziska Ivens**, Consultant, YesWeCan!cer

Assessing outcomes

Population-level data indicate how well healthcare and public health systems are delivering effective, population-wide cancer prevention, screening, detection and treatment across the cancer continuum.

See *outcomes* in the North Star Framework for more information on key metrics relating to this domain.

National cancer registries and surveillance programmes serve as critical repositories of population-level data on incidence, mortality and survival, among other metrics.[80] These data repositories enable benchmarking across hospitals, countries and regions, helping to identify variations in care delivery and patient outcomes. These systems, when comprehensive and interoperable, can serve as active tools for ongoing system monitoring and quality improvement.[81]

Only five countries in Europe—Belgium, Denmark, Finland, the Netherlands and Norway—have integrated PROs into their cancer registry data (Figure 11).[7] The application of PRO systems in healthcare has been historically under-utilised but is indispensable for providing real-world insights that help to improve cancer treatment.

Robust, interoperable clinical information systems are required to capture and analyse multifaceted data on cancer. Then, structured quality improvement processes are needed to translate these data into meaningful action. Lisa Stevens, Director of the Division of Program of Action for Cancer Therapy at the International Atomic Energy Agency, believes that more needs to be done to link existing data and develop new insights into cancer care outcomes. "I don't think that there are enough cancer registries that are tracking not only type of treatment and stage of diagnosis, but are able to link any of the interventions to survival," she says. "I think more data in that space is needed."

Figure 11: PROMs integration in cancer registries[7]

European countries that have integrated PROMs into their cancer registry data

Source: OECD. Beating cancer inequalities in the EU: spotlight on cancer prevention and early detection 2024. Paris: Organisation for Economic Co-operation and Development. Available from: https://www.oecd.org/en/publications/beating-cancer-inequalities-in-the-eu_14fdc89a-en.html.

> **"We need to be making better use of data to measure the impact of delivery of services and also to measure service quality."**
>
> **David Cameron**, Professor of Oncology, University of Edinburgh; Chair, Executive Board, Breast International Group Against Breast Cancer

Key metrics within *data and quality improvement*

- Adoption of inter-operable clinical information and data systems across the care continuum
- Robust national data collection and surveillance, feeding into national cancer registries, to monitor performance and identify areas for improvement, with ability to utilise data for quality improvement and research
- Quality improvement processes incorporating metric data to drive improvements at local and national level
- Recognition of patients' rights to have their data processed to support optimal care, including personalised diagnosis, treatment and prevention
- Continued support for research

At the health system level, quality improvement initiatives can utilise metrics to identify bottlenecks, such as delays between diagnosis and treatment, or areas of underperformance, including low uptake of shared decision-making tools. At the national level, aggregating these insights enables policymakers to set quality standards, implement evidence-based policy and reallocate resources to address unmet needs.

Of course, comprehensive data collection must be balanced with ethical obligations to protect patient rights and privacy. Implementation challenges include data privacy concerns, ensuring General Data Protection Regulation (GDPR) compliance and ensuring that digital systems directly benefit patients. A transparent, consent-driven approach to data sharing that aligns with international data governance principles is vital to maintaining public trust while enabling research, innovation and quality improvement.[82]

Conclusion: Towards a new paradigm in cancer care

While cancer incidence is rising, the odds of survival have also improved owing to medical breakthroughs, and Europe now has over 23.7m cancer survivors.[1] Shifting the focus of cancer care from survival to survivorship is key to providing patients with the support that they need to live well with and beyond cancer.

The North Star Framework aims to reframe how cancer care success is defined and measured. It promotes a model that centres on the lived experiences of patients and the systemic barriers that they face. For policymakers, the framework offers a way to measure success in cancer care, as well as a practical, evidence-based guide to designing interventions that are inclusive, scalable and measurable. By integrating these metrics into national cancer plans, governments can ensure that health systems are equipped not only to treat cancer but to support individuals throughout their cancer journey. They pave the way towards equitable, patient-centred and outcome-driven cancer care globally.

Key opportunities include:

Ensuring better access to information, tailored to the individual, to improve the odds of early and timely intervention and boost post-treatment quality of life

Information provision can save lives. Improving knowledge about risk factors, treatment options, psychosocial consequences of cancer, and economic and financial rights can help patients to thrive, not just by improving the odds of successful treatment, but also by providing the holistic support that goes beyond disease management to cover all dimensions of wellbeing.

Prioritising psychosocial care throughout the cancer journey

Cancer takes a significant toll on mental health for patients, their families and caregivers. Positively, a sea change in mental health awareness has normalised discussions about psychosocial care, but funding and training for psychological support remain inadequate. Greater inclusion of psychosocial interventions in guidelines and training curricula, as well as systematic approaches to their inclusion in routine care, can ensure that psychosocial oncology care becomes a pillar of survivorship.

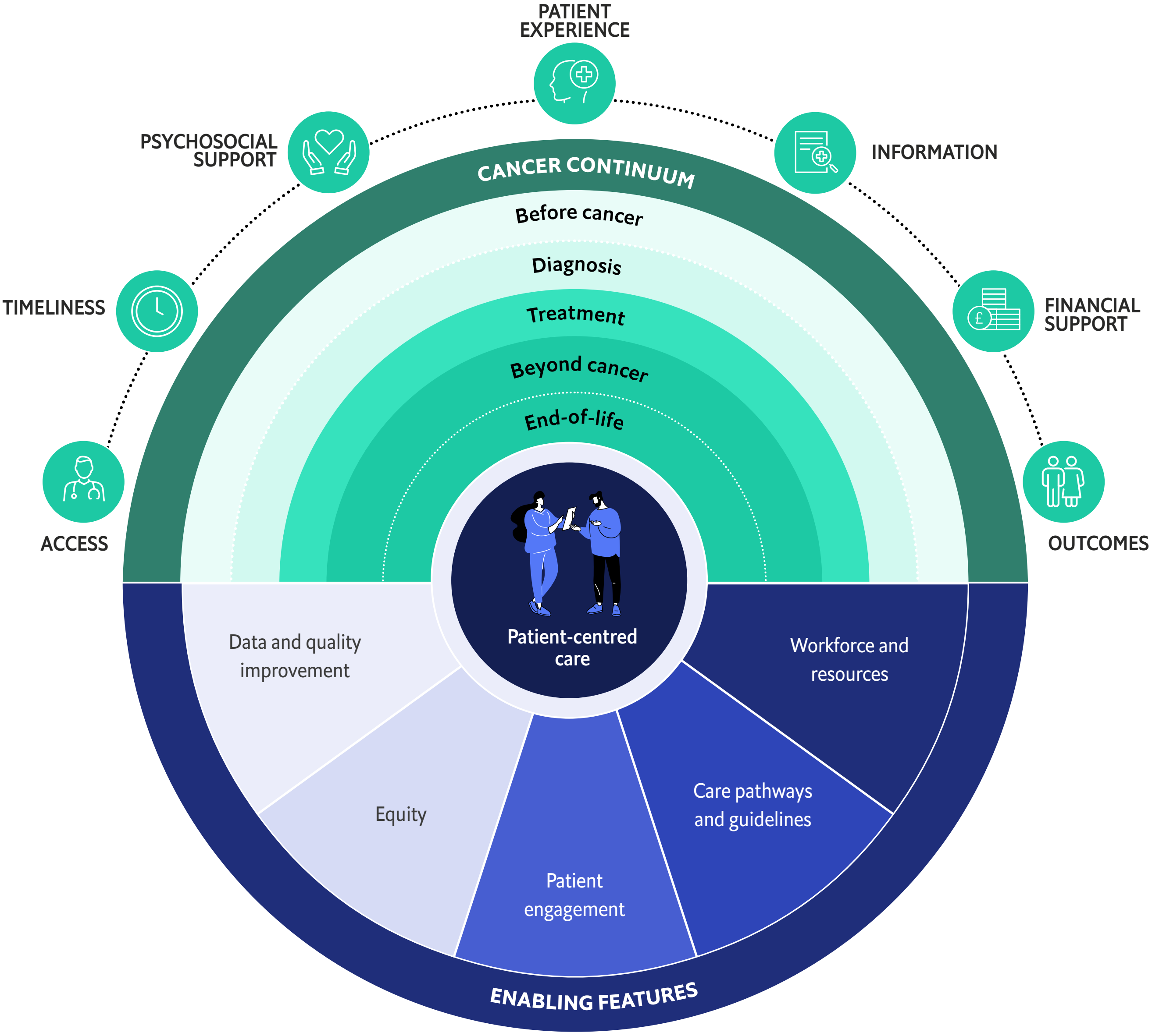
Investing in cancer care and the healthcare workforce

Promoting survivorship and improving cancer care requires a robust, well-trained healthcare workforce capable of delivering person-centred services. Multidisciplinary cancer teams are essential for addressing patients' needs holistically, including through physical, emotional and psychosocial care. Comprehensive training equips professionals with the skills to deliver coordinated, patient-centred care across the cancer continuum. A strong healthcare workforce, coupled with adequate funding, helps to ensure equitable access to high-quality care, enhance survivorship outcomes and address the complex, long-term needs of people affected by cancer.

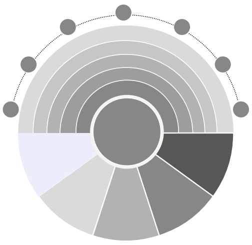
Focus on patient-centred care and shared decision-making
Cancer can be a profoundly disempowering experience for patients. Including patients in decisions and processes, from deciding the right treatment and regularly assessing their needs, through to giving patients living with and beyond cancer the opportunity to engage with health technology assessments and the development of national cancer plans, gives them greater agency. Considering patient preference can also mitigate challenges such as fear, anxiety, uncertainty, decisional conflict and regret. Patient advocacy groups can play an important role in connecting patients, HCPs and policymakers and ensuring that patient perspectives are taken into account in service design and reform.

Understanding patient experiences and outcomes to enable quality improvement initiatives and evidence-based policy action
Improved data collection, tracking, and monitoring of PROs and outcomes are critical for understanding patient experiences and identifying gaps in current systems. Leveraging these data for quality improvement and evidence-based action is key to driving meaningful change. More investment is needed to capture the outcomes and experiences of the growing group of long-term cancer survivors to ensure that treatment plans, national policies and cancer programmes address their needs.

Appendix A: The North Star Framework



ENABLING FEATURES



DATA AND QUALITY IMPROVEMENT

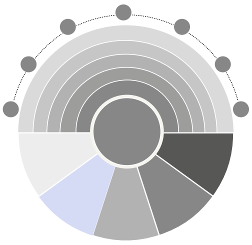
Adoption of interoperable clinical information and data systems across the care continuum

Robust national data collection and surveillance, feeding into national cancer registries, to monitor performance and identify areas for improvement, with ability to utilise data for quality improvement and research

Quality improvement processes incorporating metric data to drive improvements at local and national level

Recognition of patients' rights to have their data processed to support optimal care, including personalised diagnosis, treatment and prevention

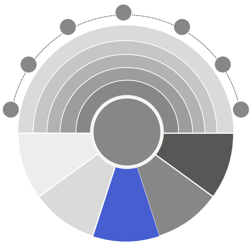
Continued support for research



EQUITY

Support to help vulnerable populations access care

Equitable availability and accessibility of information and care (including digital information and services) for all population groups, including consideration of different sociodemographic factors (including eg, literacy level/reading age, primary language and geographical location [urban vs rural]), information format and cancer types



PATIENT ENGAGEMENT

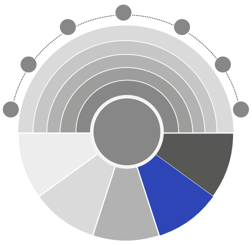
Communication and trust between healthcare professionals and patients

Support for general population and patient health literacy in relation to cancer

Patient involvement in decision-making at both clinical and policy level

Availability of and referral to patient-led groups for information, resources and support

Multidisciplinary care provision and signposting to support and care services



CARE PATHWAYS AND GUIDELINES

Availability and accessibility of evidence-based care

Timely health technology assessment to identify and implement innovative care options (eg, diagnostics or treatment) that provide value

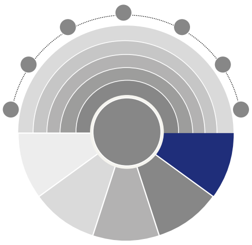
Integrated care pathways and systems for care coordination and care continuity

Up-to-date, evidence-based guidelines for cancer care pathways developed by multidisciplinary expert groups including patient representation

Adherence to evidence-based guidelines

Best practice care pathways and quality of care standards based on clinical consensus

Development and implementation of a national cancer plans, developed by a multistakeholder groups including patients and cancer survivors



WORKFORCE AND RESOURCES

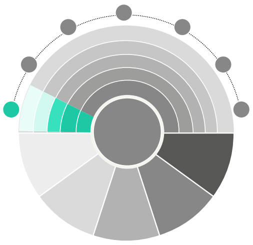
Sufficient healthcare workforce capacity to provide person-centred cancer prevention and care services

Multidisciplinary cancer teams to enable holistic needs assessment and care

Training and education of healthcare professionals to support delivery of holistic patient-centred cancer care

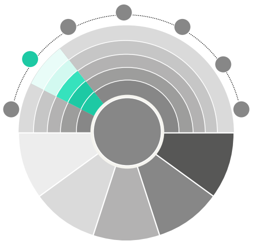
Sufficient funding and resource allocation (eg, for research, social support programmes and health systems)

CANCER CONTINUUM



ACCESS

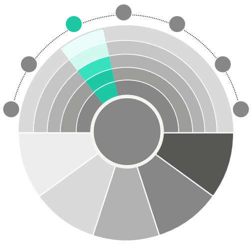
BEFORE CANCER	Availability and accessibility of screening services for eligible groups Availability and accessibility of initial assessment and/or referral for individuals based on: • screening test result • risk (eg, family history of cancer) Availability and accessibility of risk reduction interventions (eg, HPV vaccination, smoking-cessation interventions)
DIAGNOSIS	Availability and accessibility of initial assessment and referral for individuals based on experiencing symptoms that are potential indicators of cancer Availability and accessibility of high-quality diagnostic tests and technologies, including genetic/genomic testing and evidence-based innovative approaches as needed Availability and accessibility of the specialists required for accurate diagnosis (eg, surgeon, radiologist, pathologist, molecular pathologist, genomics) Availability and accessibility of initial assessment and/or referral for individuals based on positive diagnosis
TREATMENT	Availability and accessibility of evidence-based treatments, including innovative treatments Completion of treatment course Availability and accessibility of relevant specialists Availability and accessibility of appropriate symptom management Availability and accessibility of companion diagnostic genetic and/or genomic testing to guide treatment as needed Availability and accessibility of enrolment in clinical trials Availability and accessibility of consultation regarding fertility before treatment as appropriate Availability and accessibility of regular holistic assessment of needs after treatment completion
BEYOND CANCER	Ability to schedule appointments with appropriate specialists as needed Availability and accessibility of monitoring for and management of ongoing or late-presenting symptoms, including those relating to any comorbidities arising as a result of cancer treatment Availability and accessibility of rapid specialist assessment for suspected recurrence
END-OF-LIFE	Availability and accessibility of palliative care, including end-of-life care Availability and accessibility of symptom management (eg, for pain, fatigue, breathlessness) Availability and accessibility of end-of-life care facilities



TIMELINESS

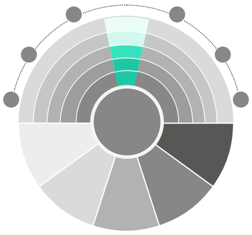
BEFORE CANCER	Ability to access screening services in a timely manner Waiting times for screening results Waiting time between formal suspicion of cancer and date of diagnostic assessment
DIAGNOSIS	Time from symptom onset to first contact with the healthcare system Time from first contact with the healthcare system to diagnosis Stage at diagnosis Route of presentation for diagnosis Waiting times for diagnostic test results and referrals
TREATMENT	Time from diagnosis to start of treatment Regularity of follow-up appointments
BEYOND CANCER	Waiting time to access care for conditions caused by cancer treatment Waiting time to re-access to services for assessment and management of new or recurring symptoms
END-OF-LIFE	Waiting time for referral to palliative care, including end-of-life care

CANCER CONTINUUM (continued)



PSYCHOSOCIAL SUPPORT

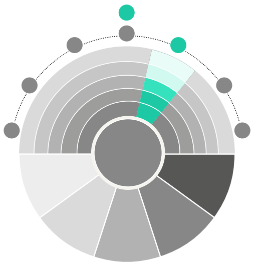
BEFORE CANCER	Availability and accessibility of psychosocial support resources and appropriate counselling as needed, (eg, in the presence of a positive screening test for cancer)
DIAGNOSIS	Availability and accessibility of psychosocial care and support Waiting times for psychosocial care and support Availability and accessibility of networks of support and community groups Availability and accessibility of psychosocial support for families and carers
TREATMENT	Assessment of psychosocial needs (eg, psychological, emotional, social and spiritual) Availability and accessibility of psychosocial care and support Waiting times for psychosocial care and support Availability and accessibility of networks of support and community groups Availability and accessibility of psychosocial support for families and carers
BEYOND CANCER	Availability and accessibility of psychosocial care and support Waiting times for psychosocial care and support Availability and accessibility of networks of support and community groups Availability and accessibility of psychosocial support for families and carers
END-OF-LIFE	Availability and accessibility of psychosocial care and support Waiting times for psychosocial care and support Availability and accessibility of networks of support and community groups Availability and accessibility of psychosocial support for carers and families



PATIENT EXPERIENCE

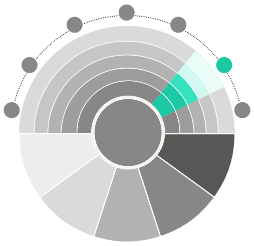
BEFORE CANCER	Patient reported experience measures (PREMs), including patient satisfaction, quality of care and communication, relating to the screening process
DIAGNOSIS	Holistic needs assessment Routine collection of relevant patient reported outcome measures (PROMs) at appropriate intervals, including eg, symptoms, side effects, function and quality of life Routine collection of PREMs at appropriate intervals, including patient satisfaction, quality of care, continuity of care and communication
TREATMENT	Holistic needs assessment Provision of integrated, multidisciplinary care Use of shared decision-making frameworks and tools Routine collection of relevant PROMs at appropriate intervals, including eg, symptoms, side effects, function and quality of life Routine collection of PREMs and caregiver-reported experience measures, including patient satisfaction, quality of care, continuity of care and communication Personalised treatment and follow-up plans
BEYOND CANCER	Holistic support services Routine collection of relevant PROMs at appropriate intervals, including eg, symptoms, side effects, function and quality of life Routine collection of PREMs at appropriate intervals, including patient satisfaction, quality of care, continuity of care and communication
END-OF-LIFE	Holistic needs assessment Provision of integrated, multidisciplinary care Use of shared decision-making frameworks and tools Routine collection of relevant PROMs and/or caregiver-reported outcome measures at appropriate intervals, including eg, symptoms, pain, function, side effects and quality of life Routine collection of PREMs and/or caregiver-reported experience measures, including patient satisfaction, quality and appropriateness of care, continuity of care, and communication Personalised palliative care plans taking into account patient preferences Quality of death, including place of death and patient preferences

CANCER CONTINUUM (continued)



INFORMATION

BEFORE CANCER	Provision of clear, accurate and accessible information about eg: • cancer risk • screening availability and access • screening tests, including possible outcomes • healthy lifestyle • risk reduction interventions (eg, HPV vaccinations, smoking-cessation interventions) and their impact • cancer symptoms and what to do if you are experiencing them Access to genetic counselling where appropriate
DIAGNOSIS	Provision of clear, accurate and accessible information about eg: • cancer symptoms and what to do if you are experiencing them • diagnostic tests, including possible outcomes • risk of comorbidities
TREATMENT	Provision of clear, accurate and accessible information to patients about eg: • prognosis • treatment options and side effects (including the availability of innovative treatments) • symptoms and symptom management • self-management • healthy lifestyle during treatment and follow-up • routine follow-up processes • comorbidities
BEYOND CANCER	Provision of clear, accurate and accessible information about eg: • healthy lifestyle beyond cancer (eg, diet, physical activity, alcohol consumption) • tertiary prevention[iv] • risk of recurrence and symptoms to look for • self-management • management of comorbidities • palliative care options
END-OF-LIFE	Provision of clear, accurate and accessible information about eg: • prognosis • what to expect • palliative care options • end-of-life care process and options



FINANCIAL SUPPORT

BEFORE CANCER	Cost of accessing screening services
DIAGNOSIS	Costs of tests and care Access to financial support (eg, to cover direct medical costs or indirect costs, including leave from work, transportation, childcare) Insurability Ability to work and the right to work as a disabled person without discrimination (for example, the Disability Discrimination Act in the UK)
TREATMENT	Costs of treatment and care Access to financial support Ability to apply for loans and other financial services Insurability Ability to work and the right to work as a disabled person without discrimination (for example, the Disability Discrimination Act in the UK)
BEYOND CANCER	Ability to apply for loans, and other financial services Access to financial support Insurability Job retention and ability to return to work, with consideration for any disability resulting from cancer treatment Continuity and quality of individuals' education, studies, vocational training
END-OF-LIFE	Costs of end-of-life care and support Access to financial support, including for family and dependents

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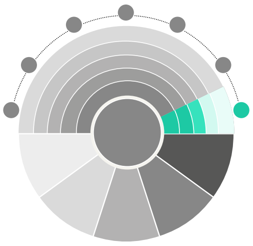
[iv] Minimisation of the impact of cancer and its treatments on everyday life, functional ability and risk of complications, recurrence or deterioration

CANCER CONTINUUM (continued)



	OUTCOMES
BEFORE CANCER	Prevalence of key risk factors Uptake of risk reduction interventions (eg, HPV vaccination) Policies to address key risk factors Uptake of screening services Cancer detection rates of screening service Incidence of cancers Prevalence of cancers
DIAGNOSIS	Stage at diagnosis (earlier is better) Route of first diagnosis (eg, via screening, non-urgent cancer-related presentation, or emergency cancer-related presentation)
TREATMENT	Remission rates Disease-free, progression-free and overall survival (eg, 30-day, 60-day, 1-year, 5-year) Prevalence and management of acute complications of treatment Cause-specific mortality (specifically cancer-related deaths) Use of emergency services and emergency hospitalisation during treatment or follow-up
BEYOND CANCER	Recurrence rate and time from treatment completion to recurrence Incidence of new cancers Long-term survival (eg, 5- or 10-year) Progression-free survival Incidence and prevalence of cancer- related and treatment-related effects or comorbidities
END-OF-LIFE	Cause-specific mortality (specifically cancer-related deaths) Use of emergency services and emergency hospitalisation rates Place of death (ideally compared with patient wishes) Overall satisfaction and experiential measures as reported by patient and next of kin

Appendix B: Methodology

Creation of the North Star Framework

The creation of the North Star Framework was informed by an in-depth analysis of existing frameworks, policy reports, cancer metrics and scholarly literature relevant to cancer care and survivorship. This analysis identified which stages of the cancer continuum were commonly addressed, which concepts were prioritised, and where gaps remained. The key sources we consulted are listed below:

- All.Can Cancer Efficiency Metric Study (2022), All.Can
- Cancer Survivorship Stratified Self-Managed Follow-Up Framework (2023), National Cancer Control Programme (Ireland)
- European Cancer Pulse: Tracking Inequalities in Cancer (2024), European Cancer Organisation
- Expert Consensus Statements on Cancer Survivorship: Promoting High-Quality Survivorship Care and Research in Europe (2022), Vaz-Luis I, Masiero M, Cavaletti G et al, European Society for Medical Oncology (ESMO)
- ICHOM Patient-Centred Outcome Measures: Oncology (accessed 2025), International Consortium for Health Outcomes Measurement (ICHOM)
- Improving the Understanding, Acceptance and Use of Oncology–Relevant Endpoints in HTA Body/Payer Decision-Making (2023), European Federation of Pharmaceutical Industries and Associations (EFPIA)
- Model of Survivorship Care (2016), Clinical Oncology Society of Australia (COSA)
- Pan-Canadian Framework for Cancer Survivorship Research (2017), Canadian Cancer Research Alliance (CCRA)
- Patient Insights on Cancer Care: Opportunities for Improving Efficiency (2019), All.Can
- Patients Waiting to Access Innovative Therapies (WAIT) Indicator 2023 Survey (2024), EFPIA
- Quality of Cancer Survivorship Care Framework (2019), Nekhlyudov L, Mollica MA, Jacobsen PB et al.
- South Australian Cancer Service Statewide Survivorship Framework (2016), South Australian Cancer Service
- Uniting Europe Against Cancer: The Push for a European Semester on Health (2024), Cancer Patients Europe

First, we extracted the content of these sources and condensed related metrics to simplify overlapping concepts. Then we qualitatively analysed the themes that arose in expert interviews and workshops, adding and adapting metrics based on expert advice to address gaps in current cancer care and in how success is measured across the cancer care journey from the perspectives of patients, healthcare professionals and policymakers.

Many metrics in the North Star Framework were shaped by multiple sources and refined through the expert consultation process. In some cases, existing sources provided strong foundations in areas such as care coordination or health system performance, while in others, the North Star Framework extends or complements the evidence by incorporating person-centred outcomes and structural enablers essential to delivering survivorship-focused care and support.

Validation

This approach was validated through a consultation process that included input from a diverse group of stakeholders, including healthcare professionals, researchers, policymakers and patient advocates from across Europe. This included a selection of experts who took part in interviews or country workshops, as well as experts attending a roundtable discussion at the 10th annual World Cancer Series Europe in June 2025, held under Chatham House rules. Their feedback helped to ensure that the North Star Framework reflects both the best available evidence and the real-world experiences of those who deliver and receive cancer care.

North Star Framework structure

The North Star Framework takes a holistic and patient-centred approach to cancer survivorship. It includes metrics spanning from the period before cancer is diagnosed through to the period after patients complete active treatment or require end-of-life care; we refer to this as the "cancer continuum". Based on the information collected, we designed the framework structure reflecting the five main stages of the cancer continuum, in which the metrics would be utilised. The stages include:

Before cancer
Population-wide prevention and screening efforts before cancer is identified

Diagnosis
The process of identifying cancer after abnormal screening results or initial symptoms appear

Treatment
Cancer treatment after diagnosis and follow-up care

Beyond cancer
Post-follow-up care, after completion of active treatment

End-of-life
Care for people with cancer who are near the end of their life and have stopped treatment to cure or control their disease

We then established a set of metrics within seven thematic groupings (domains) that apply within each stage. The domains are:

Access
Ensuring availability and accessibility of cancer-related services for every individual, regardless of their background

Timeliness
Ensuring health systems are delivering the right care at the right time to minimise disease progression and optimise patient outcomes

Psychosocial support
Providing support that addresses the mental, emotional, social and spiritual needs of individuals with cancer and their families,

such as counselling, support groups or education

Information
Ensuring that clear, comprehensive, accessible and personalised information is provided to empower the public, patients and their families to understand their risks, condition and management options; participate in decision-making; manage care; and navigate services effectively

Patient experience
Understanding patient (and caregiver) needs, preferences, wellbeing, experiences, symptoms and outcomes to ensure that cancer-related care is clinically effective, patient-centred and holistic

Financial support
Providing the resources, services and support necessary to help patients and their families manage the direct and indirect costs of cancer care, to ensure that all individuals can access the care that they need without incurring financial hardship

Outcomes
Assessing how well healthcare and public health systems are delivering effective, population-wide cancer prevention, screening, detection and treatment

During our analysis, five cross-cutting themes emerged that apply throughout the cancer continuum. These themes are essential to building the enabling environment for successful national cancer control by ensuring high-quality, equitable, standardised and evidence-based care delivery. We refer to this portion of the framework as the enabling features:

Workforce and resources
This enabler outlines the need for sufficient numbers of a well-trained, multidisciplinary workforce equipped with up-to-date, evidence-based knowledge, which is fundamental for meeting demand and providing quality care. Under-funding and under-staffing severely impact the ability to deliver patient-centred care, especially considering the rising incidence of cancer and rapid advancements in treatments.[58] Adequate resource allocation to areas of need and strong communication between multidisciplinary teams ensures holistic support for patients.

Care pathways and guidelines
This enabler focuses on the need for integrated care pathways, which are crucial for continuity and coordination between primary and secondary care. This can improve quality, reduce costs and enhance health outcomes for patients.[83] Evidence-based guidelines, developed with diverse stakeholder input including patients, aid in standardising care, ensuring consistent high-quality treatment. Translating research into these practical guidelines and ensuring effective dissemination is vital for driving meaningful changes in clinical practice.[84]

Patient engagement
Patient engagement is fundamental to capturing individual patient needs and wishes so that care can be truly patient-centric. Trust and clear communication between patients and healthcare professionals must be fostered and encouraged. Involving patients in decision-making at all levels, including individual treatment decisions and policy decisions, is key to improving care quality and outcomes. In addition, measuring the patient experience can help to identify areas for improvement and enhance care systems by allowing exploration of the linkages between patient perspectives and clinical results.[85]

Equity

This enabler emphasises the need for equitable distribution and consistent provision of quality, evidence-based services to all patients. This includes specific measures to support vulnerable populations who often face systemic and socio-economic barriers to accessing care, such as the elderly, disabled, marginalised communities and those of lower socio-economic status.[64] Disparities in cancer outcomes can be rooted in social and economic inequities, meaning that achieving universal and equitable access is a priority for improving patient outcomes.[65]

Data and quality improvement

Data and quality improvement is a key enabler for success in cancer care. Interoperable clinical information systems are vital for data sharing across the cancer care continuum. Together with robust data collection and surveillance, these systems and data can support ongoing research in cancer care and aid the identification of areas for improvement. Utilising data in this way drives enhancements at both clinical and national levels, ultimately leading to optimised care and a more efficient healthcare system.[74]

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